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Truthfully, I'm Me: Inclusive Research and Reflections on Being a Learning Disabled Researcher

En toute honnêteté, je suis qui je suis : recherche inclusive et réflexions sur le fait d'être un chercheur avec une déficience intellectuelle

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Abstract

This article gives the reader examples of my reflections and observations while taking part as a researcher in the "I'm Me" project. I have Williams Syndrome (for more information see: https://williams-syndrome.org.uk/what-is-williams-syndrome-6-2/) and am learning disabled. In the UK learning disability is the language we use for people with intellectual and developmental disabilities. I left education at 18 with the UK equivalent of a high school diploma. Hopefully my reflections presented here will help inform other researchers who are looking at inclusive research.

Résumé

Cet article présente des exemples de mes réflexions et observations personnelles en tant que chercheur ayant participé au projet « I'm Me ». Je suis une personne ayant le syndrome de Williams et une déficience intellectuelle. Au Royaume-Uni, le terme *learning disability* (trouble d'apprentissage) est utilisé pour désigner les personnes ayant une déficience intellectuelle et développementale. J'ai quitté le système scolaire à 18 ans avec l'équivalent britannique d'un diplôme d'études secondaires. J'espère que les réflexions partagées ici pourront éclairer d'autres chercheuses et chercheurs intéressés par la recherche inclusive.

This paper explores the value of the inclusion of researchers with learning disabilities in research about learning disabilities. It does so by sharing my experiences, as a writer and researcher with learning disabilities working on I'm Me, a research collaboration between Mind the Gap, an arts organisation supporting people with learning disability and autism, York St John University and six other partner organizations (About Face, Confidance, Hijinx, Lung-ha, Open Theatre and Under the Stars). Other key people within the project are Matthew Reason (primary investigator), Kelsie Acton (post-doctoral researcher) and Zara Mallinson and Alison Colborne, who alongside me have worked as research assistants. The four themes I will be talking about will be: structure and clear roles; needing to look at my own access; importance to have time to process; and representation with lived experience.

One of the most important and unexpected elements of the I'm Me project has been the opportunity to think, process and accept my own disability and how it impacts my life.

How we did the project

I'm Me started in mid 2023 and finished in June 2025 in an arts festival, with the intention of creating thought provoking pieces of art ranging from theatre, dance, music, and visual arts exploring the themes of identity, representation and voice. The intention is for learning disabled and autistic people to be able to express themselves and their experiences of the world around them.

Over the course of the first half of the project, organisations taking part used Creative Doodle Books created at Mind the Gap. These are tools that explore the themes of Identity, Representation and Voice. There is one book for each theme and each book has a selection of questions that can be answered creatively through any art form to help those using the book explore and think about what stories they want to explore what they want to tell. The creative doodle books were used by lead artists and facilitators as a series of creative prompts to explore the three themes. These prompts then were used to make creative expressions to give real, lived experiences in their respective companies and helped form what was made for the I'm Me festival.

This paper doesn't just show the positives but also highlights some of the challenges faced in dealing with my own access needs and requirements, which I hadn't had the opportunity to explore previously. I have lived experience of having a learning disability and anxiety. In this paper, I explore how, through the project, I have learnt and adapted research techniques to contribute equally alongside a more experienced research team.

Structure and clear roles

While being a research assistant on I'm Me I've worn many different hats. I have participated in creative sessions to make the Doodle Books; I've been a part of planning meetings and decisions-making; I've co-presented at conferences and co-written articles with the research team.

One area in which I felt like I've been able to add to the research process has been to help in the creation of a plain language research ethics video (available at https://www.yorksj.ac.uk/research/institute-for-social-justice/research-clusters/neurodiversity-and-learning-disabilities/im-me/ethics-and-inclusive-research/).

