FULL/LONG TITLE OF THE STUDY

Co-producing two toolkits of resources to promote EQUal Access to flexible support planning for Adults with Learning Disabilities (EQUALD)

SHORT STUDY TITLE / ACRONYM

EQUal Access to flexible support planning for Adults with Learning Disabilities (EQUALD)

PROTOCOL VERSION NUMBER AND DATE

Version 2 02.10.23

RESEARCH REFERENCE NUMBERS

IRAS Number:	N/A
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SIGNATURE PAGE

The undersigned confirm that the following protocol has been agreed and accepted and that the Chief Investigator agrees to conduct the study in compliance with the approved protocol and will adhere to the principles outlined in the Declaration of Helsinki, the Sponsor's SOPs, and other regulatory requirement.

I agree to ensure that the confidential information contained in this document will not be used for any other purpose other than the evaluation or conduct of the investigation without the prior written consent of the Sponsor

I also confirm that I will make the findings of the study publicly available through publication or other dissemination tools without any unnecessary delay and that an honest accurate and transparent account of the study will be given; and that any discrepancies from the study as planned in this protocol will be explained.

For and on behalf of the Study Sponsor:		
Signature:		Date: ....../....../.. ....
Name (please print):		
Position:		
Chief Investigator:		
Signature: Liz Croot .		Date: .10.02.23.
Name: (please print): Liz Croot		

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11. APPENDICES	

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Committees	

STUDY SUMMARY

BACKGROUND In 2020/21, 39% of the money spent on adult social care was for adults with learning disabilities. The total cost was £6.3 billion. A learning disability makes it difficult to understand information and learn new skills. This causes difficulty with everyday activities. For example; household tasks, socialising or managing money. It affects someone for their whole life. Social care for adults with learning disabilities is mostly funded through personal budgets. Personal budgets give people choice and control over their money and support. Some adults with learning disabilities cannot, or do not want to, manage their own budget. Individual service funds (ISFs) can help. They offer a way for people to choose their support without having to buy it themselves or manage a budget. With an ISF, the council pays a support provider to work with the person to choose how they receive support.

Many people feel more independent and in control when their funding is individualised. The problem is that very few adults with learning disabilities are offered an ISF. Some local authorities do not have processes in place to pay support providers. Social workers worry about how to check the quality of support. Support providers may not have ways to record how much each person has spent on their support. Some adults with learning disabilities are not sure whether an ISF is right for them, or what to do if it does not go well.

Adult social care is a network of many different parts or systems. The main systems concerned with ISFs for adults with learning disabilities are: 1. Local authorities, 2. Support providers, and 3. Adults with learning disabilities and their family and friends.

AIMS OF THE RESEARCH

We will find out how the different systems work together to make an ISF successful. We will use this information to co-produce resources to help more people to use ISFs well.

DESIGN AND METHODS USED

We will find out what people and organisations are doing to make ISFs successful. We will gather data, develop theories and work with a stakeholder group. We will review information about developing and delivering ISFs. We will find two places which already offer ISFs, and interview 20 people from each. We will talk about what makes an ISF successful, with people from all the different systems. We will hold three workshops with a bigger group of stakeholders who will help us to make a toolkit to help people to develop more and better ISFs. We will include adults with all types of learning disabilities. We will test the toolkit in two local authorities.

Study Title	Co-producing two toolkits of resources to promote Equal Access to flexible support planning for Adults with Learning Disabilities (EQUALD)
Internal ref. no. (or short title)	EQUal Access to flexible support planning for Adults with Learning Disabilities (EQUALD)

Study Design	Realist approach informed by complex systems thinking. Co-production. Realist synthesis, realist interviews, development of research derived actionable toolkits, formative evaluation
Study Participants	Adults with learning disabilities and their allies, local authority staff, adult social care providers
Planned Size of Sample (if applicable)	WP1 knowledge user group n=10 WP3 Realist interviews in two local authorities and other stakeholders in relevant roles n=40 WP4 Three stakeholder workshops n=30 WP 5 Formative evaluation in two local authorities n=20
Follow up duration (if applicable)	WP 5 Formative evaluation follow up after approx 12 weeks
Planned Study Period	1st March 2023 - 30th June 2025 28 months
Research Question/Aim(s)	Research question: How should systems be configured for optimal delivery of Individual Service Funds to adults with learning disabilities and how can guidance overcome the barriers to their use within adult social care? **Aims** 1. To understand how important mechanisms operate in the context of social care systems to support or hinder the offer, uptake, and sustained provision of successful ISFs for adults with learning disabilities. 2. To co-produce and carry out a formative evaluation of actionable toolkits of resources to support the delivery of ISFs at scale for this population.

FUNDING AND SUPPORT IN KIND

FUNDER(S) (Names and contact details of ALL organisations providing funding and/or support in kind for this study)	**FINANCIAL AND NON FINANCIALSUPPORT GIVEN**
The NIHR Health and Social Care Delivery Research (HSDR) Programme	**£518,000**

ROLE OF STUDY SPONSOR AND FUNDER

The University of Sheffield is the sponsor. The sponsor has overall responsibility for the research, including:

a) identifying and addressing poorly designed or planned research and poor-quality research proposals, protocols or applications and ensuring that research proposals and protocols:
- take into account systematic reviews of relevant existing research evidence and other relevant research in progress,
- make appropriate use of patient, service user and public involvement and
- are scientifically sound (e.g., through independent expert review)

b) satisfying itself that the investigators, research team and research sites are suitable;

c) ensuring that roles and responsibilities of the parties involved in the research and any delegation by the sponsor of its tasks are agreed and documented;

d) ensuring adequate provision is made for insurance or indemnity to cover liabilities which may arise in relation to the design, management and conduct of the research project; and

e) ensuring appropriate arrangements are made for making information about the research publicly available before it starts; agreeing appropriate arrangements for making data accessible, with adequate consent and privacy safeguards, in a timely manner after it has finished; and ensuring arrangements for information about the findings of the research to be made available, including, where appropriate, to participants.

f) ensuring that the research has approval from a research ethics committee and any other relevant approval bodies before it begins;

g) verifying that regulatory and practical arrangements are in place, before permitting the research to begin in a safe and timely manner;

h) putting and keeping in place arrangements for adequate finance and management of the research project, including its competent risk management and data management;

i) ensuring that effective procedures and arrangements are kept in place and adhered to for reporting (e.g. progress reports, safety reports) and for monitoring the research, including its conduct and the ongoing suitability of the approved proposal or protocol in light of adverse events or other developments (NHS, HRA, 2022)

Following NHS HRA guidance (2022) the funder is responsible for:

a) assessing (or arranging for assessment of) the scientific quality, the relevance of the research to the target population and, if appropriate, the value for money of the research as proposed, involving patients, service users and the public where appropriate in funding decisions;

b) reviewing information about the attribution of costs to confirm that costs to all parties (including excess treatment costs) have been identified and described in accordance with national guidance and that the costs are not disproportionate compared to the value of the output;

c) considering (with advice if necessary) whether the research is really achievable within the settings as a whole in which it is intended to be carried out, particularly in view of the priorities and constraints in health and social care if the research will have an impact on care provision;

d) making ongoing funding conditional on a sponsor and relevant approvals being in place before the research begins (but not before initial funding is released, as some funding may be needed in order to put these in place); and

e) using contracts for making information about research publicly available before it starts (unless a deferral is agreed by or on behalf of the research ethics committee) and for retaining and making accurate findings, data and tissue accessible, with adequate consent and privacy safeguards, in a timely manner after it has finished.

ROLES AND RESPONSIBILITIES OF STUDY MANAGEMENT COMMITTEES/GROUPS & INDIVIDUALS

Project Oversight Group

We will establish a Project Oversight Group to meet on three occasions over the course of the study to provide overarching strategic guidance and independent scrutiny. This group will meet virtually because this is a time and environmentally friendly way to hold these meetings. The group will include two team members (LC, qualitative researcher), representatives from policy organisations e.g. Think Local Act Personal, National Development Team for Inclusion, a representative from a practice organisations, e.g.Wilf Ward Family Trust (working with adults with profound learning disabilities and high support needs), Changing our Lives (working with adults with learning disabilities and mental health difficulties) a researcher who has undertaken social care research with adults with learning disabilities and a researcher with expertise in measuring outcomes from adult social care. We will time the meetings so that the group can discuss our detailed plans as we finalise the review and begin qualitative data collection (meeting 1), hear and discuss our prototype development and plans for the developmental evaluation (meeting 2), and discuss our findings, conclusions and plans for dissemination and impact prior to finalising our draft report (meeting 3). Relevant work package leads will be invited to make presentations to the project oversight group according to the timing and as required.

