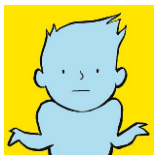
Scottish Learning Disabilities Observatory



Blog 1: An inclusive approach to recruiting our Public Engagement Lead

Written by Lois Cameron, March 2019

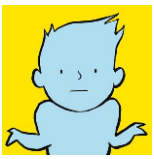
The Scottish Learning Disabilities Observatory aims to generate evidence, build understanding and provide information on the causes of poor health and health inequalities experienced by people with learning disabilities in Scotland. However, they recognised that there was a need to develop their approach to involving people with learning disabilities. They considered whether a citizens' jury for people with learning disabilities on health and health research would be a constructive way of engaging people with learning disabilities in supporting people with learning disabilities to have a voice. From the outset, they acknowledged that communication would be a key challenge and approached Talking Mats to work with them to put forward a bid to the Welcome Trust Public engagement fund. This bid was written, submitted and was successful.

To establish the project, our first task was to recruit a Public Engagement Lead to project delivery. From the outset, involvement of people with learning disabilities was seen as central to the project. Talking Mats had recently completed a course working with people with learning disabilities from the National Involvement Network to become Talking Mats interviewers, so we approached one of the participants who had completed the course and asked if he would be willing to be on the interview panel and help recruit our Public Engagement Lead. He was very happy to take part and contribute his skills and experience to the interview panel.

Planning the interview Talking Mat

We examined the job description and divided it into questions that were more factual and knowledge-based and those that we might describe as 'softer'. However, calling them soft might be misleading as they were actually value based and we felt that the successful candidate's proficiency and self-awareness in responding to these options would be central to the success of the project. After going through this sifting process we came up with eight possible options for the interview talking mat. We met with our interviewer from the National Involvement Network and with him honed the eight options down to six:

- Making information accessible
- Making sure everyone has a chance to speak
- Helping the group understand research
- Helping the group set its goals



- Involving people with severe learning disabilities in the research agenda
- Not taking power away from the group

The next step was to consider how candidates in the interview would rate themselves for each of these options. With our member from the National Involvement Network, we agreed on the following ratings: 'Extremely confident', 'Confident' and 'Not that confident'. Symbols for the talking mat were then chosen that would represent the six options.

It was agreed that candidates would be asked to justify where they placed their options. A script was developed to support the interviewer from the National Involvement Network e.g. 'It would be good if when you placed the card down you gave us a reason why you placed it there. Examples from other work you have done would be helpful'.

The interview

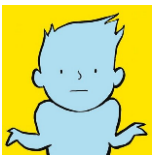
In the interview, candidates were asked to give a short presentation, and then the member of the National Involvement Network carried out the Talking Mat. After this, there were some further panel questions and a chance for the candidate to ask questions.

The experience and outcomes

"I really liked being involved in making the mat. At the interview I knew what I had to do and I felt the other interviewers listened to me and my opinion."

Other panel member's perspective:

"Having never used a Talking Mat in a recruitment interview before I was not sure how effective it would be as a recruitment tool. We wanted the process to be as inclusive as possible, where all interviewers had a clear and purposeful role. The Talking Mat worked really well, both as a way of gathering knowledge and information from the candidates, but also by providing an opportunity to observe the interactions between the candidate and the interviewer. I also think that the structured framework of the Talking Mat put the interviewer at ease and it was nice to observe his confidence in using it in this context and, where necessary, in prompting and supporting the interviewee. All in all this was an effective way of conducting an inclusive interview process that signalled to our candidates that people with learning disabilities should be involved meaningfully in all stages of the process.



It also meant that when we came to reviewing the candidates against the role criteria all members of the panel were able to contribute. I can't wait to do more interviews like this!"

Candidate perspective:

"For me, an interview process is really about making sure that you and your potential new employer have compatible values. Therefore, it was a relief to have someone with learning disabilities on the interview panel who could help direct the questions. It was also clear that the interviewer knew how he fit into the interview process and was taking the lead on his section of the interview.

The Talking Mat itself was an interesting tool for the interview discussion because the top scale allowed me to look at where my skills and confidence were but also identify some potential challenges within the project. The interviewer also really kept me on my toes with some good follow up questions. One question in particular, he asked what I would do if he was talking too much and dominating the conversation in the group. It was a challenging question and quite uncomfortable on the spot, but it forced me to be honest about my own values and say that actually, the right thing to do is to politely confront someone who is not letting others speak.

The benefit of a Talking Mat is that it has to be really clear and concrete to work, so I actually felt that I understood the demands of the role better than reading the much longer job description."

Summary

The involvement of people with learning disabilities was possible from the start of the project because we were able to harness the skills and experience of a person from the National Involvement Network who was trained in Talking Mats. He had a clear independent role which was central to the interview process and improved the quality of the information gained by panel members. The Talking Mats design gave all panel members particular insight into those 'soft skills' that were felt to be crucial to the project and that might not have come through so clearly if just the traditional presentation and questions were used.

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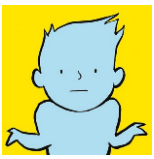


Blog 2: Easy read and inclusivity: two perspectives
Written by Rhiann McLean and Lois Cameron, July 2019

What is easy read information?

