Project Title: Creative Learning Abilities PartNerships (CLAN)

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Plain Language Summary:

Aim

To use creative methods in a fun way and build equal research partnerships between researchers, people with learning disabilities and autistic people.

Background

Learning disabled and autistic people often experience poor health and mental well-being. They are rarely involved in research.

Methods

We used creative methods with groups from two Mencap organisations in Barnet and Lowestoft. There were four parts to the project:

1. Scoping review: We looked at what had been written before about creative methods and learning disabilities / autistic communities.

2. Workshops: July 2023 to October 2024, 14 visits to each group:

'Getting to know each other. ' We joined Mencap members in their activities, finding out what they like doing. Art, music, gardening, wellbeing, healthy eating and relaxation.

'*Making plans together.'* Giving feedback and learning how to work together.

'What's important?' Over six workshops, we explored members' experiences and feelings about their health and wellbeing.

'*Making sense together.'* Creative engagement activities, to make sense of what we learned together, and topics for future research.

3. Sharing learning - A 'celebration event', to share our learning and experiences.

4. Evaluation: Easy and fun ways to create logic models with Mencap members. A logic model is a plan for research and what outcome is important.

What we learnt

Taking time and space to get to know each other is important to build trusting relationships. Using creative methods 'opened up' conversations about health and wellbeing.

What next

We are developing different ways of sharing our learning for different audiences, including accessible outputs (EasyRead materials, videos, podcasts), blogs and articles.

Public involvement

We have included members of the public throughout the project.

Conclusions

We have successfully engaged with communities who have never been involved in research before. Using creative methods, Mencap members identified what is important for their health and wellbeing.

Summary of Research Findings:

Background

In this project, we used creative methods with people with learning disabilities, autistic people and the people who care for them, to find out what is important to them for their health and wellbeing. We collaborated with two community organisations - Barnet Mencap and Lowestoft and District Mencap – and their members, who have mild to moderate learning disabilities and/or autism.

The focus of the NIHR funding stream for this project is not 'research' but about engagement and building partnerships. Accordingly, we have taken an innovative and iterative approach, to see what Mencap members enjoyed and wanted to engage with as the project progressed.

To note, some material presented in this report uses a project acronym of 'CLAPS' (Creative Learning Abilities PartnerShips), as this term was preferred by the Mencap organisations, rather than the 'official' acronym of 'CLAN'.

Definitions

Learning disabilities is defined by Mencap as: 'a reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone for their whole life.' There are different types of learning disability, which can be mild, moderate, severe or profound[1]. There are around 1.3 million people in England with a learning disability[2].

Autism is defined by the National Autistic Society as: 'a lifelong developmental disability which affects how people communicate and interact with the world. One in 100 people are on the autistic spectrum and there are around 700,000 autistic adults and children in the UK[3].

Autism is not a learning disability, but around half of autistic people may also have a learning disability[1]. In this report, we will use the term 'autistic people', which is the preferred term by the autistic community.

Why this project is important

Improving the health and wellbeing of people with learning disabilities and autistic people is a national health and care priority[4]. People with learning disabilities and autistic people are more likely to have worse physical and mental health, compared to the general population[1,5,6]. Barriers to accessing healthcare are considerable[7,8], with poorer health and barriers in accessing care leading to health inequalities and shorter lives for this population.

People with mild and moderate learning disabilities and autistic people are an underserved community, who often fall through the gaps in terms of health and social care provision[9] and financial support[10]. Our two partner community organisations - Barnet Mencap and Lowestoft and District Mencap - provide services and support for people with mild to moderate learning disabilities and autistic people, identifying them as a group with unmet needs, often falling through the net for being eligible for benefits/direct payments and not able to be in employment.

Public engagement and research activities often fail to engage and listen to the perspectives of people with learning disabilities and autistic people. In this project, we wanted to explore whether creative activities would be an inclusive approach to engage with people about their health and wellbeing.

Aim and Objectives

Aim: To make time, and give space, for researchers and people with mild to moderate learning disabilities and autistic people and their carers (paid and unpaid) in community organisations to learn together and create sustainable research partnerships.

Objectives:

1. To use creative methods to develop ideas with people with mild to moderate learning disabilities and autistic people and their carers (paid and unpaid), about their health and wellbeing, to generate research priorities and questions.

2. To explore what 'success' looks like, in terms of working together, for the mutual benefit of all partners and people involved in this project.

3. To evaluate the project from everyone's perspectives and experiences and to reflect on lessons learnt, what went well and not so well, and how to improve for future partnership working, in this project and beyond.

The aim and objectives did not change during the project.

Methods and findings

To achieve our aim and objectives, the project was organised in four parts, called work packages (WPs). The work packages are: WP1 Scoping review; WP2 Engagement Workshops; WP3 Sharing our Learning; and WP4 Evaluation and Dissemination. As this project is about engagement, not research, we are presenting the methods and findings together for each work package.

Figure 1 shows the project timeline over the 15 months; this diagram was presented at the first Advisory Group meeting.

Figure 1: Project timeline

Work package 1: *Scoping Review*

We conducted a scoping review[11] to identify what has been published on creative methods in research and engagement with people with learning disabilities and autistic people. We selected this type of literature review to enable us to search across a wide range of literature, including non-academic publications (called grey literature).

The review team included two public co-researchers, who were involved in key stages of the review process. The scoping review protocol is published on the Open Science Framework (OSF): https://osf.io/y567t

We followed a six-stage process for conducting a scoping review.

Stage 1: identifying the research question

Stage 2: identifying relevant studies

Stage 3: study selection

Stage 4: charting the data

Stage 5: collating, summarizing and reporting the results.

Stage 6: consultation with experts

The details of the six stages are provided in Appendix 2.

Findings from the scoping review

Stages 1-6 were conducted between September 2023 and January 2025. In total, 2,396 articles were found through the database and citation searching, supplemented by 14 additional articles identified through manual hand- searching. After the removal of duplicates, a total of 1,747 unique articles were screened for inclusion. Titles and abstracts were assessed for relevance against the inclusion criteria, resulting in 135 articles retained for full-text screening. Full texts were obtained and reviewed again. A final 29 articles were included in the scoping review.

Figure 2 shows a PRISMA diagram that details the scoping review process in visual form.