Project Management Group

The Project Management Group includes the lead applicant (LC), all co-applicants and the grade 8 qualitative researcher. We will hold Project Management Group meetings every two months when all co-applicants come together to discuss progress, preliminary findings and next steps. We will meet virtually for project management group meetings. LC will chair these meetings with support from AOC. CT will prepare accessible meeting documents.

Speakup Project Working Group

The Project Working Group is a key element of the co-production approach taken throughout the study. The group is made up of a group of self advocates who have mild to moderate learning disabilities, with or without autism, and who are employed by Speakup Self Advocacy (n=6). Individuals in this group opted to join a small working group to develop this research and the application for funding. They will continue their involvement in the project by meeting regularly to support JB to represent them in Project Management Group meetings. The group will be supported by three advocates working for Speakup. Speakup members meet every week in a hybrid format. LC, CT and the qualitative researcher will join these meetings, either in person or online, every two months approximately two weeks before each meeting of the Project management Group to discuss the agenda and help JB to prepare for the meeting. Two members of the Speakup project group will deputise for JB at the Project Management Group meetings when needed. Speakup are costed as collaborators for this project and their advocates and self advocates will undertake this work in the course of their paid employment.

Project Advisory group

Members of the group prefer to be known as the project advisory group. We will establish an Project Advisory Group in WP1. This group will be facilitated by Clare Tarling, an experienced advocate for inclusive research for the Health Foundation and expert co-production facilitator.

We will recruit ten knowledge users to this group ensuring we have representatives from the major subsystems associated with commissioning, support planning and service provision, as well as two adults with learning disabilities and at least one carer of someone with a severe learning disability, to ensure we discuss issues of relevance across the full range of abilities and capacities. We will work with co-applicants and collaborators to identify relevant individuals and have already had conversations with a number of people who have expressed interest in joining this group.

We have struggled to find adults with learning disabilities who are willing and able to join our advisory group meetings despite our best efforts to make these accessible and inclusive. On reflection and following discussion with the Speakup project working group and the Project Management Group, we would like to offer different ways for adults with learning disabilities to contribute to the project. We will contact learning disability organisations and self-advocacy groups to find pre-existing groups of adults with learning disabilities who are willing to take part as a group, in face to face or online workshops. We will use these workshops to discuss our ideas about how ISFs work using accessible activities and topic guides tailored to the group members' experiences and capacity. We have spoken to two self-advocacy groups who have told us they would like to contribute in this way. We would also like to be able to offer individual online interviews in case any of the people we speak to would prefer to talk to us privately. Lewisham Speaking up and Thameside Peoples' First have already told us they would like to do one or more workshops with us. If possible, we will maintain a relationship with groups throughout the project so we can hold further workshops as the project progresses, although we will also run workshops with groups who tell us they want to make a one-off contribution, to make sure we get as many perspectives from adults with learning disabilities as possible.

We anticipate the project advisory group will meet online approximately six times per year. We will work with pre-existing groups of adults with learning disabilities separately as described and their views will feed into to these meetings. All members of the advisory group, and groups of adults with learning disabilities who have contributed as advisors, will be invited to join other stakeholders for three workshops in the second year to co-produce the actionable toolkits. If adults with learning disabilities and family carers would rather meet in separate groups we will offer this option. We have allowed for some flexibility to allow the group to set their own terms of reference and have a say in how often they would like to meet. We will send agendas and presentations in advance of these meetings using accessible formats, which may include videos and Easy Read formats, as the default for maximum inclusivity. Following each meeting an accessible report will be circulated including any follow up actions. Knowledge from this group will be synthesised and integrated into the project methods, findings and outputs as applicable and this will be tracked and shared with the group in subsequent meetings. The group will be made up of people with diverse experiences and perspectives and it will be important to take time to build relationships and rapport and agree vocabulary and terms of reference to prepare the group to work together productively, balancing the demands of productivity and inclusivity. This will include considering how to negotiate tensions as they arise.

Project Advisory Group meetings will be held to align with key stages of the project, such as refining the scope of the realist review and prioritising the program theories to take forward, developing the recruitment process and interview schedules for the realist interviews, discussing analysis and refining the mechanisms that are important for the provision and uptake of ISFs, planning the co-production workshops and the iterative refining of prototypes and planning the developmental evaluation. Meetings will focus on one main topic, dependent on the stage of the project, to ensure knowledge users are able to engage and play a significant role in developing, critiquing, prioritising and refining program theory throughout the project, as well as co-producing the final guidance.

We anticipate that project advisory group meetings will be online to allow a wide geographical spread and to reduce the travel and time commitment for members. We have budgeted £5 per person per hour for data usage. We have also included a small budget for travel and refreshments to allow flexibility for one face to face meeting per year to help build and maintain relationships. We have included payment based on NIHR INCLUDE guidance, for two adults with learning disabilities to join this group along with payment for a personal assistant or other support needed to ensure members can contribute to these meetings.

PROTOCOL CONTRIBUTORS

The research team brings together experienced researchers and people with specific expertise who share a commitment to making sure that people with learning disabilities are seen as equal human beings and to developing services that promote equality and improved quality of life.

Dr Liz Croot (lead applicant) has expertise in participatory research with people with LD, complex intervention development and realist methods. She will lead the project with mentorship from AOC, chair the Project Management Group, supervise the research associate and lead WP3 and 5. She will support Ms Jodie Bradley, PPI co-applicant, to ensure excellent PPI contribution to the project.

Professor A O’Cathain (Co-applicant) is an NIHR senior Investigator and experienced PI. She will meet regularly with LC to provide PI mentorship;

Professor Andrew Booth (Co-applicant) has extensive expertise in evidence synthesis and realist methods and will lead WP2;

Professor Chris Hatton (Co-applicant) has over 30 years' experience of policy-relevant research with people with LD in England, he will advise and provide connections to social care and learning disability researchers and relevant organisations;

Professor Robin Miller (Co-applicant) has an international reputation for leadership and implementation in health and social care, he has co-authored a guide to individual service funds and will ensure that this project is at the cutting edge of the latest evidence and experience in terms of adult social care implementation;

Mr Chris Watson (Co-applicant) is the founder of Self Directed Futures (https://www.selfdirectedfutures.co.uk/our-story) and has over 20 years' experience of working across the public and voluntary sector in health and social care and developing ISFs for adults with learning disabilities. He will identify and facilitate access to relevant ISF sites.

Mrs Clare Tarling (Co-applicant) (https://www.claretarling.co.uk/about) has a background in advocacy and support for people with LD and produces accessible materials for the Health Foundation's Inclusion Panel. She has expertise in co-production with people with learning disabilities and will lead WP1 and 4;

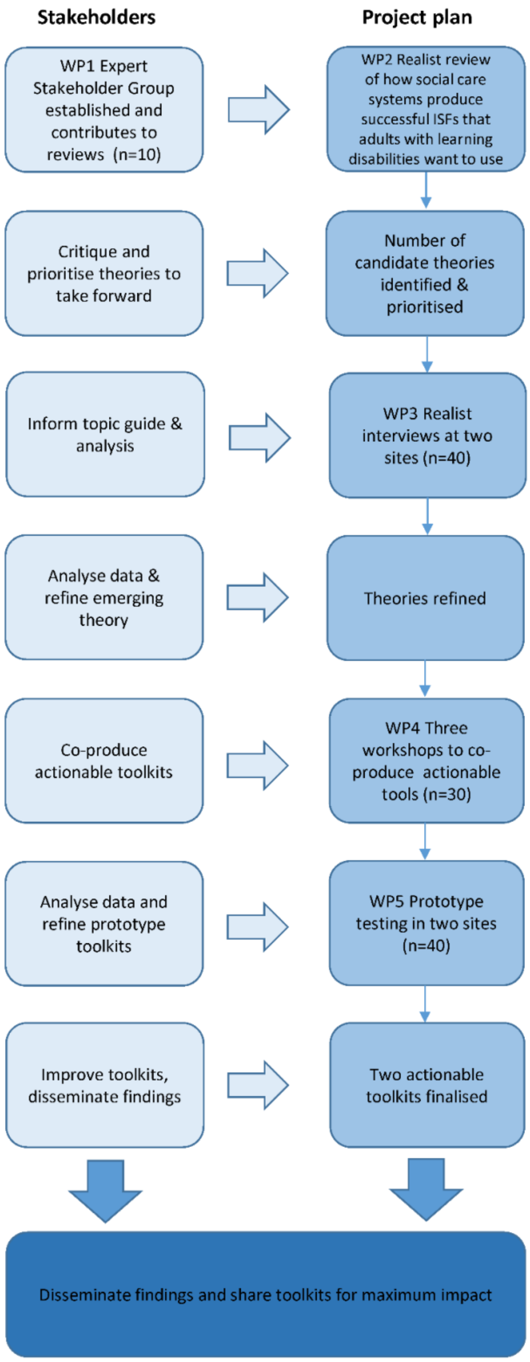
Ms Jodie Bradley (PPI Co-applicant) is a self-advocate from Speakup (https://www.speakup.org.uk/), she has worked as an advisor on previous research projects with LC, e.g. https://beingwarmbeinghappy.org and will ensure excellent PPI and service user input with support from LC and colleagues at Speakup;