"The easy read format was created to help people with learning disabilities understand information easily... Easy read uses pictures to support the meaning of text. It can be used by a carer to talk through a communication with someone with learning difficulties so that they can understand it, for example a letter from the council about council tax charges... Easy read is often also preferred by readers without learning disabilities, as it gives the essential information on a topic without a lot of background information. It can be especially helpful for people who are not fluent in English."
(https://www.gov.uk/government/publications/inclusive-communication/accessible-communication-formats#easy-read-and-makaton)

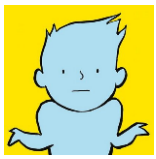
Rhiann's reflections on easy read

The advice I was given in my early career in learning disability services was to commission easy read outputs from expert organisations who would effectively act as a translator for pieces of writing. But whenever I read easy read content once it had been commissioned, it was always 'wrong' to me. But 'wrong' in a way that I found really hard to define. I would sit and say things like "that's not quite what I meant" or "I think we're missing some of the narrative". The reality is that it was wrong because easy read is a process of refinement in itself, a process I should have remained involved in.

As part of the Research Voices Project, we decided to develop easy read information for people with learning disabilities on a range of complex topics. Some of the things we grappled with communicating as a project team included:

- Essential and desirable selection criteria (the concept that even if you met the selection criteria, there may be some people who would be better suited)
- Explaining what health research means (and the range of health research that is out there from clinical trials to census data)
- Explaining the difference between participation in research and engagement
- Explaining how data will be held and stored

Documents went through more than 8 iterations, and I'm sure we could keep making changes based on feedback. But the process itself allowed us to refine our thinking in ways that were extremely helpful.



For example, we are able to think in depth about what level of detail is needed to make an informed choice about participation, and what then needs to be shared at a later date face to face.

My view is that easy read is a tool to support learning but largely, it is insufficient on its own. Many people with learning disabilities cannot engage with it at all, because of challenges in literacy or visual impairment. So for some individuals we met throughout the Citizens' Jury recruitment process, the easy read served as a guide for conversation for the staff member.

A recent meta-analysis showed that there is a very limited amount of evidence that outlines the impact that easy read and "a lack of information about how people with intellectual disabilities and the people with support them use accessible information in their everyday lives." (Chinn and Homeyard, 2017)

In my own experience, the value of easy read is actually in

1. The value of producing documents with meaning in refining our own thinking
2. The value of having a tool/framework to support engagement and communication (when combined with face to face input etc)

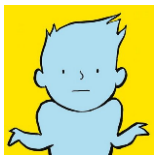
Lois's perspective: A response

If the advice Rhiann got early on in her career was leave easy read until the end then it is no surprise to me that she ended up feeling a bit frustrated by her early experience of easy read.

If easy read becomes a translation activity then it's missing the point and you lose the benefit of approaching an activity or project thinking about the communication requirements that that are necessary to promote effective participation.

To achieve effective participation communication needs to move much higher up the agenda. There needs to be more explicit consideration of its demands for example exploring

- The order and flow of the information presented
- Unpicking the specific meaning of a word or concept
- The visual images used so that the visual helps explain the concepts it is trying to support and are not just there for the sake of having a picture
- The best mode of communicating information, one size does not fit all



This in-depth thinking will add to the quality of a project because if communication becomes a focus then this will help develop a shared understanding for everyone involved in the project. No one can hide behind the jargon and cloudy unstructured thinking that is often lapsed into. Everyone benefits from that.

Reference

Chinn, D. and Homeyard, C. (2017), Easy read and accessible information for people with intellectual disabilities: Is it worth it? A meta-narrative literature review. Health Expect, 20: 1189-1200.

Blog 3: Engagement, involvement and the barriers we face to achieving inclusion

Written by Rhiann McLean, August 2019

At the recent SLDO Conference in May 2019, we had the opportunity to co-facilitate a workshop with Lois Cameron from Talking Mats on the topic of Inclusive Research.

The aim of the workshop was for delegates to:

- Learn more about the Research Voices project
- Understand more about the benefits and barriers of inclusive research
- Think more about how to bring the principles of inclusivity into our practice

In our presentation, we discussed the Research Voices project and some of the barriers we had faced as a team in trying to be inclusive. We talked about some of the challenges of finding funding when an idea still felt a bit like 'jelly', as well as the benefits of using an inclusive approach to appointing a project lead.

We asked groups to look at complex academic information and abstract ideas and try to explain them in ways that were grounded and easy to understand. Groups recognised how much time is needed to really look at communication and cut through the jargon

One of the key talking points of the session was exploring the difference between engagement and involvement and which we do more professionally.

Engagement is… "*where information and knowledge about research is provided and disseminated*"

Involvement is… *"research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them"*. (NIHR, https://www.rds-sc.nihr.ac.uk/information-for-researchers/)

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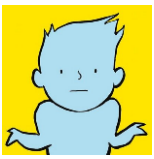
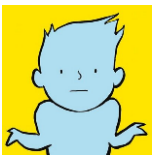


Some delegates talked about engagement being part of their day-to-day activities but some delegates struggled to achieve involvement because of institutional barriers, funding limitations and time constraints. Some of our delegates came from a practice background rather than a research background so looked at involvement from a service design perspective.

The most interesting discussion from the session came from the group, we asked people what their strengths were when it came to engagement and involvement and what barriers got in the way.