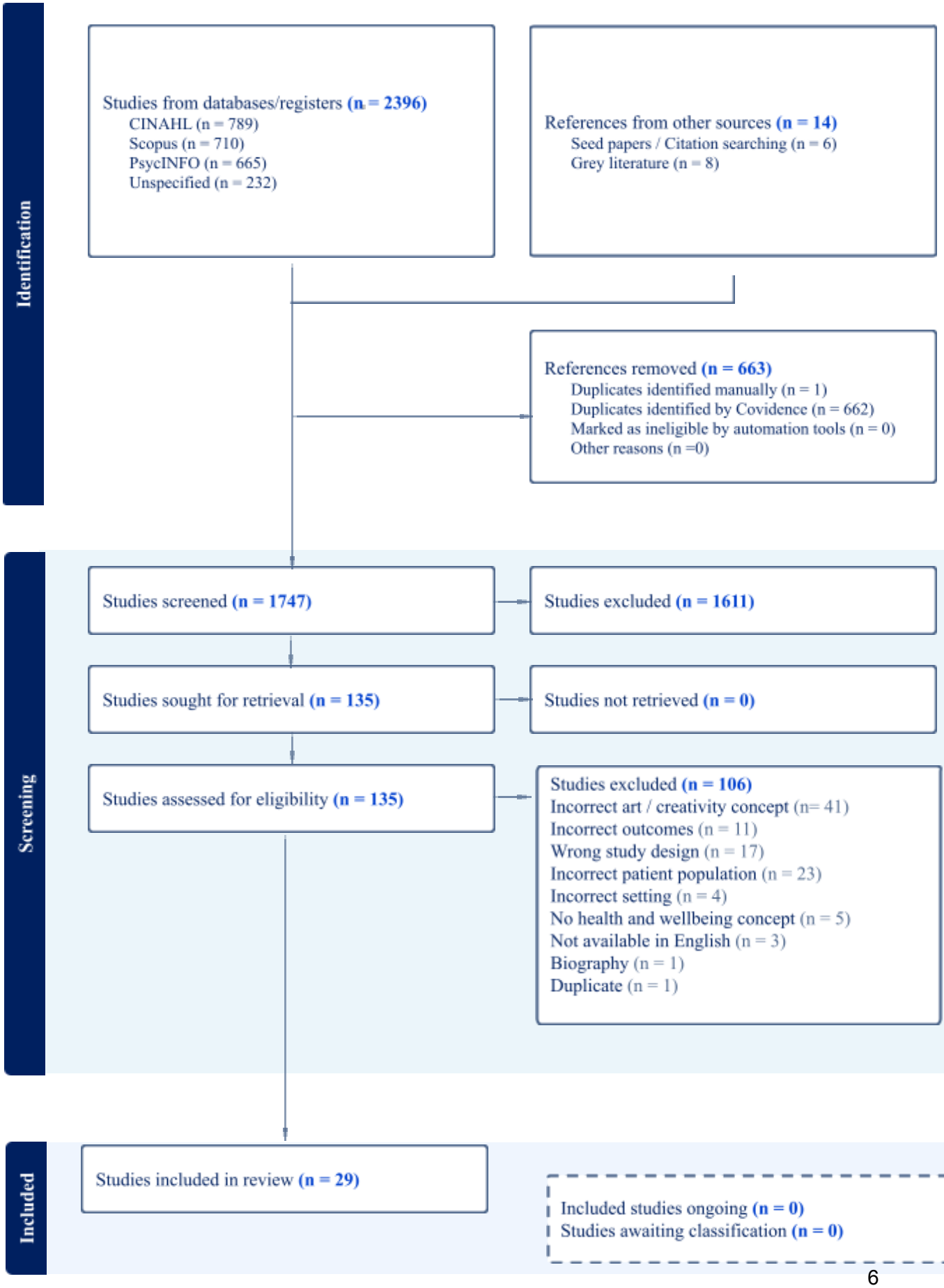
Of the 29 articles, 23 were research studies, with two literature reviews, three reflective commentaries and one research report. The papers spanned eight years, from 2016 to 2024. The articles were from 11 countries, with 11 from the United Kingdom, nine from the United States, three from Australia and one study each from China, Hong Kong, Korea, Poland, Spain, the Netherlands, and Ireland. One study reported a global survey. Sixteen studies included people with learning disabilities, eight included autistic people and five included mixed groups.

The health topics covered were various, including wellbeing and quality of life (six studies) and mental health (six studies). The use of visual arts methods was prominent, with photography featured in nine studies, and art activities (such as drawing, painting, digital arts, and sculpture) in four studies. Musical arts (music, composition, or singing) were reported in four studies and dramatic arts (comedy, theatre, story-telling) in three.

The studies measured success in various ways, with eight articles reporting success based on facilitator or author reflections. In twelve articles, success was not explicitly reported or measured.

Only four of the 29 articles (14%) mentioned any public involvement, with the use of consultation groups. This finding demonstrates limited public involvement in this area. The scoping review findings fed into the workshops.

Figure 2: PRISMA diagram



Work package 2: ***Engagement workshops***

Between July 2023 and October 2024, the project team visited the Mencap organisations a total of 28 times (14 visits each), with a focus on:

'Getting to know each other ' Over eight visits, we joined Mencap members in their activities including: art, music, gardening and cooking.

'*Making plans together'* In six workshops, we provided feedback to Mencap members from our visits and asked them how they wanted to get involved in the project.

'*What's important*? Over six workshops, we explored members' experiences and feelings about their health and wellbeing.

'*Making sense together'* In eight workshops we used creative engagement activities, to make sense of what we had learned together and what topics are important for future research together.

A more detailed description of the workshops is provided in Tables 1-4.

Table 1: Getting to know each other workshop

Getting to know each other (4 visits at each Mencap organisation)

Members of the project team undertook four visits to each local Mencap organisation. The purpose of these visits was to allow time for Mencap members and researchers to get to know each other, before working together in engagement workshops. The team joined in with existing activities, including Art and Crafts, Gardening, Wellbeing, Music, and Healthy Eating.