Dr Steve Ariss (Co-applicant) is an expert in realist methodology and will support this aspect of the work. He has led approximately 15 evaluations over the past 5 years, many of which use Realist approaches and principles. He has published 10 peer-reviewed papers for studies that used Realist methodology and numerous evaluation reports;

Mr Clive Parry (Co-applicant) is the Director of the Association for Real Change (ARC England https://arcengland.org.uk/), the only membership organisation specifically for learning disability and autism providers. He will facilitate access to ARC membership and his networks

KEY WORDS:	Adults with learning disabilities, adult social care, personalised support, personal budget, individual service fund, co-production, realist research

STUDY FLOW CHART



Co-producing two toolkits of resources to promote EQUal Access to flexible support planning for Adults with Learning Disabilities (EQUALD)

1 BACKGROUND

In 2020/21, 39% of the total council spend on adult social care in England was for adults with learning disabilities, at a cost of £6.3 billion[1]. Learning disabilities are defined as a significant reduced ability to understand new or complex information and to learn new skills, with a reduced ability to cope independently, which started before adulthood[2]. They are distinct from learning difficulties like dyspraxia and dyslexia because they affect learning across all areas of life meaning people are more likely to need support to live their lives[3].

In 2020/21, 76% of adults with learning disabilities getting long-term social care were allocated some form of personal budget. Of the 76%, most (60%) had a council-managed personal budget[1]. Personal budgets are allocated according to an assessment of an individual's eligible support needs, as a means to allow people choice and control over the support they receive. However, these aims are not realised for many adults with learning disabilities because they have neither the knowledge or skills to manage their budget for themselves as a direct payment[4, 5]. Instead, most personal budgets for adults with learning disabilities are held and managed by local councils. This often means the individual does not know, or is not told, their own budget allocation or how their money is spent. Also the support available to meet people's eligible needs is often limited to block funded segregated services, for example a day service, or time and task focussed activities, for example 10 hours of one to one support per week, so the individual and their family and other allies do not have any control over the support they receive or how it is provided[6]. There is little flexibility to support individual interests and preferences, limited opportunity to participate in or take advantage of community assets, and systems are bureaucratic and unable to respond quickly when support needs change.

The Health and Social Care Act[7] introduced Individual Service Funds (ISFs) as a way to decouple a personal budget from a block grant so it can be used flexibly to tailor support to the individual, without the individual having to manage their own budget[8]. An ISF is defined as an arrangement where a council contracts with a service provider, who then works with the individual to hold their budget and determine how best to use this to accommodate their support needs according to their preferences and priorities[9]. Successful ISFs allow adults with learning disabilities and their allies to work creatively with a provider to develop a tailored support plan, linked to their assessed outcomes, that uses their strengths and community assets, and which is agile enough to adapt quickly to changing needs. An international evaluation of individualised funding for adults with learning disabilities found participants considered themselves to be more successful, empowered, independent, in control and with a greater sense of purpose when funding was individualised rather than block managed[6].

However ISFs are not yet widely offered to, or taken up by, adults with learning disabilities, despite the Care Act[7] identifying them as the preferred option for managing personal budgets. Therefore, attention is needed to support their reach and implementation[10] into complex real-world social care provision. Adult social care is a complex system made up of many different parts or subsystems[11]. The subsystems concerned with ISFs for adults with learning disabilities are: 1. Local authorities, 2. Support providers, and 3. Adults with learning disabilities and their allies. There are considerable gaps in knowledge about how these interdependent subsystems need to operate and interact in order to deliver and sustain successful ISFs.

Additionally, there is evidence that measures imposed through austerity and cuts to social care are having an adverse effect on local authorities' commitment to person-centred practice and service user empowerment[12]. Guidance is needed to help those working in social care to balance the demands on commissioning, planning, provision and governance of support, against the need to promote individual choice and control[9].

Finally, adults with learning disabilities may have reservations about taking up an ISF if processes are overly complex and systems are inflexible[6]. They need accessible resources to help them to decide whether an ISF is the right choice, and to both understand their allocation and to make meaningful decisions over how it is used[8].

Fleming et al[6] carried out a multi component international evaluation of individualised funding which included ISFs for adults with learning disabilities. They found participants considered themselves to be more successful, empowered, independent, in control and with a greater sense of purpose when funding was individualised rather than block managed. Adults with learning disabilities also enjoyed more opportunities to develop independent life skills, social and community connections and to engage with new opportunities and experiences.

A recent synthesis of qualitative evidence relating to individualised funding sought to identify key causal factors by which individualised funding improves self-direction, empowerment, independence, and self-determination. This review found that access to individualised funding was the key contextual factor, leading to a sense of freedom and flexibility not previously experienced by adults with disabilities within traditional models of service provision[13].

Evidence suggests that existing systems impede access to individualised funding for adults with learning disabilities where it has to be decoupled from a block grant[14]. Furthermore, people who lack the skills or capacity to act as consumers of care are often excluded from individualised funding in the form of direct payments[5]. ISFs offer the benefits of individualised funding without the recipient or their allies taking on the burden of managing a budget. However, significant gaps in knowledge persist regarding how best to implement ISFs and how to overcome the barriers to their use within adult social care.

2 RATIONALE

Social care for adults with learning disabilities is under researched and there are long-standing problems associated with the current funding arrangements, and the impact that cuts to funding have on packages of care, provider sustainability and recipient outcomes[15]. ISFs offer the potential to improve this situation by allowing providers to work with the people they support to develop creative care packages tailored to their preferences and needs[13].

The UK Government White Paper, ‘People at The Heart of Care: adult social care reform’ is built on the principles of choice, control and fair access to outstanding support[16]. This project contributes to these principles by increasing access to ISFs.

ISFs also have the potential to increase capacity within the social care workforce by reducing bureaucratic processes. Outputs from this project will be relevant across the whole of adult social care for people with learning disabilities. There are an estimated 1.5 million jobs in the adult social care workforce of which 41% (665,000 jobs) are involved in providing care and support to people with learning disabilities[17] Transferring the work of support planning to care providers and allowing them to subcontract at a local level can extend the social care workforce. Providing opportunity for joint working with other providers and social workers may also build job satisfaction leading to increased recruitment and retention of the workforce.

This new way of working harnesses momentum from the pandemic during which support providers had to think creatively about how to meet needs and make changes to support without getting needs reassessed.

Finally, ISFs are also a potential means for delivering personal health and social care budgets[18] to other populations who lack the skills or capacity to manage a direct payment, for example people with dementia or mental health service users, thereby broadening the reach and relevance of this work.

3 THEORETICAL FRAMEWORK

This work is grounded in the social model of disability which situates the oppression, exclusion and discrimination experienced by disabled people in society that serves to exclude and discriminate against them [19]. We believe that people are equal citizens and have the same human, legal and civil rights as each other. The project aims to improve equality of access to personalised care planning so that people can exercise choice and control over their lives with as much or as little support as they need, recognising that we are all interdependent and we all need support in our lives.

Furthermore, we aim to co-produce the project with adults with learning disabilities, adhering to the principles of: sharing power; including all perspectives and skills; respecting and valuing the knowledge of everyone; reciprocity and mutuality; and understanding each other, as far as possible within the embedded hierarchies and structural limitations of universities and research funding systems [20].

The project takes a realist perspective incorporating a complex systems approach. Realist perspectives are theory driven and aim to offer causal explanations for observable phenomena, answering the question what works, for whom, in what circumstances and how? [21] The project will explore the observable architecture of a successful ISF offer by describing the resources offered by the different subsystems involved in the development or delivery of an ISF. However, realist approaches aim to go beneath the observable efforts of a programme to explore how actors respond to those resources, in order to hypothesise the generative forces that are the cause of things happening. These hypotheses are typically described using Context-Mechanism-Outcome chains (CMOCs) in which the **M**echanism is the resource and the response to that resource, triggered by a particular physical or social environment or **C**ontext, to produce an **O**utcome, which may be intended or unintended. In line with our commitment to co-production we will work with stakeholders to prioritise and explore relationships between CMOCs to propose mid-range theories, thereby providing a level of abstraction that is more 'portable' than the empirical data.