Some key themes that emerged were

- **What works well/what do we do well?**
- Communication- using adapted approaches like Talking Mats or creative approaches
- Relationship and trust building with groups
- Allowing for meaningful choices
- Recording our success
- Sharing skills and acknowledging what we each offer
- Working with disabled peoples' organisations to bring together focus groups of people with lived experience
- Getting good feedback on services
- **What are the barriers we face?**
- Ethics processes acting as a barrier
- Activity focused in cities rather than rural communities – excluding some voices and presenting fewer opportunities
- Getting access to groups
- Not formally recording the process and feedback
- Engaging with groups with different support needs and balancing everyone's outcomes in this
- Understaffing, underfunding and lack of investment
- Finding a clear focus in working together



- Developing accessible information and designing accessible meetings
- Making sure we meet new people rather than the same group

An important point that some delegates talked was about the important details of engagement – who sets the agenda? Where do we meet? And often, these details are what really makes the experience meaningful for people.

Overall, the group discussion echoed many of the challenges and opportunities of involvement presented in the evidence base around inclusive research. But having the opportunity to connect with people in different environments and share ideas around inclusion brought a renewed sense of energy to the work the Research Voices team is doing.

Blog 4 "Is it one of those weight loss groups?" The experience of recruiting jurors for the Research Voices Project

Rhiann McLean 2019

Evidence suggests that recruiting people with learning disabilities into research studies that directly impact them is an ongoing challenge (Cleaver et al, 2010). The Research Voices project recruited a demographically representative group of 12 people with learning disabilities from the Greater Glasgow and Clyde health board area to form a Citizens' Jury.

While a typical Citizens' Jury may use truly random selection using electoral registers or phone books, this process was more purposeful given the size of the population. The project experienced many of the challenges recorded in the literature around barriers to recruitment of people with learning disabilities.

What were the challenges we had to overcome?

Demographics

Recruiting a demographically representative group was difficult to achieve as we were not able to select from a large volume of applications. This meant we had to be specific towards the end of the project about who we would like to meet (for example, asking intermediary organisations to meet with older people who might be interested).

Gatekeeping

The project team did encounter gatekeeping from organisations, some of whom assumed that the people they supported would have no interest in the project or no capacity to contribute. In these instances, we were often unable to directly contact people with learning disabilities using that service to ask them their views.

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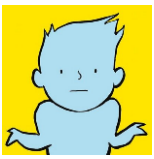

Timings and scheduling

The project allocated two months for recruitment, with a dedicated part time Project Lead to prioritise this activity. However, this deadline was difficult to meet and some applicants who were otherwise a good fit for the project could not be selected because they were not able to meet with the scheduling demands.

What even is a Citizens' Jury?

One of the draws of this project are that there has never been a Citizens' Jury on health research done in this population before. However, this meant that some applicants didn't have a frame of reference, leading to confusion. Applicants wanted to know 'Is this one of those weight loss groups?' or ask if the group could help them to manage long term conditions. The process of recruitment was designed to help unpick some of the more complex ideas. For example, the interview process used a Talking Mat to discuss how much each applicant knew about health research, and concepts such as consent and risk. This allowed applicants to get to know more about the subject matter. However, for some applicants, this wasn't something they could connect to and they ultimately did not join as jurors.

What worked well?

Dedicated staff time

Having a Project Lead who was able to prioritise recruitment and be flexible about how and when it happened. For example, meeting people for coffee locally or doing home visits. This flexibility allowed the project to pursue multiple opportunities for recruitment.

Purposeful recruitment

Recruitment was purposeful to achieve a good mix of participants from different backgrounds and demographics. For example, to recruit people in age range 16-24, we worked with an inclusion officer in Glasgow who was able to introduce us to a school where we recruited our two youngest participants.

Highlighting the benefits of taking part

While understanding of the process was a barrier for some people who took part, we found success in highlighting that the purpose of the project was to pave the way for other people with learning disabilities to have their voice heard. Many participants felt drawn to feeling like they were helping and making a contribution.

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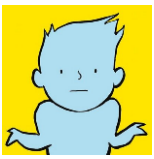

Active recruitment

The approach used for recruitment in this project mirrors what Nicholson et al (2012) refer to in their study as 'active recruitment', where the project lead and intermediaries do more than just distribute information and take an active role in following up with potential applicants. For some individuals, this meant more than one visit or multiple phone calls to go over what the project is about and what their involvement would mean. An indicator that this approach worked well was that some individuals who had initially expressed interest in the project later chose not to take part. For one applicant, this was because they understood the time commitment of the project and felt they could not commit fully. While disappointing, this was good evidence to the team that people were making an informed choice.

The use of Talking Mats

Talking Mats were used during the interview stage to explore two key topics: communication skills and knowledge of health research. These Talking Mats were a very useful tool for engaging applicants in meaningful conversation, but also allowed us to express some of the activities and topics that the person may encounter in the project (for example, by asking how the person felt about asking questions, we may be able to introduce the idea of expert witnesses).

Quieter Voices Network

The process of recruitment was most accessible for people with mild to moderate learning disabilities, though communication support was available to invite a wider range to participate than applied. However, the quieter voices network was established as a parallel engagement project to the Citizens' Jury. It was useful to be able to tell people with more severe learning disabilities and their families that there would be an opportunity to get involved, without excluding them from the project.