Mencap Organisation	Visit	Date	Members present	Activities attended
Lowestoft and District Mencap	1	20th July 2023	14	Art Café
	2	2nd August 2023	11	Music
	3	8th September 2023	13	Art Café
	4	12th October 2023	5	Wellbeing
Barnet Mencap	1	15th August 2023	7	Gardening
	2	24th October 2023	8	Gardening
	3	23rd November 2023	12	Wellbeing, Harvest Celebration
	4	28th November 2023	14	Gardening, Healthy Eating

Table 2: Making plans together workshops

Making plans together (3 workshops at each Mencap organisation)

In the first phase of the engagement workshops, we introduced the project to Mencap members, to explore ways of working together in future creative workshops. This involved: inviting members to share the creative activities they enjoy, discussing and reflecting on creative activities that have been used within research; installing a 'Creativi-tree' (a picture of a tree, with leaf shaped post-it-notes, to write ideas. Described further in WP4 and Figures 3 and 4) for growing ideas together. We also invited members to vote on a 'team name' to be used throughout the project. We also discussed creative activities used in previous research, from one of the 'seed' scoping review articles (see Appendix 2), to introduce the meaning of 'research' and gain views from members about the creative activities used.

Mencap Organisation	Workshop	Date	Attendees	Workshop aims & activities
Lowestoft and District Mencap	1	25th October 2023	9	Introduce the project Invite members to share what creative activities they enjoy

	2	1st February 2024	6	(Repeat of first workshop)
	3	28th February 2024	14	Talk about creative activities that have be used in research (from scoping review article) Start to grow ideas together with our 'Creativi-tree' Choose team name: *Mencap Research Partners*
Barnet Mencap	1	25th January 2024	15	Introduce the project Invite members to share what creative activities they enjoy
	2	30th January 2024	9	(Repeat of first workshop)
	3	19th March 2025	10	Talk about creative activities that have be used in research (from scoping review article) Start to grow ideas together with our 'Creativi-tree' Choose team name: *Dream Team*

Table 3: What's important? Workshops

What's important? (3 workshops at each Mencap organisation)

For the second phase of engagement workshops, the project team combined the 'Creativi-trees' from the previous Barnet and Lowestoft workshops and presented to the members for 'sense checking' and further discussion. We launched the 'Breakfast Bingo' activity, an idea originating from Barnet members, across both groups. This was a fun game, following a bingo format, with pictures of typical breakfast food and drinks. We also introduced plans for new creative activities, to explore the question 'What's important for health and wellbeing?' We also discussed creative activities used in previous research, from a 'seed' article from the scoping review.

Mencap Organisation	**Workshop no.**	**Date**	**Attendees**	**Workshop aims & activities**
Lowestoft and District Mencap	4	27th March 2024	9	To sense-check the combined creative-tree. Launch of 'Breakfast Bingo' activity. Introduction of creative activities for following workshop
	5	24th April 2024	7	Discussion about ways of sharing research, based on article from scoping review Introduce creative activity -mugs
	6	15th May 2024	7	Continue creative activity – mugs Sharing of photos of Barnet Mencap workshop, to introduce Barnet members Short videos of members, to share with Barnet members Podcast recorded with project team and Lowestoft staff
Barnet Mencap	4	4th April 2024	12	To sense-check the combined creative-tree. 'Breakfast Bingo' activity.

				Introduction of creative activities for following workshop
	5	30th April 2024	10	Discussion about ways of sharing research, based on article from scoping review Introduce creative activities - mugs
	6	23rd May 2025	14	Continue creative activity – mugs Sharing of photos of Barnet Mencap workshop, to introduce Barnet members Short videos of members, to share with Barnet members

Table 4: Making sense together workshops

Making sense together (4 workshops at each Mencap organisation)

For the third phase of engagement workshops, a number of activities were undertaken. These included: planning the celebration event (WP 3) with discussions around the music playlist and activities; creative activity with 'mug shot' photoshoot; and the introduction to accessible logic models, with activity of 'mountain climbing' to a healthy body and 'characters' for logic model storytelling. Workshop 10 was held after the celebration event, to share feedback, reflections and next steps.

Mencap Organisation	**Workshop no.**	**Date**	**Attendees**	**Workshop aims & activities**
Lowestoft and District Mencap	7	19th June 2024	6	Creative activity with 'mug shot' photoshoot Making plans for celebration event
	8	10th July 2024	7	Introduce accessible logic model activity - mountain climbing to a *healthy body*
	9	4th September 2024	7	Continuation of accessible logic model activity - mountain climbing to a *healthy mind* Finalising plans for celebration event
	10	23rd October 2024	7	Reflections on involvement in project (verbally and on video) Viewing of film of celebration event
Barnet Mencap	7	13th June 2024	12	Creative activity with 'mug shot' photoshoot Making plans for celebration event
	8	18th July 2024	10	Introduce accessible logic model activity (mountain climbing to a health body)

	9	12th September 2025	8	Continuation of accessible logic model activity - mountain climbing to a *healthy mind* Finalising plans for celebration event
	10	17th October 2024	13	Reflections on involvement in project (verbally and on video) Viewing of film of celebration event

During the workshops, activities were created together with Mencap members' suggestions. This included familiar games such as Bingo, using a 'food' theme of breakfast, musical interludes picked by the group to create a relaxed, informal atmosphere and trying out different creative engagement activities.

The main creative engagement activities undertaken are now described in more detail – mugshots, Creativi-trees and mountain climbing.

Mugshots

Exploring the question *What's important for health and wellbeing?* was a key objective of the project, and the theme underpinning *Making Plans Together* workshops. From the visits, we learned that Mencap members enjoyed doing a range of activities, but not a clear, standout interest in specific creative arts activities, such as drama, painting, or poetry. Therefore, it was felt important to engage the members in a creative activity that would offer choice and flexibility to cater to their varied interests.

The mug consisted of a plastic mug (10cm tall), with a blank white rectangular paper 'insert' on which to create a design. We wanted to offer members a range of options for designing their mug. This included: colouring pens and pencils, stickers, and collage materials, with a range of colouring-in materials, based on themes and topics that had arisen in earlier workshop discussions, including popular song lyrics, nature, and hobbies. As we began the activity, care was taken to encourage the members to express themselves, with a slide designed by AW displayed on the large screen, which stated: *Freely express yourself – your story is golden! No 'right' or 'wrong' way*. Topics highlighted on their mugs included making music, food and being safe on the internet.