This video was collaborated between myself and Zara Mallinson, who was my fellow co-researcher on the project, along with the whole research team. Over the course of about three weeks, we began making a script and looked at five clear rights to research. The rights were: The right to have your say, the right to privacy, the right to support, the right to feel safe and say no, and the right for it to feel worthwhile. Zara and I were both in the video and gave examples of how each right can be applied practically. To give an example, for the right to privacy in the video I had my face to the camera and Zara had her back to it to remain anonymous. We got feedback from artists at Mind the Gap on what areas were clear and which were less so clear. This was before we sent out the video to all the I'm Me partners. Reminding people about their rights to research included reminding them that they didn't need to share anything they didn't want to. Sometimes, however, given the themes of the project, people were reminded of negative experiences.

Sometimes my role has changed, as we've learnt what suits me and the project best. During a workshop there is usually a lot going on and initially I wasn't always clear what my role was as a researcher or how to keep track of everything. We then found that we needed a clearer role for me in the post-workshop debriefs.

Since then, during the workshops I make notes in the sessions and lead the debriefs through asking a set series of questions. I typically handwrite observations during workshops as I find having a laptop hard to manage when also participating in sessions. I try in the debriefs to condense these notes and observations, so things were concise and to the point and to help me to articulate a point I wished to contribute. This also assisted in increasing my skills in thinking on my feet. As well as helping with my anxiety levels and overall confidence.

When participating in sessions at Mind the Gap I find having the session plan in advance very helpful to assist the facilitator where I can. This helps me plan in advance what to look out for in my note taking. Or it can give me the time I need to research something for the session that might be helpful.

Throughout the course of the project, it is occasionally very difficult for people to discuss things in the room. The difficulty we quickly found easier to overcome was to let an artist discuss why and how they found something difficult. This involved having a support worker in the room. However, one thing I did find hard was that I am very close to a number of the artists as I have worked with many of them for many years. As a result, sometimes they felt like if there was a problem they could come to me. To make things clear, I definitely care for the people involved and helped where I could but within this project my role was not to be a support worker, and I had to do my job in order to help collect data. After discussing things with colleagues at Mind the Gap it was quickly reassured to me it was fine to pass people over to the support workers in the room and not feel bad for doing so. This area of being empathetic and balancing my role was a real learning curve which has taken time to learn and apply.

As a part of the role of being an assistant researcher I have assisted and took part in interviewing our partners at regular intervals. This included talking about how they were getting on using the Doodle Books and what art they have created, as well as things they have learnt as a company and difficulties and challenges they find when talking about difficult or challenging topics.

Needing to look at my own access

As a part of my learning disability and my Williams Syndrome I also have a form of anxiety that can be very intrusive in every sense of the word. Previously I have sought to mask this in different ways. For myself, masking is keeping a composed front and never showing that I am anxious, in pain or struggling. I never want people to see me in a vulnerable state. In contrast, since beginning the I'm Me project I have really made an attempt in admitting where I need to help myself, and in turn others, in getting tasks done.

One thing I used to do is ask for some information and struggle to process the quantity and understanding. This then led to me to repeatedly going back to the person to get additional clarification or information. This would effectively waste time for both me and the person in question and would cause me to build up different levels of anxiety. This would range from annoyance from not remembering meanings, then to self-anger for not being able to remember facts, and then I start to tunnel focus and not to be able to see larger pictures. That alone would just be the beginning that would then cause me to spiral overthinking and give me acute anxiety. I would take more time away from other work which would become overwhelming and cause an anxiety attack.

Over the course of the I'm Me project I've learnt that to avoid the need to ask for information again is to ask for a clear email or ask for a session plan in advance. Another thing I discovered which has been useful is to make notes and observations during sessions and meetings in a notebook. This has helped reassure me that I don't need to try to keep it all in my head and it has also helped with letting me phrase what I want to say without causing an anxiety spike.

I have also learnt the importance of maintaining both my physical and mental health, which can change quickly. Previously, I had through a variety of reasons ignored or blatantly disregarded my own access requirements for being able to function in order to do whatever job I am set out to do. This ranges from the personal to the professional and rather than requesting access adaptations I would go to unnecessary lengths to avoid changing my ways.