References

Cleaver, S. , Ouellette-Kuntz, H. and Sakar, A. (2010), Participation in intellectual disability research: a review of 20 years of studies. Journal of Intellectual Disability Research, 54: 187-193. doi:10.1111/j.1365-2788.2010.01256.x

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Nicholson, L. , Colyer, M. and Cooper, S. (2013), Recruitment to intellectual disability research: a qualitative study. Journal of Intellectual Disability Research, 57: 647-656. doi:10.1111/j.1365-2788.2012.01573.x

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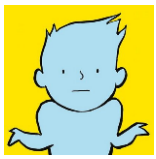

Oliver-Africano P., Dickens S., Ahmed Z., Bouras N., Cooray S., Deb S. et al. (2010) Overcoming the barriers experienced in conducting a medication trial in adults with aggressive challenging behaviour. Journal of Intellectual Disability Research 54, 17– 25.

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Blog 5: Including the voices of people with Learning Disabilities: A 2019 IASSIDD Roundtable
Rhiann McLean, November 2019

The annual International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) Conference is an opportunity for researchers across the world to collaborate and share new knowledge in intellectual disability health research. The Research Voices team were given the opportunity to host a roundtable discussion at IASSID, which we saw as an opportunity to invite feedback on inclusive research from a wide range of international perspectives.

The roundtable included individuals from a range of backgrounds including people who are participants and champions of inclusive research and researchers with an interest in inclusive research. We had representation from the UK, South Africa, Australia and New Zealand.

The aims of this roundtable were to:

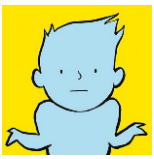
1. Present, in brief, the objectives of the Research Voices Citizens' Jury

2. Discuss and deliberate on issues associated with the inclusion of people with intellectual disabilities in health research, as subjects of research and as collaborators in the research process.

After an introduction and a short presentation about the Research Voices Citizens' Jury Project, we opened up to lively discussion about inclusive research in practice using prompt questions to promote debate. The main discussion points from this roundtable are described below.

Question 1: How do the priorities of people with intellectual disabilities inform health research?

The group discussed the complexity of defining research priorities: with funding often dictating the direction of research. One roundtable participant said *"I don't think that they do"* while another participant felt that *"We do bring some voices to the agenda"*



However, the group discussed how the need to secure funding is often the key driver for priority setting. The group also discussed balance in priority setting, as experts by experience may not be the only experts in the picture who can contribute to shaping the priorities of health research. People with intellectual disabilities can work alongside experts in methods and experts from fields of study. The group discussed the need to move away from multidisciplinary groups towards trans-disciplinary groups, which transcend traditional boundaries between partners in research.

In addition, some roundtable participants said that they felt they did not hear from a diverse enough group of people with intellectual disabilities. People with mild to moderate intellectual disabilities may have more opportunity to participate, while some voices remain unheard. The group agreed that research should be more inclusive of those 'harder to reach' voices and emphasized the need to develop methods for more diverse approaches to inclusive research.

Question 2: Do you have examples of good practice in involving people with intellectual disabilities in health research?

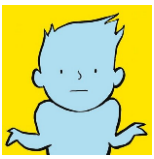
One delegate suggested that perhaps we should look outside of academia and look at great work done in non-governmental organisations around rights based issues and examine how these other groups are developing opportunities to talk about health and research.

One participant discussed the format of her group's approach to inclusive research. The group meets regularly to identify research topics and pairs co-researchers with disabilities and without to work together. Another delegate spoke about the success that they had with inviting disabled facilitators to run events and felt that trust was developed through that mutual experience.

Question 3: What are the practical barriers to including people with intellectual disabilities in the early stages of the research process?

A core theme in this discussion was funding. Finding the funding to add in the additional time and resources needed to make research inclusive can be challenging. The Research Voices project team talked about the challenge of writing funding applications that felt like 'jelly', because they did not want to predetermine the work before people with intellectual disabilities had the opportunity to shape it.

Funding can also prevent participation of people with intellectual disabilities. One international delegate gave the example of how a shift from state to federal funding for support organisations affected co-researchers' ability to take part in research.



Moving from state to federal funding for support organisations meant that individuals could not access the support they needed to continue being co-researchers. Finding sponsorships and grants to support participation can be challenging in this context.

Another practical barrier identified was the role of other people, such as support workers and family members in the research process. Support workers and family members may influence the individuals taking part, and contribute to group dynamics in unforeseen ways. The group talked about the struggle of finding support workers who could take on the role needed, and then not being able to guarantee that these same staff members could attend all of the meetings needed and support the person through the whole process.

The discussion also identified challenges in recruiting a diverse and representative range of people with intellectual disabilities, often finding they were hearing from the same group. People with profound and multiple intellectual disabilities (PMLD) were identified as lacking a voice in health research, and the group discussed the question of including parents as proxy, as they may be best placed to represent their child's needs and preferences. A challenge of the Research Voices methodology is that it doesn't allow for proxy representation, and this brought up the question of whether these methods were not flexible enough to include a wider range of voices.

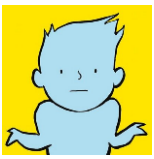
Question 4: What tools and supports might help overcome these?

The group discussed the importance of good quality facilitation, which could take many forms. For example, having co-facilitators with intellectual disabilities could support more ownership within the group. One delegate discussed their experience of having disabled people facilitate and support groups for other disabled people and noted that shared experience can be meaningful for relationship building.