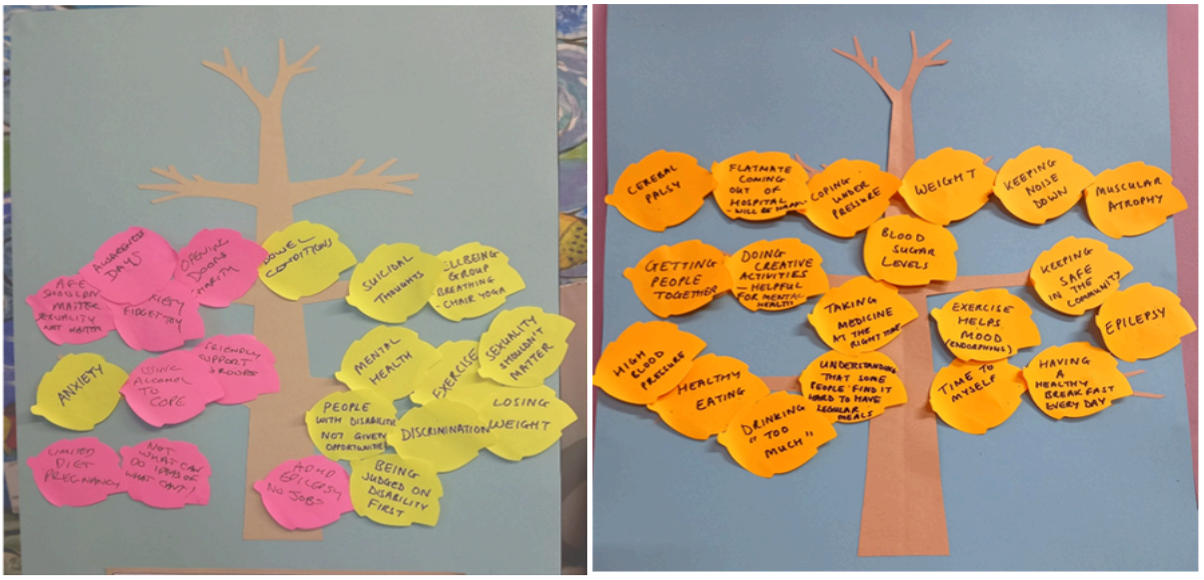
When the mugs were completed, members were invited to share with each other and say why this was important to their health and wellbeing. Most members agreed for these reflections to be filmed. These were shared in subsequent workshops at the other Mencap organisation – representing an important milestone: the first time that members from both groups had seen each other. Mugshot photos were combined into a group output, which was displayed at the Celebration event in Cambridge (WP3).

The mugshots are available to view in Appendix 4.

'Creativi-trees'

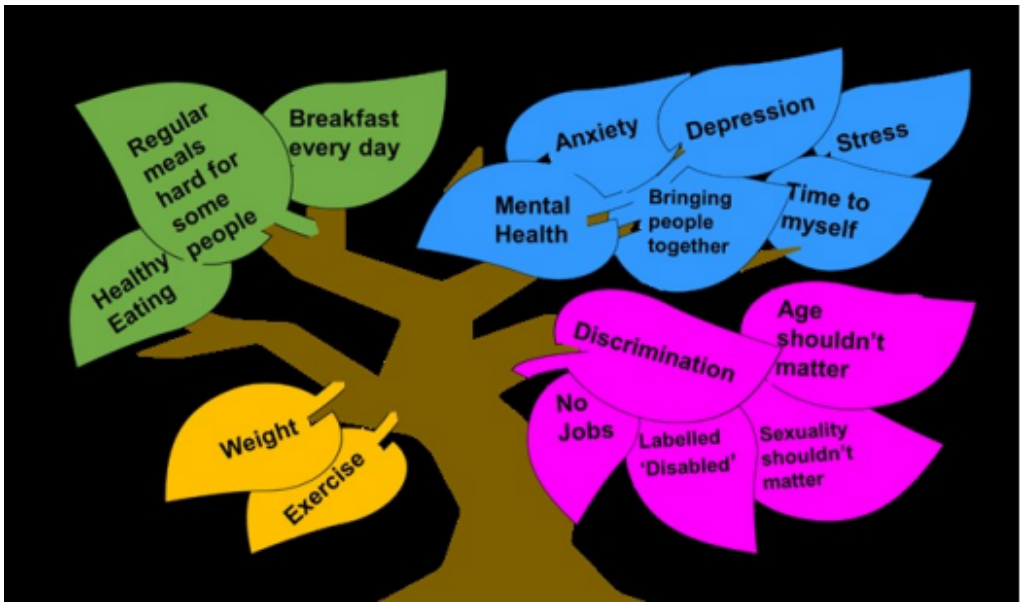
In Workshop 3, we introduced 'Creativi-trees', a basic outline of a tree, with leaf-shaped post-it notes to write down ideas. The Creativi-tree activity involved a group discussion prompted by the question: *What does health and wellbeing mean to you?* The aim of this exercise was to begin to understand the health and wellbeing priorities of the members. The workshop co-facilitators wrote down ideas suggested by the Mencap members on post-it-notes. Following this workshop, each Mencap group produced their own trees (Figure 3).

Figure 3: Creativi-trees from the two Mencap groups



Between sessions, we 'combined' the trees to form a combined Creativi-tree (Figure 4). This Creativi-tree was then presented to both groups. Co-producing Creativi-trees provided a visual and 'uncomplicated' method for generating initial ideas around health and wellbeing for Mencap members.

Figure 4: Creativi-tree, combining ideas from both Mencap groups



Mountain-climbing

To further develop the work around health and wellbeing priorities, an activity based on a mountain-climbing metaphor was introduced across the eighth and ninth workshops. It was reflected by the team that for people with a learning disability and autistic people, getting to better health is often a challenging journey, like climbing a mountain. This built on previous work by co-lead AW (ALPS)[13].

When planning this activity, the team reviewed the combined Creativi-tree, with a decision to undertake two mountain-climbing activities based on two broad themes: a 'healthy body' (Workshop 8) and a 'healthy mind' (Workshop 9). The activity involved displaying a basic outline of a mountain with a flag displaying healthy body/ mind at the summit. Mencap members were told that we would be climbing a mountain together to find out what people with a learning disability and autistic people need to get to a healthy body/mind. Rather than using conventional logic model terminology (such as inputs, resources, outputs and impact), the discussion relating to these elements was elicited through four questions:

For people with a learning disability and autistic people:

1. What challenges can stop them getting to a Healthy Body/ Mind;
2. Who do they need to help them get to a Healthy Body/ Mind
3. What needs to happen to get to a Healthy Body/Mind
4. What difference will having a Healthy Body/Mind make to their lives?