4 RESEARCH QUESTION/AIM(S)

How should systems be configured for optimal delivery of ISFs to adults with learning disabilities and how can guidance overcome the barriers to their use within adult social care?

Aims

3. To understand how important mechanisms operate in the context of social care systems to support or hinder the offer, uptake, and sustained provision of successful ISFs for adults with learning disabilities.
4. To co-produce and carry out a formative evaluation of actionable toolkits of resources to support the delivery of ISFs at scale for this population.

4.1 Objectives

1. To ensure strong and early engagement with practice by working with knowledge users throughout the project

2. To identify initial programme theories that lead to successful and sustained provision of ISFs by carrying out a realist synthesis of research evidence, policy documents and grey literature.
3. To refine and consolidate theories by carrying out interviews in two local authorities offering ISFs.
4. To identify mid-range theories that provide a broad explanatory schema of transferable lessons.
5. To co-produce two actionable toolkits: to support development, delivery, and sustained provision of ISFs; and to support uptake and optimal use of ISFs by recipients.
6. To evaluate and further develop these toolkits by using them in two local authorities not yet offering ISFs.

4.2 Outcome

The outcome for the study will include two research derived actionable toolkits. The first will support local authorities and support provider organisations in the development, provision and governance of ISFs. The second will support adults with learning disabilities and their allies to make decisions about whether to take up the offer of an ISF and how to get the most from an ISF.

5 STUDY DESIGN and METHODS of DATA COLLECTION AND DATA ANALYSIS

We will use a realist perspective incorporating a complex systems approach to guide the design and conduct of the project[10, 22, 23]. We will also work closely with knowledge users to co-produce the research[24] and actionable toolkits[25] for the delivery of successful ISFs[26].

Adult social care is a complex adaptive system[27] comprising numerous interdependent subsystems involved in funding, commissioning, assessing, planning and delivering, monitoring and reviewing support. Adults with learning disabilities and their allies have to interact with these subsystems at multiple points in order to access the support they need to live their lives. Understanding how ISFs can be used to develop and fund packages of support in the context of adult social care, requires a complex systems approach to explore the interests, relationships, functioning and interactions within and across sub-systems[28], as well as an exploration of the experience and outcomes for adults with learning disabilities and their allies.

Realist methods use multiple knowledge sources to generate and test theories about how and why policies and interventions work or do not work under a particular set of circumstances for certain people[11]. Using these methods, we will combine desk-based realist synthesis with primary data from interviews with key informants[29, 30]. We will also work with knowledge users in an Project Advisory Group throughout the project, to identify and prioritise critical issues relating to the provision and uptake of ISFs. We will build and refine programme theory within sub-systems and explore areas of contact and relationships between subsystems and across the entire system in order to develop an understanding of the mechanisms by which social care systems can produce a successful ISF offer. We will also identify and prioritise critical issues relating to decision making about whether to take up an ISF offer for adults with learning disabilities and their allies.

We will use this learning to work with a larger group of stakeholders, to co-produce two toolkits of actionable tools[25] to support the provision and uptake of ISFs in practice. We will work within a minimum of two local authorities, using Developmental Evaluation principles[31] to test and refine prototype resources before producing the final toolkits to support the development, provision and uptake of future ISFs at scale.

DESIGN

Five work packages to be undertaken sequentially.

Work package 1 Utilising a research co-production model.

This WP will be led by Clare Tarling, an experienced advocate for inclusive research for the Health Foundation and expert co-production facilitator.

Research co-production is a model of collaborative research that explicitly responds to knowledge user needs in order to produce research findings that are useful, useable and used. Collaboration in co-production research is characterised by shared decision-making between knowledge users and researchers, with mutual learning and respect[24]. Knowledge users are a subset of stakeholders who are going to use knowledge including but not limited to policy makers, local authorities, commissioners, social care providers and adults with learning disabilities and their allies. In line with the principles of co-production[32] we will work with knowledge users throughout the research process and aim to include all relevant perspectives and experiences, paying particular attention to those working in underserved areas or from seldom heard groups.

We will recruit ten knowledge users to a project advisory group ensuring we have representatives from the major subsystems associated with commissioning, support planning and service provision, and at least one carer of someone with a severe learning disability, to ensure we discuss issues of relevance across the full range of abilities and capacities. We will work with co-applicants and collaborators to identify relevant individuals and have already had conversations with a number of people who have expressed interest in joining the project advisory group . We will develop an information sheet for prospective members of this group outlining the aims of the project and the nature of their involvement. The information sheet will also be produced in accessible formats, depending on the access needs of the prospective group member. For example, we may use a short video to explain the project and the work of the project advisory group to supplement an Easy Read information sheet. We would like to offer a range of ways for adults with learning disabilities to contribute to the advisory group. We will contact learning disability organisations and self-advocacy groups to find pre-existing groups of adults with learning disabilities who are willing to take part as a group, in face to face or online workshops. We will use these workshops to discuss our ideas about how ISFs work using accessible activities and topic guides tailored to the group members' experiences and capacity. We have spoken to two self-advocacy groups, Lewisham Speaking up and Thameside Peoples' First, who have told us they would like to contribute in this way. If possible, we will maintain a relationship with groups throughout the project so we can hold further workshops as the project progresses, although we will also run workshops with groups who tell us they want to make a one-off contribution, to make sure we get as many perspectives from adults with learning disabilities as possible. We will consider all these contributions part of the project advisory group. We would also like to be able to offer individual online interviews in case any of the people we speak to would prefer to talk to us privately. We will offer £25 per person as vouchers or cash, to anyone who takes part in an interview, or a workshop and we will ask whether people would prefer to be receive this individually or as a contribution to their group. We have obtained University ethical approval to allow use to treat conversations that take place with any members of our advisory group, as data.

We anticipate the advisory group will meet online approximately six times per year and members will be invited to join additional stakeholders for three workshops in the second year to co-produce the actionable toolkits. However, we have allowed for some flexibility to allow the group to set their own terms of reference and have a say in how often they would like to meet. We will send agendas and presentations in advance of these meetings using accessible formats, which may include videos and Easy Read formats, as the default for maximum inclusivity. Following each meeting an accessible report will be circulated including any follow up actions. Knowledge from this group will be synthesised and integrated into the project methods, findings and outputs as applicable and this will be tracked and shared with the group in subsequent meetings. The group will be made up of people with diverse experiences and perspectives and it will be important to take time to build relationships and rapport and agree vocabulary and terms of reference to prepare the group to work together productively, balancing the demands of productivity and inclusivity. This will include considering how to negotiate tensions as they arise[24]. Subsequent meetings will focus on one main topic, dependent on the stage of the project, to ensure knowledge users are able to engage and play a significant role in developing, critiquing, prioritising and refining programme theory throughout the project, as well as co-producing the final guidance[26]. For example, in year one, a meeting will focus on refining the scope and questions for the realist review – see WP 2.1.A.

We anticipate that co-production meetings will be online because of the geographical spread. We have budgeted £5 per person per hour for data usage. We have also included a small budget for travel and refreshments to allow flexibility for one face to face meeting per year to help build and maintain relationships. We have included payment based on NIHR INCLUDE guidance, for two people with learning disabilities to join this group along with support costs. We have also included payment for two family members of adults with severe learning disabilities to join the group. We anticipate that other members will contribute to this co-production group in their paid roles.

Work package 2 Realist review of published research, policy and grey literature

This WP will be led by Professor Andrew Booth, a co-developer of realist search methods and experienced leader of NIHR realist synthesis.

Our initial systematic scoping search has revealed that the evidence base for individual service funds is small, with fewer than two hundred peer reviewed articles of direct relevance. Insights from the wider literature relating to “personal budgets” and “self-directed support” may prove valuable but must be moderated by recognition that this could extend the focus beyond the populations and contexts that form the basis for this proposal. We have therefore privileged depth, rather than breadth, in seeking to develop and test theories of change associated with ISFs using realist approaches rather than descriptive mapping through conventional systematic review methods. Nevertheless, the tight focus of this realist review, feeding into *WP2.1 Refining the Review Scope and Developing Initial Programme Theories*, permits a comprehensive approach to current ISF models clustered around their principal characteristics. More importantly, it allows us to focus on mechanisms critical to successful delivery of individualised funding as perceived by different stakeholder groups. Subsequently, we will prioritise these according to their explanatory potential so that we can identify and explore pathways to delivering successful ISFs.