Some of the discussion around facilitation was about how to address bias in facilitators. For example, having people in the role of 'observers' may mean there is a more objective view of a group discussion. Equally, reflexive practice such as a researchers' diary was suggested as supporting researchers to acknowledge how their bias was impacting on their work.

A discussion emerged around time, and how much time projects need to support real inclusion. The Research Voices project is an 18-month project. Some delegates felt that might not be enough time, while others felt it was sufficient.

A discussion point was whether we would get the most from people with intellectual disabilities if we use group engagement as a default approach.



Some voices could be lost in this process, and having the option of using one to one conversations could make sure that quieter voices are heard in the process.

Tools to manage group dynamics were seen as important, as well as channels to share best practice approaches. However, it was also noted that challenges in group dynamics are prevalent across all groups, and that the challenge in group dynamics is not an intellectual disabilities specific experience.

Following the roundtable, one participant sent an email that explained how using a robust process for research selection and ethics is important:

"The research questions are decided by the people with learning disabilities/intellectual disabilities. First, topics are decided by the people with disabilities and the topic that gets the most votes will be the topic that is chosen to undertake the research. All research is approved by the human research ethics committee and if the human research ethics committee does not approve the research the research cannot be undertaken…Nothing can be changed after the human research ethics committee has approved the research."

Question 5: In your experience, how does the inclusion of people with intellectual disabilities in research enhance research outcomes/impact?

One participant noted that inclusive research may yield different results:

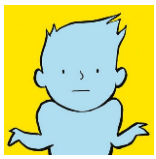
"You will find that the outcomes from the research when done by a person with LD - your analysis and findings will be much more different than with a non - disabled researcher."

One participant thought that by including people with intellectual disabilities in the process, researchers could harness the natural skills and strengths of people with intellectual disabilities and build in additional training or support to develop new skills.

Question 6: If you were part of the Research Voices Citizens' Jury, what question would you put forward?

The group was invited to put forward questions they would want to be discussed by a Citizens' jury of people with intellectual disabilities. Below are those suggestions:

1. What is the wider impact of informed and meaningful engagement in health (ie. cancer treatment decisions, experience of GP appointments?)



2. How can we match theoretical knowledge and practice and what do we need to do to disseminate and implement all of this knowledge? How much difference does research currently make to the lives of people with intellectual disabilities?

3. How do you create spaces in government policy that are appropriate for the input of people with intellectual disabilities in those spaces - what would that person need?

4. Questions of psychosocial research including sadness/happiness/loneliness/wellbeing/psychological state - do you feel good about your life? "What is wellness for this group?"

5. How can I take risks and make choices without losing my safety net?

6. You want to know about health research? My voice is the last to be asked? Why am I the last one to be asked to share my voice?

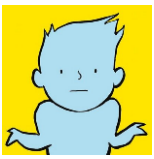
7. Should people with intellectual disabilities be involved in health research?

8. What do Citizens in the general population know about health and wellbeing and how does that translate to people with LD? Do people with LD know about health and wellbeing but don't act on it?

Blog 6 Our children are invisible": Including the voices of people with Profound and Multiple Learning Disabilities and their families in health research
Rhiann McLean, November 2019

In October 2019, SLDO and PAMIS hosted a one-day workshop for people with Profound and Multiple Learning Disabilities (PMLD) and their families to explore the question: **"How would you like to be involved in health research?"**

This workshop was part of the Research Voices project. This project is funded by the Wellcome Trust and aims to work with people with learning disabilities to include their voices in health research. As a part of this project, we are facilitating a Citizens' Jury for people with learning disabilities.



This group will listen to evidence from 'Expert Witnesses' to have a chance to have an informed discussion before making recommendations. However, we recognise that a Citizens' Jury may not be an inclusive way to connect with adults with PMLD and their families, so we brought together an additional network of people with PMLD and their families to explore health research with the support of PAMIS.

Throughout the day, we had attendance from seven family members of people with PMLD and one PAMIS staff member. All of the family participants were mothers of children or adult children with PMLD. The group was given conversation prompts throughout the session to guide conversation, though many of topics were overlapping. The conversation was not recorded, but detailed notes were taken, including quotes from participants. Personal details have been changed so that people who shared their stories cannot be identified. Below is a summary of the conversation at the workshop, organized into themes, where relevant.

The context

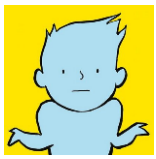
At the start of the workshop participants took the time to share their background, their experience and their interest in research. As part of these introductions, the group spoke about their experiences of health and care provision more generally. Some group members spoke about experiencing discrimination and isolation. Some parents discussed the stress involved with having to advocate for their child and make very difficult decisions in a health system that often didn't cater to their child's needs.

One group member with a younger child with PMLD said that their experience as a carer had made them feel powerless at first, but that they had then attended a course about influencing policy and decided, *"My voice is very important, so I will go to these government meetings."*

In fact, some group members noted that there was progress in terms of the quality of service provision available, but that this progress was:

- Not quick enough
- Not wide enough
- Not consistent enough

Some participants described the experience of caring for someone with PMLD as isolating and described feeling segregated. However, the group overall agreed that there was a lot of benefit to being involved in networks and meeting other people with similar experiences. In addition, one group member spoke about how deficit based their conversations about their children were, specifically citing applying for benefits.