The responses to these questions are summarised in Tables 5-6. This iterative process led to the development of a project logic model (see WP4).

Table 5: Getting to a healthy body (workshop 8)

Getting to a Healthy Body (Workshop 8)		
	Lowestoft Mencap	**Barnet Mencap**
What challenges can stop them getting to a Healthy Body	- Not enough rest - Sport is hard - frustrating if I can't do it - Barriers to doing sport - Side effects of medication - Cost of healthy food - Pain disrupts sleep - Losing weight - Alcohol is bad for your health - Smoking	- sleep routine - too tired to exercise - drugs and alcohol - medication affects your energy - medication makes it hard to do what you want to - enjoyment comes first - fatty fried food - bad food, not eating properly - scared of medical appointments - not everyone goes swimming - smoking
Who do they need to help them get to a Healthy Body	- Health services and professionals (doctors, A&E, nutrition therapists/ dieticians/ smoking clinic, therapists) - Support workers - Cooking programmes - Google - NHS Website - Videos - Yourself, to be on the journey - Confidence - Support network - Unity Centre	- support workers - families - friends - Barnet Mencap - hospitals - paramedics - counsellors - doctors - might not know what someone's role is - ourselves - "trusted websites" – like NHS website
What needs to happen to get to a Healthy Body	- Don't drink too much, know your safe limits - Aerobics	- drink more water - learn to cook - eat less

	- Swimming - Eat fresh food - Avoid processed food - Learn to cook - Cook from scratch - Learn how to cope with special diets - Exercise - Sexercise	- exercise more - go to bed earlier - learn to enjoy healthy stuff - challenge each other - stop smoking - change medication - cut down alcohol - asking for help when something is wrong
What difference will having a healthy body make to their lives?	- Better stamina - Better fitness - Feel proud and happy - Raise confidence - Weight loss - (Able to) "Do more"	- more energy - stamina - feel healthier

Table 6: Getting to a healthy mind (workshop 9)

Getting to a Healthy Mind (Workshop 9)		
	Lowestoft Mencap	**Barnet Mencap**
What challenges can stop them getting to a Healthy Mind	- insomnia - faulty beliefs - stop eating - bad decisions - lack of choices - feeling like you don't have the answer - (struggling with) non-verbal communication - stress - being overweight - financial difficulties - discrimination - being abused - comfort eating - someone invading your personal space - depression - jealousy - unhealthy relationships - poor nutrition - isolation - diagnosed mental health conditions	- eating too much junk food - worrying about money - worried about what people think of you - if someone upsets you - worried about friends and family - being teased - bereavement - not being understood (some people use sign language) - confidence - being stared at

Who do they need to help them get to a Healthy Mind	- benefit agencies - relationship counsellors - advice from health professionals - psychiatrists - Mencap - friends - charity referral - other charities - drug/ alcohol counsellors - counsellors	- Mencap staff - NHS (who? A nurse) - Family members - Friends - Key workers, support workers to help you “get out” - Housemates/ neighbours
What needs to happen to get to a Healthy Mind	- more opportunities - equality - equal relationships - sexercise - financial stability - exercise - music, relaxation - pleasure - medication - helping others - meditation - focus on yourself - listening to music - giving yourself a break	- talking about problems - swimming - doing exercise - listen to music - eat healthily - television takes my mind off things - being yourself - colouring - being positive - play games, on phone, board games - being with your mates - advice and support “don’t get stressed” - being a good friend to others
What difference will having a healthy mind make to their lives?	- more able to exercise - happy - feel good in yourself - fulfil potential - want to help others - better self esteem - confidence	- talking about your problems to people - be strong to help others - make them feel happy - go for a walk - take your mind off everything

Work package 3: *Sharing our Learning*

The celebration event was held in a hotel in Cambridge in September 2024. The event was attended by 37 people from across the CLAPS partnership, including: 16 Mencap members; staff from both MENCAP organisations; a family carer; six project Advisory Group members (including people with lived experience), and researchers.

Together, we celebrated what had been achieved over the project. This included sharing our learning, the different engagement methods used, photos and a short video summary which included voices from the two MENCAP groups. It also included games and activities we used during the project, music and dancing and plenty of time and opportunities to socialise between the two groups and the project team.

We asked members about their experience of the celebration event:

"My biggest highlight was going to Cambridge. I saw lots of happy faces. I really enjoyed doing the drums with the Lowestoft group" (Barnet Member)

"I met all the new people from another part of the country. Got on with them really well." (Lowestoft member)

"The lovely thing I suggested was that we link arm in arm with the other group, and it bought us all together" (Lowestoft Member)

A description of the event has been written as a blog, which can be found here: https://arc-eoe.nihr.ac.uk/news-blogs/blogs/celebrating-working-partnership-alongside-people-learning-disabilities-and