We will use three principal types of literature; published research, policy documents and grey literature. This requires three different but complementary search strategies as detailed below. At the same time we will scope and map the evidence base for any type of individualised funding which includes direct payments, in order to identify contexts, mechanisms and outcomes that are meaningful indicators of success.

Realist methods provide a way of generating theories about policies and processes and why they work, for whom and in what context, optimising the value of a relatively small number of studies privileged according to relevance, richness and rigour. We will augment this review of literature with discussions with our Project Advisory Group to prioritise and validate findings from the literature review. A particular feature of realist methods is its focus on outcomes. As a social care topic our review potentially benefits from the Adult Social Care Outcomes Framework (ASCOF) which measures how well care and support services perform nationally[33]. Consequently, selected ASCOF outcome indicators will inform the review. Relevant indicators may include; Indicator 1B. Proportion of people who feel they have control over their daily life; and Indicator 3D1. Proportion of service users who find it easy to find information about support. Potential outcomes for family members and carers include ASCOF indicators 1d) Carer-reported quality of life, 3b) overall satisfaction of carers with social services and 3c) the proportion of carers who report they have been included or consulted in discussion about the person they care for. If necessary our review will start from proximal and/or surrogate outcomes that are theorised to relate to distal ASCOF outcome indicators, for example we may focus on mechanisms that increase time with friends or family as a proximal indicator leading towards Indicator 1I(1) Proportion of people who have as much social contact as they would like. We will work with the Project Advisory Group to select relevant outcomes.

Overarching Approach to Literature Searching

The overall search approach will follow the published approach to the "realist search", co-developed by AB[34]. The realist search outlines 4 separate and distinct phases of searching using different retrieval techniques and targeted at different evidence bases (conducting the background search, searching for programme theory, searching for empirical studies, searching to refine programme theory and identify relevant mid-range theory)[34].

Search strategies within each phase will be developed and operationalised by an experienced information specialist (AB), balancing the specificity of "individual service funds" with the sensitivity of terms relating to personal budgets, self directed support, direct payments and personalisation. Given that the intervention is self-defining no date limits will be used when operationalising the search; preliminary searches indicate little or no mention of "Individual service funds" prior to 2004. Likewise, inclusion of evidence will be limited to papers in the English language and in high-income settings (OECD countries) to maximise retrieval of evidence of relevance to the UK health and social care systems.

Policy documents. Previous reviews only utilised reports commissioned by the Department of Health and the then Scottish Executive to identify additional studies missed by the search process[35]. In contrast, realist methodology recognises that such policy documents provide potentially valuable insights into the putative mechanisms advanced by programme developers. We shall therefore follow up all relevant policy documents and analyse their descriptions of how ISFs are planned and expected to work including local policies and service specifications. Recommendations set out in policy guidance or service specifications rest upon implicit or explicit theoretical assumptions regarding implementation. Moreover, inclusion of policy documents will help to ensure that governance issues are considered alongside intervention success so that the review is appropriately contextualised. The National Archives website http://nationalarchives.gov.uk/cabinetpapers and http://www.legislation.gov.uk/ will be accessed to identify relevant government discussion papers and legislation.

The search approach will be truly consultative, engaging with the Project Advisory Group throughout[34], consulting as required to provide advice (for example clarifying terminology) and help with identifying relevant literature.

Review Phases

WP 2. 1: Refining the Review Scope and Developing Initial Programme Theories

This phase aims to identify and make explicit (through CIMO configurations[36, 37]) an initial set of programme theories to explain how ISFs can be developed and used to achieve optimal outcomes, for whom and in what contexts? Given the variability of policies and use of ISFs across different local authorities, an important part of this process will be to prioritise the most important questions and outcomes. WP2.1 involves 3 inter-linked stages (A-C).

WP 2.1.A – Refining the Review Scope - Consultation and Formulation of the Focused Question

We will work with our Project Advisory Group to refine the review questions and shape the associated search strategies. We will ask the Group to share their own stories and experiences of ISFs and describe what best practice looks like, either for themselves or for people like them. This early work to share different experiences and perspectives will foster team building and sensitise the Group to realist review methodology and the project plan. We will ask people to consider different contexts and populations, as capacity allows, and discuss how (i.e. through which mechanisms) they feel best practice can be achieved. They will be asked to prioritise the key questions and outcomes they feel are most relevant as lines of enquiry for achievement of ISF success. WP2.1.A will yield a refined set of research questions and an initial set of programme theories.

WP2.1.B – Searching to Identify and Develop Initial Programme Theories

This stage will utilise the insights from WP2.1.A to search for, and identify, key papers (of any study design) on delivery of ISFs that can yield insights for programme theory development. The search is iterative, utilising searches on electronic databases, suggestions from the Project Advisory Group , citation tracking and reference list searching of conceptually rich ‘index papers’.

Grey literature searching. Initial scoping searches suggest that grey literature sources are potentially plentiful and valuable. We have developed a series of Internet domain-specific searches related to local government (site: gov.uk) and health services (site: nhs.uk) to allow systematic harvesting of grey literature. We will also access the collections of UK health and social care libraries such as the King’s Fund, The Nuffield Institute and The Health Services Management Centre (HSMC) Library at the University of Birmingham and the Scottish Health Service Centre Health Management Library.

Each included paper will be scrutinised to elucidate how ‘success’ in ISFs is defined and to identify mechanisms through which successful interactions are purported to work within different configurations of context and population groups. Reviewers will extract details of key theories (‘candidate theories’) as used to explain mechanisms by which ISFs achieve success. Key characteristics for each paper will be extracted to Excel. The team will then use NVivo to code key findings related to success factors. Where possible, findings will be coded and analysed against If, Then, Leading to statements (Context, Mechanism and Outcome Configurations)[38], helping to generate initial ideas around relevant programme theories. The coding and analysis templates for the reviews in this stage will be developed and piloted by the review team. The majority of the coding will be undertaken by the Gd7 reviewer, with the Gd8 completing a random sample of approximately 20% to monitor quality and consistency. The findings of this stage will be presented using tables, figures, flow charts and narrative summaries highlighting key features of the evidence and describing potential programme theories. We will also record an accessible video to explain this stage and share findings more widely.

We have found little empirical literature focusing on ISFs and so our searching has focussed on the different components that make up an ISF, that is, individualised budget, person centred planning, asset-based care and outcome focussed support. We originally planned to generate theory from the literature and with the help of our advisory group, then carry out interviews in work package 3 to test and refine theory, in two distinct stages. However, we are finding that the processes of theory gleaning, theory refining, and theory testing are highly iterative and overlapping and so we would like to start our interviews now.

We are aware that there is considerable expertise in developing, delivering and using ISFs within our project team and advisory group. We would like to use individual semi-structured interviews with members of these groups to capture more in-depth information than is possible in the full project team or advisory group setting. We plan to carry out semi structured interviews (n=10-12) to contribute to theory gleaning and refining thereby supplementing what we have found in the literature and what we hope to learn from the proposed workshops and interviews with adults with learning disabilities prior to recruiting two local authorities for work package 3 – theory testing and refining. There is a lack of clarity about the nature and contribution of knowledge generated through patient and public involvement and used in realist theory development, and the extent to which this is considered data. As a result we have applied for, and been granted, university ethical approval to consider interviews and conversations with members of the project team and the advisory group, as data.

Output of WP 2.1.B: Accessible summary report to be shared with the whole project team and to inform ongoing work.

WP 2.1.C – Consultations and Development of Initial Programme Theories

The final stage of this work package will comprise another Project Advisory Group meeting in which the findings of the theory-identification searches and analyses will be presented in accessible formats and discussed. The Group will discuss and refine the key focus of the review and critique the initial programme theories. These will then be tested and explored in WP2.2. Outcomes for discussion may include patient-focused outcomes such as increased social contact (towards ASCOF Indicator 1I.1) , increased opportunity to choose activity (towards ASCOF Indicator 1B) , and a focus on relationships, empowerment, and improved wellbeing and quality of life in line with Adult Social Care Outcomes Framework (ASCOF) indicators.

WP2.2: Evidence Retrieval, Review and Synthesis

The aim of WP2.2 is to determine whether initial programme theories are supported by empirical evidence and to analyse this evidence to elaborate, refine, adjust and test the theories. This Phase continues the iterative process of literature searching, data extraction and analysis.

Search Strategy. The search for empirical studies will use iterative, carefully formulated searches based on sub-sets of literature constructed using terms generated from the initial programme theories (CIMO frameworks) and key concepts[34, 39]. Given the focus on knowledge user perspectives throughout this review it is appropriate that most identified empirical studies will be qualitative research studies although quantitative and mixed methods studies will be identified and assessed as appropriate. Extracted data will be used to explore and elaborate the initial programme theories.