The need to shift from deficit-based thinking is reflected in the research questions the groups identified later in conversation.

The group felt that there was an overall lack of accountability in the systems of care and support around them. These contextual experiences and opinions are important because they inform the way in which the group approached questions around health research.

Discussion point 1: The role of family voices in research

Research often relies on families or 'proxies' for the person with profound learning disabilities to express what the individual's views and experiences are. But there is evidence to suggest that proxies find it hard to divest themselves of own views (Cummins, 2002)

- How do you feel about the role of families as proxy?
- Can families be 'neutral' in presenting their child's views and preferences?

Understanding our children

The group questioned the idea of neutrality in research in principal: "*Who is neutral? Nobody!*"

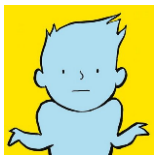
One group member felt that some family members can act as proxy and are capable of separating their own feelings and experiences from their children. An example this participant gave was her experience of taking her child to respite in a facility that also provides palliative care to children at the end of their life:

"When I go to respite to [respite location], my son sees it as a place of laughter and fun… but I see it as a place where children come to die"

The example illustrates this group member's ability to separate her own emotional experience, and be able to read cues from her child's communication and behaviour about their experience separately.

A carer's emotions or experience clouding their interpretation of their children's experience was something the group said could happen, but one group member suggested that emotion was how she was "deeply" connected to her child and how she could understand their experience: "*we use empathy for that, we need to*"

The group also acknowledged that there were limitations of a proxy; *"I can't always know what he's doing."* Two parents spoke about this being particularly challenging during times of transition (for example, puberty), where they needed to step back and reevaluate their understanding of their child to fit in with their child's stage in life.



One mother had to be told by a friend "*He's an f-ing teeny bopper now!"* to reframe her understanding of her child's communication.

The sacrifice of participation

Some participants in the group spoke about participating in research as being minimally rewarding, and often requiring a lot of emotional labour and distress.

This was compounded when research participants were not able to see the benefit of their participation in the long term: *"You see the poster. But where does it go?"* The view of the group was that research should have demonstrable impact, and it is frustrating for families to make the sacrifices involved in taking part to have no follow up or no funded intervention because of the research.

This was also difficult in the case of trialing new assistive technologies. One family member had the experience of testing an assistive communication technology which was effective for her and her adult child, before learning that the trial wouldn't go any further and there was no way to implement this technology in her adult child's day to day life. She continues to follow this up but has not been able to use this technology for her adult child.

Another perspective in the group was that families should question the agenda behind research, particularly how that research was funded and whether the findings may be used in a way that has a negative impact on the people who took part. An example given was that findings are used to show inconsistencies in service delivery, which serves to divide otherwise coherent groups of families.

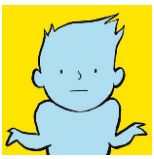
Discussion point 2: Allies in research

'Most people with learning disabilities need allies to do research' (Walmsley, 2001 p. 198)

- Do we agree with this point?
- Who are these allies to you?
- What connections should be made between people who are responsible for research and their allies?

Who are allies?

The group broadly agreed with the statement: *"we all need allies!"* However, members of the group also noted that people with PMLD have fewer opportunities to have allies, and have fewer avenues to self-present in research.



The voice of people with learning disabilities in research and policy is often people with moderate learning disabilities, which can mean the experiences of people with PMLD and their families are lost.

The group named allies such as PAMIS, SLDO and charities who work with disabled people.

In an interesting discussion, the group said they would not consider the NHS to be an ally in research, but could name single link people involved in their child's health care who they would trust to approach them about relevant health research opportunities.

The relationship that participants in the discussion described with the NHS was sometimes fraught, complex and often crisis-based. In fact, some of the group felt that recruiting participants with PMLD and their families through the NHS would not be appropriate, going so far as to say, *"They're not our allies, they're our enemies"*. This statement did not relate to all NHS staff, but spoke to a wider mistrust that some members of the group had after traumatic experiences and challenging interactions with health professionals and the wider health system. This point may be important for researchers when considering recruiting individuals with PMLD and their families.

Discussion point 3: Research into practice

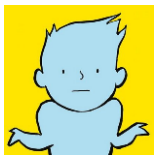
How do we get more research into practice in ways that are meaningful to the lives of people with profound and multiple learning disabilities and their families?

- What kind of research would make the most difference?
- What are the best methods of getting research into practice?

Making a difference

The group were able to develop research themes and questions naturally through conversation, looking at where they felt gaps in knowledge and provision were. These questions are noted in the final section of this write-up.

The group felt that research should focus on intervention and improvement. It should not just be about practitioner views or individual experiences, but about the structural barriers that stop progress, and the good practice interventions that address them. Two members of the group discussed their very different experiences of calling an ambulance for their child. Both parents had a traumatic experience with hospital admittance for their children and discussed the ways in which they had to work with inflexible systems and demand to be heard. However, the disparity in both parents' stories acted as evidence to the group that there were wider systems challenges that



needed to change for both families to get the quality of care they needed. Throughout the discussion, inconsistency of experience was something families brought up.

One group member felt that employing co-researchers with learning disabilities could help researchers understand more about the experience of PMLD, as co-researchers with learning disabilities may have more empathy and understanding of their experience.