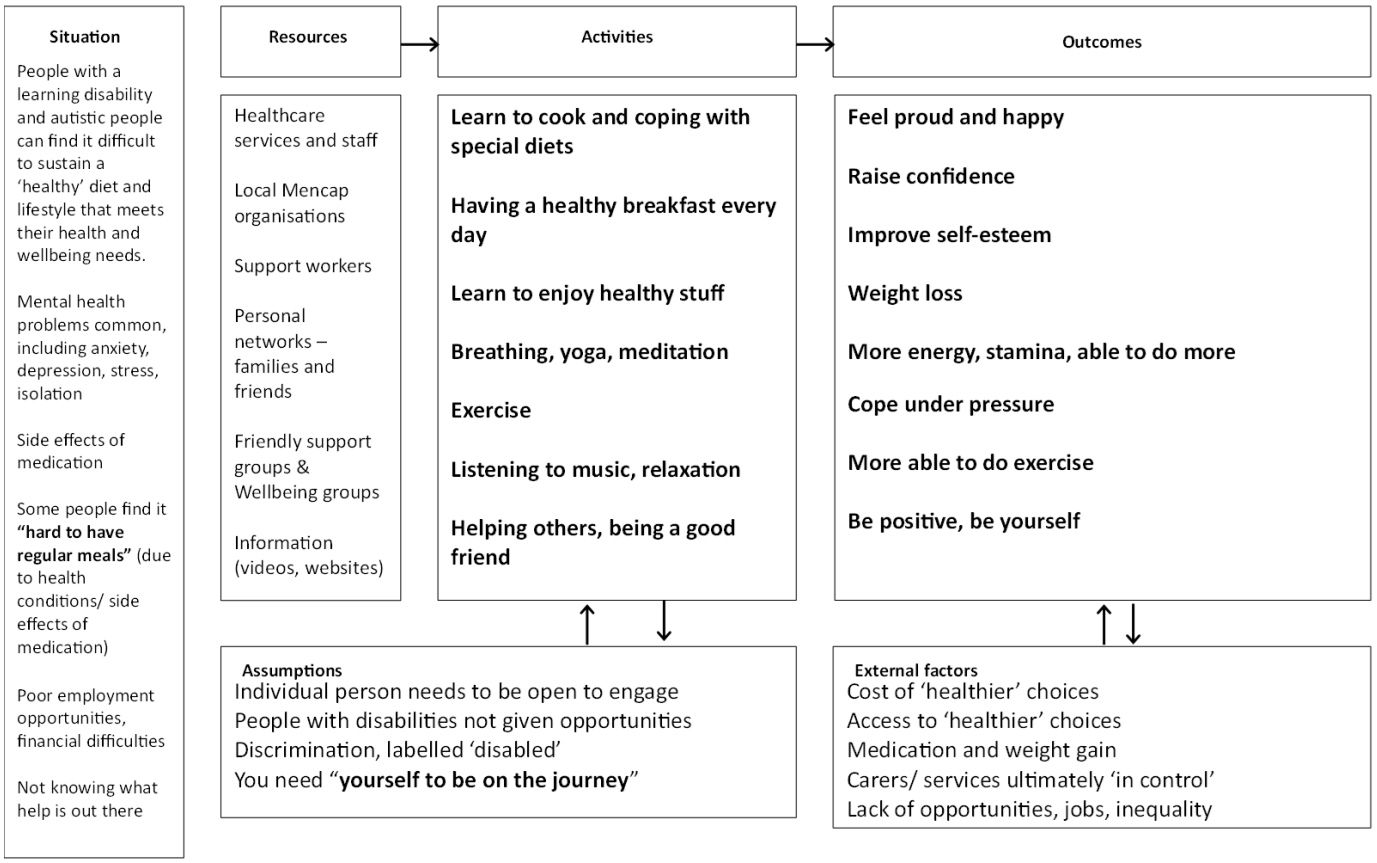
Work package 4: *Evaluation and dissemination*

Throughout the workshops, we used creative methods - mugshots, creative-trees and mountain-climbing – to 'grow ideas' in a fun and accessible way with Mencap members. Our approach was iterative, with the aim of finding an uncomplicated way of co-producing 'accessible' logic models with people with learning disabilities and autistic people. Co-producing the Creativi-trees provided a simple method to generate initial ideas around health and wellbeing. These ideas were then built on with the mountain climbing activities. This iterative process led to the development of logic models, to be used for future research together.

Figure 5 shows a logic model for 'healthy body, healthy mind'. We developed another logic model about healthy eating.

Figure 5: Mencap members' Logic Model for a 'Healthy Body, Healthy Mind'

Mencap members' Logic Model: Healthy Body & Mind



Evaluating the success of the partnership working

To evaluate the partnership working, during bi-monthly team meetings, advisory group meetings and the engagement workshops, we made time for our reflections, to discuss how things were going from people's different perspectives. We made notes of what was discussed, to record what was working well, challenges faced, and solutions found together. Here are some examples of reflections made:

"This project emphasises what people can do – it is a creative learning abilities partnership." (Public Partner)

"It was fantastic to see both Mencap groups together [at celebration event], *as if they had known each other forever."* (Chairperson, Lowestoft and District Mencap)

"The whole point of the project is partnership working. The link we have with Lowestoft, we don't want to lose it." (Manager, Barnet Mencap).

Amander Wellings has written a poem about the project (Appendix 5).

Discussion

We have used creative methods in a fun and innovative way to build new research partnerships with two Mencap organisations and their members. Addressing our project aim, our work has demonstrated the importance of taking **time and space** to get to know each other and gain trust and 'acceptance' from Mencap members and the people who support them. The trusting relationships developed, with an informal, inclusive and fun format of workshops, led to the engagement activities being well attended, with members engaged and enthusiastic about what we were doing together.

A key ‘success’ of this project has been the use of creative engagement to support Mencap members to contribute and find uncomplicated ways of co-producing ‘accessible’ logic models. Moving away from the conventional framework for logic models as a starting point, we instead adopted an iterative and ‘paced’ process, using simple and visual metaphors (trees and mountains) in a fun and ‘accessible’ way, that made sense to people with learning disabilities and autistic people. From this, we built up to a more ‘conventional’ logic model framework (Figure 6), but without using research language and tools that was considered ‘inaccessible’ for people with learning disabilities and autistic people.

It is important to highlight that in this project, we have successfully engaged with communities who:

- have never been involved in research before;
- were not an established creative arts group (unlike several studies found in the scoping review);
- were not a self-advocacy group, with limited experience of being asked to reflect on the broader experiences of people with a learning disability and autistic people.

These characteristics shaped our journey of creative engagement with the Mencap members. We (arguably) had ‘further’ distance to travel to engage the groups to do creative activities together, and to discuss their health and wellbeing priorities. However, we would also argue that with the design and ethos of our project, the researchers were able to ‘reach further out’ to include people who are so often excluded from research.

Conclusions

We have demonstrated that creative engagement activities are an inclusive and accessible approach with people with mild to moderate learning disabilities and autistic people. We have successfully engaged with a traditionally perceived ‘underserved’ community, who have become ‘research active’ organisations and individuals from their involvement in this project.

Key learning points:

- It takes time and space to engage with people with learning disabilities and autistic people, to build relationships and research partnerships;
- People with learning disabilities and autistic people are perceived as ‘underserved’ in research. We recommend that researchers need to take the time, with adequate resources, to ‘reach further out’ to involve underserved communities in a meaningful way;
- Creative engagement activities are a supportive way to 'open up' conversations with people with mild to moderate learning disabilities and autistic people about their health and wellbeing.