In the first instance, the main focus of the search for evidence will be for literature related directly to UK settings. However, in a realist review, the focus of analysis is the programme theory (or mechanism of action) – hence we may also draw upon wider literature to seek opportunities for transferable learning.

The searches will include systematic reviews and empirical research of any study design, including service evaluation, audit and quality improvement projects. As in WP2.1, search sources will include electronic databases, grey literature and knowledge users (see Table 1 below). Additional search approaches will include reference list searching, citation tracking and identification of sibling papers (linked papers from a single study). The team has developed methods of cluster searching[39] which involves building up rich 'cases' of different models of delivery of ISFs in order to grow a cluster of related reports around named or identifiable initiatives to offer both richness and detail. Searches in a realist review are not necessarily exhaustive but follow the principles of theoretical saturation.

Table 1 -Sources of Evidence

Peer Reviewed Literature	**Policy documents**	**Grey Literature**
• ASSIA Cambridge Scientific Abstracts (Applied Social Sciences Index and Abstracts)	National Archives website http://nationalarchives.gov.uk/cabinetpapers	http://www.york.ac.uk/crd/web
• British Nursing Index	http://www.legislation.gov.uk/	http://www.scie-socialcareonline.org.uk/

• CINAHL Plus (Cumulative Index to Nursing and Allied Health Literature)	Domain-specific searches for local government (site: gov.uk)	http://scholar.google.co.uk/
• Cochrane Central Register of Controlled Trials		http://www.scie-socialcareonline.org.uk/
• Cochrane Database of Systematic Reviews		http://www.campbellcollaboration.org/
• Embase Ovid		http://www.cochrane.org/cochrane-reviews
• Google Scholar		http://www.york.ac.uk/crd/web
• JBI Library		http://www.joannabriggs.edu.au
• MEDLINE Ovid		http://www.latrobe.edu.au/socialwork/schoolstaff/chris.htm
• PsycINFO Ovid		• Conference proceedings
		• ProQuest Dissertations & Theses
		• EThOS – British Library Electronic Theses Online

		• Project Advisory Group
		• Stakeholder groups
		• Others (e.g. via social media requests, email listservs)
		COPAC
		• OpenGrey
		• Domain-specific searches for health services (site: nhs.uk)
		UK health and social care libraries (e.g. King's Fund, Nuffield Institute, Health Services Management Centre (HSMC) Library (University of Birmingham)

Selection and Appraisal

The information specialist (AB) will import records into EndNote and remove duplicates. Two reviewers will undertake study screening and selection independently, with reference to other team members in cases of disagreement. Records will initially be screened by title and abstract. All seemingly relevant full-texts will then be examined and reasons for exclusion noted in a table. In line with realist methodology, the reviewers will screen records for inclusion based on relevance, rigour and richness.

Quality assessment examines specific data relevant to a specific programme theory, rather than a global evaluation of overall study quality. For each included paper, the team will ask: "is the evidence provided in this theory area good enough and relevant enough to be included?" The team will articulate and record these judgements for each study during the screening and data extraction process (see below).

Data Extraction, Analysis and Synthesis

Reviewers will extract data from included studies in two ways[40]. First, they will extract information about study characteristics into a summary table[28] (as with a conventional systematic review). This will include information on features such as study setting, design, methods, and technology, participants, outcomes and characteristics of the individual service fund scheme. Second, the team will develop a purpose-specific data extraction form based on the initial programme theories. The form will include sections in which to note assessments of relevance, richness and rigour. Theory-based coding and charting of relevant data will identify elements of the theory related to what works, for whom, how and in what contexts. The analytical process involves both deductive and inductive coding. Deductive coding involves extracting data that appears to be directly related to aspects of the programme theory. Where it is possible to make relevant inferences, data is also coded in relation to contexts, mechanisms or outcomes. However, the evidence may also reveal new contexts, mechanisms or outcomes which are identified and then coded inductively.

The review team will work collaboratively to develop data extraction templates and associated analytical processes and these will be extensively piloted. Once the team has achieved a coherent, transparent and consistent approach, the remaining data extraction will be undertaken by one reviewer, with a second reviewer checking approximately 20%. The outputs of this stage will be a set of evidence tables. A single overarching table will represent the key characteristics of all the studies included in the review. Supplementary tables will then represent each initial programme theory and the literature that supports it. Thus, each theory area will be supported by its own evidence table.

Data analysis will be ongoing and iterative. The team will review evidence within and across the theory areas to explore how it builds upon, refutes or provides alternative explanations for the initial CIMO configurations. Analysis involves asking: “What does this evidence suggest about this aspect of our theory? Does it support it? Does it disprove it? Does it suggest an amendment to it?”[41] This analytic process involves both abductive and retroductive reasoning – i.e. making new observations from the evidence, inferring plausible explanations related to the programme theory, seeking to understand the cause of perceived events beyond what can be observed and seeking to identify over-arching patterns.

The analytic process is highly resource intensive. The entire research team will be engaged in frequent meetings, requiring much discussion and deliberation. Findings from these searches will require testing of new insights, adjustments or elaborations made to the theoretical propositions. We will work closely with the Project Advisory Group to seek their views and test out new ideas.

Output of WP 2.2: A comprehensive set of evidence tables and refined programme theories about how adult social care systems can be configured to deliver ISFs which appeal to adults with learning disabilities and contribute to improved outcomes from social care

Work package 3 Realist interviews with key informants.

This WP will help us to understand what success looks like from the perspectives of participants and understand what contributes to the success of an ISF offer[30]. Dr Liz Croot is an experienced qualitative and realist researcher and will lead this work package with realist methods support from Dr Steve Ariss. We will apply for ethical approval from a social care flagged research ethics committee.

Site recruitment

We will identify two local authorities with a functional ISF offer who have contrasting demographics and experiences of developing, delivering and monitoring ISFs. The Project Advisory Group (WP1) and the evidence review (WP2) will help us identify important variations to consider when selecting sites. Chris Watson (co-applicant) from Self Directed Futures will facilitate access to relevant local authorities and individuals through his networks.

For example, we plan to work with a site in Dorset for this work package. In Dorset there are problems with the availability of support because of the rural nature of communities. Commissioners have found solutions to this by working with a number of small provider organisations to develop creative support packages using ISFs. We plan to recruit a second site which includes urban areas to provide some variation in the contexts in which ISFs have been used and the challenges and experiences of those commissioning and delivering services as well as those receiving support.

Sampling for interviews

The sampling strategy for these interviews will be theoretically driven and carried out according to systemic and individual features of each setting. We aim to interview potential enactors and beneficiaries[42] who are likely to have insight into the mechanisms by which ISFs are developed and delivered, and the contexts that mediate these mechanisms, as well as the desired and potential unintended outcomes from an ISF. We will work with local authority contacts to identify and recruit approx. 20 participants from each site. We anticipate recruiting 4 adults with learning disabilities who have an ISF, from each site. We will aim for maximum diversity across a range of different support needs, co-morbidity, ethnicity, gender and other characteristics identified as important during WP1 and 2. We will also recruit family carers of adults with severe learning disabilities who have an ISF but do not have capacity to be interviewed to ensure we capture information about the use of ISFs across a range of abilities and support needs. We will include family members, social care providers, learning disability commissioning managers and other local authority staff concerned with the provision of ISFs. Through our discussion with the advisory group it has become clear that there is considerable variation in the way that local authorities develop and deliver ISFs therefore we would like to recruit interview participants from more than two local authorities. We plan to focus on at least one urban and one rural site, in line with our original proposal, but to augment these with individuals from sites with a different ISF offer. We hope this will also help us meet potential gaps in expertise or recruitment within our main two Local Authorities. We will still carry out 40 semi structured interviews in total, including 8 adults with learning disabilities who have ISFs, or their carers.

Recruitment

We will develop accessible study information with Jodie Bradley our PPI co-applicant and the group at Speakup. We will work with our stakeholders to identify potential participants with learning disabilities and family members and ask a trusted person, for example a support provider, to discuss the project information with them. The trusted person will ask permission for us to contact the participant. We will send accessible project information and contact them by telephone or email to ask if they have any questions and if they would like to take part in an interview. Where we are recruiting an adult with learning disabilities we will check whether they prefer to be contacted directly or via trusted third party.

We will work with each local authority to identify social care providers, learning disability commissioning managers and other local authority staff concerned with the provision of ISFs. We will work with each site to identify ways to engage with potential participants, for example, presenting at relevant meetings, publicising the project via relevant staff group email lists and writing for organisational newsletters. We will ask for permission to contact those who express interest in taking part. We will share project information and contact potential participants by telephone or email to answer any questions and arrange an online or telephone interview.