The group were disappointed about research not making enough impact on their lives, and repeated this throughout the workshop. One participant gave the example of the 'Coming Home' report produced by the Scottish Government as an example of vital research with strong recommendations that has yet to influence policymakers in a way that had changed her child's situation.

Research priorities may be different at different stages of life

Some group members felt that research questions and research projects should acknowledge that the experience of people with PMLD and their carers is not the same throughout their lives. One person suggested that it might be useful to break this down into neonatal experience, childhood, education, transition and adulthood. This is the same for parents and families, who may have different experiences based on milestones and age. The group also noted that work with families should also include siblings.

Recording PMLD in routinely collected data

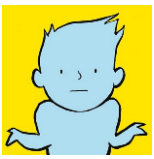
The group looked at examples of research done by the Scottish Learning Disabilities Observatory using routinely collected data and data linkage to understand the health of people with learning disabilities. The group noted that people with PMLD were not always identifiable in routinely collected data, and wondered why the severity of a person's learning disability was not included as a question on the census or pupil census. This was a recommendation they put forward so that people with PMLD were not lost. One member noted; *"We are a minority of a minority"*

There is data available from GPs that does identify people with PMLD, which can be used in research. However, there are also flaws in this data that pose challenges.

Conversations around consent

Towards the end of the workshop, the facilitator introduced the idea of consent and assent to the group, to understand how they felt about the potential complexity around people with PMLD consenting to participate in health research.

The group felt that families should not just be seen as research participants, but



support in the planning of research, so that the methods used in research would reflect their children's abilities and the reality of PMLD:

"This is why the families of people with profound learning disabilities need to be involved in the [research] design. We could say, you know, that's just not going to work"

Generally, the group felt that decisions would need to take into account what is in the best interest for the person. They also noted that the onus should be on researchers to meet people with PMLD at home where they are comfortable and calm.

How would you like to be involved in health research?

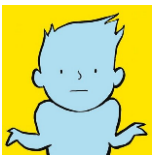
Overall, the group was enthusiastic about the opportunities of health research despite feelings of frustration at the pace of change in their children's lives. They understood that it might seem complex to plan research with people with PMLD and their parents without context. However, none of the mothers present knew much about PMLD before their journey either, but are now immersed in the world. One group member noted: *"None of us bought our ticket… we were given it, but you can come along with us. It's a golden ticket, it really is."*

One member answered the question: *"It is really nice to be asked"*

Research questions

Through the course of the workshop, participants identified research themes and research questions they felt were relevant and interesting.

- What is the experience of loss like for people with PMLD? Not just of grief, but of the routine loss of staff, teachers, and the loss that comes with insecure living situations. This research could benefit from the experience of people with more moderate learning disabilities who experience the same transient relationships and may be able to express this loss.
- What is the impact of people with PMLD's health and health experiences on their carers' mental health?
- How does spirituality help carers of people with profound and multiple learning disabilities cope? Can we explore the impact of hope on the experience of people with PMLD and their carers?
- What is the experience of Self Directed Support for families of people with PMLD - how is it inconsistent? How can it save money? How does it impact on quality of life?
- What is the impact of diet and food on the wellbeing of people with PMLD?
- Should we have mandatory training on PMLD for NHS staff?



- What are the positives of having a child with PMLD for families?
- In developing small supported housing services - What works? What are the facilitators? What legal processes need to be in place? How can we relate to the local authority in these services?
- What planning and support do people with PMLD need in a hospital setting? How do we move from bad practice to good practice? **

**This question relates not just to the experience in hospital, but also to the experience of getting to the hospital by ambulance or alternative transport, which is often a challenge in itself. The group discussed how poor planning and inflexible experiences around hospitalizations could lead to otherwise preventable health crises and potentially even preventable deaths.

November 2019

Blog 7: Choosing a Jury Question

Rhiann McLean, September 2020.

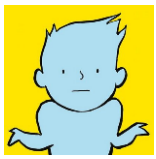
One of the key differences between the Research Voices Citizens' Jury and other Citizens' Juries was the decision to allow the group to develop their own Jury question. This decision was made because it was important for people with learning disabilities to set their own agenda and pursue a discussion they felt was important for their community.

It was vital for the group to use a democratic process to find the right question, but it was also important for the Jury process that this question was fit for purpose and would allow for deliberation. The project team used a 3 phased approach to decide on a question for the Citizens' Jury, splitting the task into smaller activities to be more engaging and less overwhelming.

Phase 1: Setting the parameters

The Research Voices project was funded to focus on learning disabilities and health research, and group members had been recruited on this foundation, which already narrowed the focus. With this in mind, conversation about the 'right' question was guided by facilitators who could build some parameters for the jury questions.

Scottish Learning Disabilities Observatory



The agreed upon parameters for the jury question were:

- It had to be about Health Research and Learning disabilities
- It had to be something that people had not asked at a Citizens' Jury before
- It had to be something that people could use their experience to help answer
- It did not have to be something that people knew a lot about

These parameters were shared with jury members with the rationale behind them. The group then looked at previous Citizens' Juries questions from across the world. The group were asked to critique these questions to decide what they liked or didn't like. The aim of this was to critique question structure and focus. However, this wasn't always the focus of feedback as some jurors were more focused on talking about the topic of the questions. It was a challenge to refocus the group on the more abstract task of what types of questions would work.