Patient and Public Involvement:

Aim: To involve people with lived experience of learning disabilities and/or autistic people in every stage of the project.

Methods: At the development of ideas stage, we held a workshop with members from two Public Involvement in Research groups at the University of Hertfordshire. They decided to focus on learning disabilities and autism and to use creative methods. We then talked to staff and members from two Mencap community organisations in Barnet and Lowestoft. They told us they enjoyed creative activities and having parties, which we incorporated into the study.

The project co-lead (AW) has relevant lived experience for this project, being neurodivergent -autistic, ADHD, and a lifelong family carer of a person with autism and learning disabilities. AW co-wrote the research application and was involved in every stage of the project, leading the engagement workshops and creative activities (work package 2) and supporting the public co-applicants and co-researchers. Two

co-applicants have lived experience as carers of people with learning disabilities and/or autism. The Project Advisory Group included people with lived experience of learning disabilities and autism. The Project Advisory Group (PAG) was co-chaired by the co-lead and an Expert by Experience with lived experience, who co-designed an EasyRead 'Ways of Working' document for the PAG.

Two public co-researchers were actively involved in the scoping review. They attended regular meetings and received training to undertake different aspects of the review. They were involved in data inclusion/extraction, learning to use COVIDENCE (systematic review on-line tool) to undertake this process. They attended an 'all team' workshop to discuss, and practise, data extraction and reviewed papers. They are co-authors of the scoping review article being written.

The workshops and celebration event were co-produced with Mencap members, staff and carers. The members suggested a music playlist for a disco, with a Mencap member offering to be the DJ. Some Mencap members were very vocal when sharing their ideas for the celebration event, and while these contributions were valued, we did not want the perspectives of quieter members, or people with additional communication barriers to be less involved. To ensure that everyone's voice could help to shape the event, we introduced 'thumbs up/ thumbs down' paddles, as a 'yes or no' voting system, into our planning discussions.

Members of the project team and PAG led the development of accessible outputs, including EasyRead documents, blogs and presentations, that can be shared with diverse audiences. The project co-lead (AW) has written a poem based on the project. The public co-applicants and co-researchers are involved in writing two articles about the findings of the scoping review and the project as a whole.

Discussion and conclusions: There has been public involvement throughout the project, influencing the direction of the project at each stage. This has had an extremely positive effect on the project, with the involvement of the public identifying the topic, and having the connections with the two partner Mencap organisations who agreed to collaborate with us. The development of the creative methods used was shaped by the public co-lead and Mencap members, who co-produced the creative activities, outputs and logic model. This project would not have happened without public involvement!

Reflective / critical perspective: We consider our partnership working to represent true co-production, as all partners have been involved equally at every stage. We have reflected a lot on a comment from another grant holder, who said at a NIHR meeting: "*If it isn't messy, it's not real co production*". Our work was very messy in construction, as all workshops were planned from previous workshops and incorporated the ideas of the Mencap members throughout. We adopted a 'you said, we did' approach, constantly feeding back and charting a new course for moving forward.

In terms of ethical considerations, we have reflected greatly that the nature of the project, to build relationships and partnerships, has raised expectations of the Mencap groups (and team) of working together after this project finishes. We have tried to manage these expectations, as applying for further funding takes time and success is not guaranteed. We are also seeking other ways to continue our collaboration.

A major challenge was the very late, first NIHR payment, which wasn't released for seven months. Our community partners are charities, with limited resources, and were not able to self-fund all the proposed engagement activities until payment was received. This delayed the timings of engagement activities, including the purchase of Podcasting equipment. Such delay in funding, from a programme that was targeting the involvement of community organisations, was unfortunate.

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Data Sharing Statement:

[https://www.nihr.ac.uk/documents/nihr-position-on-the-sharing-of-research-data/12253] for the NIHR position of the sharing of research data. The NIHR strongly supports the sharing of data in the most appropriate way, to help deliver research that maximises benefits to patients and the wider public, the health and care system and which contributes to economic growth in the UK. All requests for data should be directed to the award holder and managed by the award holder.

Appendix 1: Tables, Figures and Appendices

Figures

Tables

Appendices

Appendix 2: Six stages of the scoping review

We followed a six-stage process for conducting a scoping review, adapted from Arksey and O'Malley[1]:

Stage 1: identifying the research question

Stage 2: identifying relevant studies

Stage 3: study selection

Stage 4: charting the data

Stage 5: collating, summarizing and reporting the results.

Stage 6: consultation with experts

Stage 1: Identifying the research questions

The review was guided by the following questions:

1. What creative arts methods have been used with people with mild to moderate learning disabilities and autistic people to explore their health and wellbeing?
2. What measures of success have been used to assess the use of these methods, how were these measures decided upon and who were they intended for?
3. What involvement did people with mild to moderate learning disabilities and autistic people have in planning these projects and reviewing their 'success'?

Stage 2: Identifying relevant studies

For guidance on the scoping review process, we referred to Peters et al[2] and their 'PCC' mnemonic which stands for '*Population*', '*Concept*' and '*Context*'. We also followed guidance from the JBI Manual of Evidence Synthesis[3]. An expert health librarian helped to develop the search strategy.

Population: People with learning disabilities and/or autistic people

Concept: There are two concepts:

- Art
- Health and wellbeing

The conceptualisation and definitions of art and health was informed by the World Health Organisation's (WHO) Health Evidence Synthesis Report[4], promoting a holistic model of health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity."

Context:

Settings: All

Geographical: International

Timeframe: We included publications between 2001 and 2024. We started from 2001 onwards, to acknowledge the key Government report: Valuing People - A New Strategy for Learning Disability for the 21st Century[5]

Databases: We searched the following databases: PsychInfo, CINAHL Plus, PubMed Central, Medline, Scopus, TRIP, APA PsycArticles, Clarivate Proquest (previously called Web of Science which encompasses IBSS (International Bibliography of the Social Sciences), Cochrane, Performing Arts Periodicals Databases. Art Full TextSocial Care Online.

We also searched relevant journals: Journal of Applied Research in Intellectual Disabilities; International Journal of Developmental Disabilities; and Learning Disability Practice.