Additional participants from outside the two main Local Authorities will be recruited via our networks, for example, the ISF Forum, Self-Directed Futures, ARC England and Citizen Network. Purposive sampling will be used to identify participants who have expertise in specific aspects of ISF development or delivery or who offer a different service model to that of our two main sites. Ethical approval from the University of Sheffield has already been granted for the interviews recruited outside of the Local Authorities.

Data collection

Interviews will take place either online or by telephone. Interview schedules will be informed by WP1 and 2. They will be tailored to the roles of respondents to align with their experiences of commissioning, delivering or taking up an ISF offer[43]. Interviews will cover experiences of ISFs and factors that contribute to their success, barriers to widespread use, resources required, outcomes observed or expected, unintended consequences and any other behaviours or mechanisms that may impact on the success of ISFs[44]. We will use ASCOF indicators ((see WP2) as indicators of successful delivery of individualised funding (what works) and we will seek to identify mechanisms that lead to these, or to proximal components of these outcomes, Interviews with adults with learning disabilities will use inclusive methods in a responsive way, for example asking about concrete experiences rather than abstract ideas and asking either/or questions if participants appear to be acquiescing with either the researcher or their supporter[45]. They may also use visual materials, for example a weekly planner, to prompt discussion. We will pilot interview schedules and methods for interviews with adults with learning disabilities with our PPI co-applicant and the group at Speakup.

Data Analysis

Interviews will be audio recorded and transcribed. Data will be analysed iteratively by the research team based on a ‘best fit framework synthesis’ approach[46]. This comprises a deductive stage where data are mapped to programme theories from WP2, in order to test, refine, or refute them. An abductive analysis will take place concurrently to elicit new theories not yet accommodated by the framework. New and developing theories will be included in subsequent interview schedules and refined theories will be updated. In this way we will both refine and expand the programme theories.

Output from WP3 will be a set of refined and preliminarily prioritised explanations about how adult social care systems can be configured to deliver ISFs which appeal to adults with learning disabilities and contribute to improved outcomes from social care. These explanations will display an awareness of the interplay of complex systems, incorporate relevant contextual factors and indicate what works best for whom, in what circumstances and why.

Work package 4 Co-producing research derived actionable toolkits.

Clare Tarling (co-applicant) has expertise in advocacy and co-production with adults with learning disabilities. She will lead this work package.

We will co-produce two parallel toolkits of accessible research derived actionable tools[25].

1. One toolkit will support systems within adult social care to develop, deliver and maintain successful ISFs
2. One toolkit will support adults with learning disabilities to decide whether to take up an ISF offer and to ensure their voice is heard in the planning of their support package.

Actionable tools are designed to communicate new knowledge in a format that prompts and enables the end user to take action, or to implement that knowledge within the local setting[25]. Examples of actionable tools include guidelines, service specifications or decision aids. Important features include: the ability to tailor to local context; information on who needs to take action; information to support implementation; testimonies from other users; and information on outcome measures to support the tool in practice. Refined and tested assumptions about how the tools will work in different settings will be a key focus informed by user engagement throughout the project. The toolkits are likely to distinguish between core elements (‘must-haves’) and peripheral elements (tailored for each setting) to ensure that implementation can be informed by local knowledge.

We will work with our project advisory group (WP1) and collaborators to identify approximately 30 additional participants to join up to three online workshops to co-produce the actionable toolkits. We aim to recruit a purposive sample of people to ensure representation from across adult social care as well as adults with learning disabilities and their allies and carers of adults with severe disabilities.

Materials for these workshops will be in an Easy Read format as default. We have also budgeted for two to three smaller workshops which will allow us the flexibility to consult with other groups, for example from a particular ethnic background, who may otherwise be under-represented in the larger workshops and who may prefer to contribute in a smaller, homogenous group. Where possible we will offer these smaller groups the option of face to face or online meetings to try to maximise participation.

The co-production workshops will bring people with different experiences and perspectives together as active partners. Co-producing actionable tools with partners who have insider knowledge of the context in which they will be used is helpful in supporting the impact of the tools and reducing research waste[47, 48]. Refined and tested assumptions about how the toolkits will work in different settings will be a key focus of the project informed by extensive user engagement throughout the project. The tools are likely to consist of core elements (‘must-haves’) and peripheral elements (tailored for each setting) to ensure that implementation is informed by local knowledge. The format of these workshops and the design and content of the toolkits cannot be pre-empted, but we will use iterative and collaborative processes to share findings from WP2 and WP3 and elicit experiential knowledge from stakeholders in the co-production workshops. For example, we may use personas, which are fictional accounts of individuals that represent people with specific characteristics[49], to illustrate how particular mechanisms of action may differ depending on context. We may also use visioning[50], where participants are asked to imagine what an ideal ISF would look like from a range of different perspectives and then to consider steps to make this possible. By valuing all contributions and using creative activities we will facilitate a shared understanding of diverse problems, identify important needs and consider ways to address these. Data from these workshops will include notes, audio recordings and other digital or material products generated during the meetings. We will use iterative prototyping between workshops to translate knowledge into practical tangible objects which are useful for generating feedback in subsequent workshops to inform further development[51].

Our intention is that these workshops will be iterative, and the outputs will be cumulative, so we aim to retain the same group of stakeholders throughout as far as possible. We recognise this might not always be possible and will work with participants to identify replacements where necessary.

Outputs from WP4 will be two prototype actionable toolkits.

Work package 5 Prototype testing

Dr Liz Croot will lead this workshop with support from Dr Steve Ariss and Professor O’Cathain who have expertise in evaluation across a variety of contexts. We will include this work package in our application for ethical approval from a social care flagged research ethics committee.

Site recruitment

We will identify two local authorities not currently offering ISFs to take part in a developmental evaluation[31] to explore relevance, acceptability and utility of the prototype tools and inform further refinement. We have had preliminary talks with commissioners at Sheffield and Oldham Councils about collaborating on this stage of the research. These are two councils that are actively exploring the use of ISFs so there may be mutual benefit from collaborating at this stage of the project. These two sites will allow us to access diverse ethnic and socioeconomic populations and to contrast urban and suburban settings with more rural areas, for example Dorset, the possible site for WP3.

Recruitment and Sampling

We will work with each site to identify relevant individuals to test the prototypes. The sample will include local authority staff and service providers who will test the first toolkit. Adults with learning disabilities and their allies will test the second toolkit. We cannot predict exactly how many people will be offered an ISF at each site so we cannot be precise about the sample size for this work package. However we aim to recruit approximately 10 people to test each toolkit in each site, including a minimum of 6 adults with learning disabilities in total. We will ask the two local authorities to contact relevant people with information on the evaluation to ask if they would be willing to take part. Contact details of those willing to take part will be passed to the research team. Potential participants will be contacted by a member of the evaluation team to answer any questions, gain consent and provide the actionable toolkits. We will use accessible project information and trusted third parties for adults with learning disabilities, as described in WP3.

Data collection

We will ask local authority staff and service providers to use the first toolkit and adults with learning disabilities to use the second toolkit for approximately 12 weeks. We anticipate that this duration will allow for meaningful use of the toolkits. As services adapt over time, we will explore within and between service adaptations, as well as any challenges that arise and the extent to which the toolkits help to address these. We will do this using semi structured interviews which will cover relevance, acceptability, feasibility and areas for improvement. We will also ask about views of ISFs, challenges and facilitators for their use and any changes in perceptions about ISFs that have arisen whilst using the toolkits. We will formulate interview questions for adults for with learning disabilities and their family or informal carers based on the ASCOF indicators identified in WP2, or their composite parts. For example, we will ask family member or informal carers whether they have been involved in discussions about support or services provided to the person during the period of prototype testing, giving four options: always; usually; sometimes; and never. We will use probes to explore in more depth why they have chosen a particular option and ask for any suggestions for improvement.

Data analysis

Interviews will be recorded and transcribed. Data will be analysed thematically to identify areas for further development as well as emergent outcomes which will be mapped to ASCOF indicators where applicable. Findings will be shared with our project advisory group to decide on final revisions to the prototypes and to develop final versions of the toolkits.

Output from WP5: Two research derived actionable toolkits. The first to support the development, delivery and monitoring of ISFs by those working in adult social care. The second to support the uptake and management of an ISF by adults with learning disabilities and their allies.

Data Access

Access to the recording of the interviews and co-production workshops will only be shared with members of the research team as necessary. Data and the analysis will be backed up daily on a password protected document on the University of Sheffield server for WPs 3,4 and 5.