However, with some additional prompting and group work, some jurors were able to comment on what they thought a good question should look like, including:

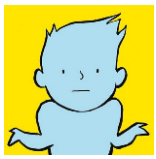
- not too big, not too small (this was a comment on both the scope of the jury and the actual length of the question)
- not too complicated
- something we could answer in a 5 day jury

Facilitators stressed the importance of narrow focus, giving examples of questions that might be too big to answer in 5 days, drawing on evidence that;
'Time and time again, evidence from citizens juries demonstrates that, where there is not a clearly defined, narrow and focused agenda there will be poor quality deliberation' (Elstub 2014).

Phase 2: Narrowing our options

Before the workshop itself, facilitators had taken prompt questions from three sources: the IASSID roundtable and the National Involvement Network and sample questions the group had formed in their 'Communication' workshop. These questions were already focused on the topic of health research and learning disabilities but had two very different sources.

However, it was important for facilitators to have a starting point as the group responded well to prompts and ideas, and free-forming a question for the Citizens' Jury would have been a more complex task that would have required more time.



The facilitators used a tiered approach to question forming. The Jury panel was arranged into small groups. Each group was given all of the questions, colour coded to show their origin:

Pink questions are from our group (The Research Voices Group)
Blue questions are from the IASSID conference (Research people)
Yellow questions are from the National Involvement Group (People with learning disabilities)

The first task was to eliminate any questions that were not relevant. This could be because of their subject or because they were simply not seen as important by the sub-group.

Then, the groups were given time to choose their top 3 questions. This was a much more challenging task. One facilitator used Talking Mats to visually support this debate, while others categorised questions with similar teams. There was in-depth deliberation across all groups at this stage. Some groups added notes or combined questions they felt were similar enough.

After this process, the wider group debated whether they thought it was important where their selected questions came from (for example, did a question feel more 'valid' if it came from a group of researchers?) However, the group didn't feel that the origin of the question was important, particularly because the questions were being selected on merit.

Following this initial selection, each group was asked to place their top 3 questions up on the wall for consideration. Before the next phase of voting, the group were asked to decide on what the word 'consensus' meant for them. Would they be satisfied with a majority vote? Did everyone have to feel happy? The group decided that some level of compromise was appropriate, and as long as everyone could accept the choice (not necessarily be "happy" about it), then it would be consensus. We discussed what feelings might come from having a favourite question that wasn't selected by the group. The group agreed that they might feel "disappointed" or "annoyed", but that ultimately they would feel comfortable with those choices.

Over lunch, facilitators looked at the overall question choices, removed any duplicates and physically placed questions together that were similarly themed, bringing the initial 9 questions down to 5. This allowed facilitators a chance to reflect on the direction of the process, and plan for any clarification.

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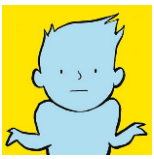

Phase 3: Nominal Voting

The final voting process used nominal voting. Each Juror was given 3 stickers: 1st choice, 2nd choice and 3rd choice. They were encouraged to take their time looking at all of the questions on the wall and given support to read or clarify questions by facilitators. Then, each juror placed their 3 stickers next to the questions they ranked first, second and third.

Facilitators allocated 3 points to a first choice sticker, 2 points to a 2nd choice sticker and 1 point to a 3rd choice. This allowed for the possibility for consensus to be found across questions without them having to be 'the favourite'. The votes were tallied and a question was selected.

An interesting moment in this voting process was a question raised by facilitators "Do we get a vote?". It was challenging for facilitators who had been involved in the planning of this project to hand over this control, but important for the process itself that they did. So facilitators did not vote and did not influence voting.

The process of question refinement was complex as it required focus on each individual word and thumbs up/thumbs down voting on sentence structure. Facilitators and group members puzzled through the best use of language. For example, the group debated the word 'involve'; does everyone know what it means? Should it be 'influence'? The phrase 'be part of' was also a challenge - did it capture what the group was curious about? Did it include the dynamic of power?

Some jurors were disengaged with the process after 25 minutes of refining words and choosing sub-questions. Others were able to present opinions throughout this process. There were moments where facilitators questioned whether the issue should be tabled and reflected on in a future workshop.

However, it was important to choose the jury question on the day because:

- The project team needed enough notice to recruit expert witnesses before the Jury itself
- There was momentum, recognition and ownership of questions built through the process of staged voting which may have been lost before the next workshop
- The group needed to practice finding 'good enough' consensus in the moment, a skill necessary for the jury itself

Ultimately, the group was able to use thumbs up voting on the final wording and chose a question:

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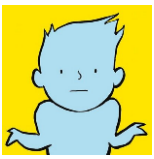

How can people with learning disabilities influence health research?
Including influencing:

- What research is done to help people with learning disabilities
- How this research is done

The ultimate question had elements from both pink, blue and yellow question banks and was shaped by the group. On reflection, more could have been done to slow this final process down and give it structure and build more universal understanding. Key words like ‘influence’ didn’t have universal meaning across the group, but easier to understand words like ‘take part’ didn’t carry enough weight for the group to feel they were right. In the future, it may be helpful to allow for Phase 1 and 2 to be explored before approaching Phase 3 in a second workshop. Ultimately, the group found consensus together and the short timeline allowed us to see some of their debate and deliberation skills in action in advance of the Citizens’ Jury.