Grey literature: Searches for relevant grey literature, which are sources produced outside of the formal academic peer review and publication process, were also undertaken. We searched EBSCO Open Dissertations, a database containing theses and dissertations. Additionally, the websites of relevant charities and organisations were searched: SCOPE, The King's Fund, Learning Disability England, Outward, The Royal Mencap Society.

Stage 3: Study selection

Study selection was based on the following inclusion criteria:

- Published studies of any design, including commentaries, research (primary or secondary data), literature reviews, descriptive accounts of engagement activities (participation, involvement, etc) and theses;
- Studies or descriptive accounts about art by people with learning disabilities and/or autistic people to talk/think/explore their health and wellbeing;
- Publications published in English language, due to limitation of translation resources.

Exclusion criteria:

- Studies or descriptive accounts about art used as a prescribed therapy for a specific predefined health outcome e.g. art therapy.

Three reviewers (HW, CB and FI) used the selection criteria to independently screen titles and abstracts to identify potentially relevant studies. Four seed papers were initially identified, considered to be 'definite' inclusion papers, and these were used to check and test our searching techniques. The team then met to modify the search terms and criteria, before continuing with full text screening that was again conducted by three reviewers (HW, CB and FI). Search results from the databases and grey literature sources were extracted and imported into Covidence (a literature review on-line management system). Duplicates were removed.

Stage 4: Charting the data

The papers were read and relevant information extracted and recorded in a data extraction form. The purpose of a data extraction form is to provide relevant and contextual information about each publication. The project team met regularly to talk about, and practice, data extraction together (including the public co-researchers). During this process, the form was refined. The final extraction form included the following information: author(s) and year, country, aim/purpose; type of study (research, descriptive, engagement) population, concepts and context (settings, geography and timeframes) type of art; whether there was any public involvement (using the GRIPP2 checklist[6]).

Stage 5: Collating, summarising and reporting of the results

The results of the data extraction were presented in a large excel spreadsheet, that was then summarised by one team member (CB) into a table. This was reviewed and agreed by other team members (JJ, HW, FI, EM). A PRISMA diagram from this process shows the results (see Figure 2).

Stage 6: consultation with experts

The two public co-researchers (IS, SH) were actively involved in the review process as members of the team. They attended regular team meetings and received training and support to undertake different aspects of the review. They were involved in data inclusion/extraction, learning to use COVIDENCE to undertake this process. They attended an 'all team' workshop to discuss, and practise, data extraction. The final included articles were divided among all team members, who reviewed the papers independently and met regularly to discuss any queries around eligibility and any necessary changes to the data extraction form.

The ‘seed’ papers were shared with Mencap members during the workshops, using Easy Read power point presentations, to discuss the creative methods used and to introduce the idea of research (see Tables 1-4). The members enjoyed hearing about, and seeing pictures of, how other similar groups were using creative methods to talk about health and wellbeing. They particularly like the more ‘readily accessible’ articles presented, with creative methods explained in the articles with photos and pictures, rather than large blocks of text. It was helpful for the team to understand the preferred ways of presenting research articles to the groups.

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Appendix 3: Current and planned outputs

Current Outputs:

Type of output	**Title**	**Description and date**
Workshop presentation	Creative Learning Abilities Partnerships (CLAPS)	NIHR Workshop, Birmingham, 19 October 2023
Scoping review protocol	Creative Learning Abilities Partnerships (CLAPS) Scoping Review Protocol	Open Science Framework (OFS) Registries. https://osf.io/y567t https://doi.org/10.17605/OSF.IO/Y567T 22 April 2024
PPI workshop	Introduction to PPI: Inclusive Involvement in the CLAPS project	Doctoral students and Early Career Researchers attending a PPI workshop as part of ESRC SeNSS (South East Network for Social Sciences) Doctoral Training Programme. April 2024
Conference presentation	Using creative methods to build health and social care research collaborations with Mencap members	Creative Research Methods Conference, University of Hertfordshire, 28 June 2024. 15 people attended – academics, PhD students, PPI contributors
Poster	Creative Learning Abilities Partnerships (CLAPS) – Library Search	Presented at the CLAPS Celebration Event, Cambridge, 25 September 2024 and Final workshops in October in Barnet and Lowestoft
Presentation	Making Public Partnerships Fun	Presented at the NIHR ARC East of England Inclusive Involvement Community of Practice on 26th November 2024. 12 people attended – academics, PhD students, Public Partners, on ARC website. https://arc-eoe.nihr.ac.uk/inclusive-involvement-research-community-practice
Blog article	Celebrating working in partnership alongside people with learning disabilities and autistic people	NIHR ARC East of England website: https://arc-eoe.nihr.ac.uk/news-blogs/blogs/celebrating-working-partnership-alongside-people-learning- disabilities-and February 2025
Poem	Celebrating Abilities	Host platform to be confirmed

Planned outputs:

Type of output	**Working Title**	**Description**
Journal article	Using creative arts methods to explore the health and wellbeing of people with mild to moderate learning disabilities and autistic people: A Scoping Review with Public Involvement	Target journal: Research Engagement and Involvement
Journal article	Using creative methods to build health and care research partnerships with people with learning disabilities and autistic people	Target journal: Health Expectations

Appendix 4: Mugshots poster

Appendix 5: Celebrating Abilities poem

Celebrating Abilities

A poetical Blog by Amander Wellings

Imagine a world with no room for individuality?
One size, fits, nobody approach.
All required to fit into existing
ways of working.
Only a few heard, their views create
everything.

Or we celebrate individuality
We all choose our colours!
Services co created, ask the end users,
listen and adapt.
Many sizes possible so better fit guaranteed.
All ideas equally valued.

We Invite all, join together,
break down power barriers, learn from each other.
Us with Learning disabilities and or autism
understand the challenges we face.
The way society makes us more disabled by decisions
without our input.
One size doesn't fit us we are individuals
and have varying needs.

MENCAP Members lead the researchers
and service providers follow,
Celebrate our abilities, adapt your methods,
give us a voice as loud as your own.
Having fun together along the journey,
learning what's important to us about our health
wellbeing and social care.
We enjoy working together, we all have
the same goal,
Services that match our needs and not
waste scarce funds.
Creating Learning Abilities Partnerships
Using creative ways to work together and enjoy
coproduction.

Everyone Claps each Other!