Where data needs to be transferred between members of the research team, this will be done by sharing secure data folders using google Drive. No data will be shared by other means (e.g.: email).

Storage

Raw data will be saved on the University of Sheffield server and stored on password protected work laptops or PCs used by members of the research team. After saving the raw data will be destroyed from the recording device.

Information for WP 1,2,3,4 & 5 will be stored on a University of Sheffield Google Drive. Access will only be granted to members of the research team where needed.

Personal details will be stored on the secure University of Sheffield server, UniFileStore which is the accepted secure storage for personal data as per University of Sheffield guidelines.

8 ETHICAL AND REGULATORY CONSIDERATIONS

Local Authority staff and adult social care service users will contribute to WP 1 & 2 as part of the Project Advisory Group . This group will not provide research data and in line with the principles of patient and public involvement in research we will not seek ethical approval for their involvement in these work packages. We will use learning from WP 1 & 2 to inform our protocol for WP 3,4 & 5 and so we will apply for ethical approval when we have elicited the relevant information from the preliminary work packages. We will seek ethical approval for WP 3,4 & 5, from a research ethics committee flagged to review social care research with adult social care users. We will do this prior to the start of WP 3, realist interviews.

We will ensure that we comply with local authority governance arrangements prior to the start of recruitment. We have yet to identify participating sites because we will identify sites based on parameters that will be determined during WP 2.

There are different ethical considerations across the research design including informed consent and power. Power imbalances may occur between researchers and participants and between participants with different backgrounds, experiences and priorities. Researcher-participant power imbalances will be minimised by the both parties spending time getting to know one another and by the researchers explaining the purpose and processes of the research to participants in advance of participation and reiterating the importance of their contribution. The researchers will constantly pay attention to whether people feel comfortable. Researchers will also take care to notice any distress caused by any questions, discussion, interviews or workshop activity. Activity will be paused/stopped in this case. Accessible formats, including videos, signs and symbols as well as photographs, will be used for all activities alongside documents in plain English, to avoid differentiating between those who can or can't access written materials. Natural breaks will be taken according to whether participants become tired or just need a rest from participation. We will ensure that we provide signposts to where people might get help if questions arise from the interviews or workshops.

This research will be guided by the British Psychological Society Code of Human Research Ethics (2021)[52] and will uphold the principles of:

- respect for participants;
- scientific integrity;
- social responsibility;
- maximising benefit and minimising harm.

Much of the research will take place on-line. We will provide remuneration for data costs and can fund travel expenses if participants wish to meet face to face in their homes or another venue.

8.1 Assessment and management of risk

To be completed on or before project start date

8.2 Research Ethics Committee (REC) and other Regulatory review & reports

We have received University ethical approval to allow us to use conversations, workshops and individual interviews with our advisory group, project management team, and other relevant stakeholders from our networks, as data.

We will apply for HRA ethical approval to recruit participants through local authorities for work packages 3, 4 & 5.

Regulatory Review & Compliance

Amendments

To be completed prior to application for ethical approval

8.3 Peer review

The National Institute Health Research (NIHR) Clinical Research Network (CRN) provide the following standard for peer review for studies:

High quality peer review

Peer review must be independent, expert, and proportionate:

a) **Independent**: At least two individual experts should have reviewed the study. The definition of independent used here is that the reviewers must be external to the investigators' host institution and not involved in the study in any way.

b) **Expert**: Reviewers should have knowledge of the relevant discipline to consider the service based aspects of the protocol, and/or have the expertise to assess the methodological qualitative aspects of the study.

c) **Proportionate**: Peer review should be commensurate with the size and complexity of the study.

8.4 Patient & Public Involvement

Liz Croot (PI) will lead the PPI work. Jodie Bradley, a self-advocate from Speakup, is a co-applicant and will sit on the project management group. She will work with Liz to facilitate excellent PPI for the project. Jodie will be supported by a project working group at Speakup, who will help her prepare for project meetings. Clare Tarling (co-applicant) will produce accessible meeting documents. SpeakUp members are salaried employees and regularly advise researchers on the design and acceptability of research methods and materials. Speakup are collaborators and their contribution is costed into the project.

8.5 Protocol compliance

Accidental protocol deviations can happen at any time. They must be adequately documented on the relevant forms and reported to the Chief Investigator and Sponsor immediately.

Deviations from the protocol which are found to frequently recur are not acceptable, will require immediate action and could potentially be classified as a serious breach.

8.6 Data protection and patient confidentiality

To be completed prior to the application for ethical approval and any primary data collection

8.7 Indemnity

The University of Sheffield has in place insurance against liabilities for which it may be legally liable and this cover includes any such liabilities arising out of the above research project/study

8.8 Access to the final study dataset

9 DISSEMINATION POLICY

9.1 Dissemination policy

DISSEMINATION We will undertake academic dissemination by publishing a full report in the NIHR Libraries Journal, publishing articles in academic journals targeted at the learning disability and social care research community (e.g. Journal of Applied Research in Intellectual Disabilities, the Journal of Long Term Care) and presenting the research at relevant conferences and meetings (e.g. NIHR SSCR, The Seattle Club conference on Research in Intellectual and Developmental Disabilities).

OUTPUTS We plan to produce outputs in a variety of formats to meet the requirements of different audiences throughout the project.

We will disseminate written accessible project updates via an e-newsletter produced four times per year. We will create video clips, webinars and accessible presentations to be hosted on the National Care Forum, The Association for Real Change (ARC) and other relevant websites at regular intervals to build and maintain interest in the project.

We will produce two research derived actionable toolkits containing resources. The first will support the development, delivery and monitoring of ISFs by those working in adult social care. The second will support the uptake and management of an ISF by adults with learning disabilities and their allies. Given the co-produced and participatory nature of the project, we cannot pre-empt the exact content and format of these toolkits, however, as we are committed to the principles of equality, diversity and inclusion, they will include plain English, easy read and community language resources. They will not rely exclusively on text and will include pictorial, video and audio resources. The toolkits will be free to access and download through the University of Sheffield. We will seek formal endorsement of the toolkits from recognised social care and / or learning disability bodies such as the Association of Directors of Adult Social Services (ADASS), the Local Government Association and Learning Disability England.

The final toolkits will be introduced through webinars aimed at relevant practice networks and / or networks of people with a learning disability and their families. The webinars will be recorded and available through the project webpage. presentations to relevant practice audiences (such as the National Children and Adults Conference, the European Social Network) as well as events attended by adults with learning disabilities and their allies.

We will produce three peer-reviewed publications reporting theory development, the co-production of toolkits and the formative evaluation of the use of the toolkits in practice, alongside presentation to relevant UK and international conferences.

It will be important to reach national and local policy makers and provider chief executives as well as service managers, practitioners and people with learning disabilities and their allies.

We will produce a Plain English project e-newsletter four times a year with information and updates. These will include testimonies from people delivering or using an ISF which are particularly useful to engage audiences with the topic.

We will compile separate emails lists for different ‘types’ of interested parties to disseminate the newsletter and project information. For example, we will compile an email list of carer groups nationally and use this to disseminate tailored information. We will draw on relevant practice networks such as those for Principal Social Workers (facilitated by Research in Practice), regional commissioning networks (ADASS), and Voluntary Organisations Disability Group.

We will develop a project website to host accessible information about the project, the team, project activities and any outputs.

We will use our team member Twitter accounts to disseminate project information and to direct people to our website. We will also look for relevant Twitter accounts to share information with, for example, Networks such as Learning Disability England (@LearningDisEng), learning disability advocacy groups such as People First (@Peoplefirst111) and the National Development Team for Inclusion (@NDTi).

We will write accessible summaries for publications read by people with learning disabilities, for example, Community Living magazine, and we will film video and YouTube clips about the project and our findings. We will also present at conferences attended by people with learning disabilities for example, the Learning Disability England Annual conference.

Given the fragmented nature of adult social care we are already working with our collaborators to build strategic networks to establish interest in the project as it progresses and to facilitate dissemination of findings and outputs. For example, we are making connections with organisations with strong links to national policy including ADASS and Think Local Act Personal as well as organisations with links to practice including Skills for Care and the British Association of Social Work. We have costed time for Liz Jones, policy director for the National Care Forum (NCF) and our co-applicant Clive Parry, Director of ARC England, to support communication about the project and dissemination of the findings using their knowledge of, and extensive networks across, the care provider sector. Examples of dissemination activities will include presentations at NCF and other relevant conferences, webinars and discussions of outputs in online forums.

We will work with our stakeholder groups to identify additional ways to disseminate findings across the sector.

9.2 Authorship eligibility guidelines and any intended use of professional writers

To be completed – no intended use of professional writers

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