To give an example, I'd avoid asking for a chair when I needed one due to my physical disability and would struggle and later have consequences that might mean more time to rest due to pain levels. A lot of the reasons for this is down to a lot of internalised and deep-seated ableism that through the course of time I have been addressing and keep re-addressing throughout the project. This has led to me not having a feeling of imposter syndrome and has made me feel like I am giving meaningful and helpful contributions to the wider researcher team.

Therefore, one of the many things I have learnt in the course of the I'm Me project is the importance of my own access. Specifically, how I can contribute in the room, to the best of my ability, mentally and physically.

One reason for this change has been the project providing me with examples of different ways of doing things. For example, during a planning meeting as a part of the agenda we discussed access and Kelsie Acton (post-doctoral researcher on I'm Me) shared her own access needs to the rest of the research team.

From this, I learnt there is no need to be apologetic and that what helps you do your work should always be the route to take. Simple as this sounds my core reasoning in the past for not helping myself was a mixture of pride, being stuck in my ways and a desire to some degree to people please and not put people out of their way. Kelsie says in her access rider:

> You should be excited and interested in questioning your assumptions and trying new ways of working prompted by my access needs and the access needs of everyone else you work with. If you are not excited and interested, you should ask yourself why you are so attached to particular ways of doing things.

She means it as a joke about non-disabled people and organizations who won't change how they do things but then call autistic people rigid. Reflecting on this I realise that I don't like changes to my routine and find it very difficult. I have, however, taken this to heart in the course of the last year or so and really questioned why I don't change how I do things, both personally and professionally.

Not wanting to change came from deep-seated ableism ingrained in my life from the culture around me. I hoped that I could integrate into the non-disabled world. I'm Me gave me permission to not keep struggling on. It gave me permission to experiment and find out what my access requirements were.

Importance of having time to process

When looking at how I can effectively contribute to the wider research team, one of the things I need is to have time in order to process what I need to say. This is relevant in all sorts of contexts, such as during the planning meetings and workshops, and has also been an issue during data collection interviews and working on writing papers with the wider research team. Through exploring my own access, I have discovered that live captioning when in either a meeting or in an interview for data collection is a form of access I need. I found looking back at what got said very helpful when thinking of a follow up question. This has been particularly useful when trying to process what people are saying when absorbing large amounts of information.

For example, during the first cycle of interviews I discovered that while I was comfortable with the pre-arranged questions, I struggled to think of follow up questions in the moment. I often found I thought of a few later on. This then prompted me to ask that for future interviews there was a note that follow up emails might be sent with questions that might have been missed during previous interviews. Adding this took pressure off me and helped with my anxiety of always getting it right when interviewing. Through exploring and admitting that I have both willingly and unknowingly have been resisting the need to help my own access, I have realised a number of things about myself as both a person and a researcher. One key thing has been finally being able to admit that I’m not able to rely upon my short-term memory in order to recall information. Also, I have come to accept and acknowledge that I probably haven’t ever really been able to use my short-term memory and the only reason I said I could was to appease people around me and to attempt to conform to what’s expected of me.

Importance of lived experience

One main area I personally have been working on with I’m Me has been data collection when interviewing the various partners in the research. By participating I have at once brought my own lived experience to the meetings as well as adding a voice not normally a part of typical academic research in the UK.

A very clear point I do want to stress is that I am just one voice that wants to help make a change from a community of thousands of people with a learning disability. I find a great value in taking part in research projects and find them fascinating, adding my own voice in there is part of it but the full value is to push boundaries and to challenge preconceptions that people with a learning disability either can’t or won’t take part in research that includes and involves us.

When we interviewed our partners, as well as an overview of how the project was working for them, sometimes I would specifically ask questions to a lead artist. It's important to note that all the companies had a designated lead artists who had a learning disability or autism. They role was to help plan and facilitate workshops and attend the interviews. I felt it was important that I could encourage lead artists to share their lived experiences and bring their voices to the interviews, separate from the lead facilitators.

I believe it is important for people with learning disabilities to be involved in research and take an active role in working alongside a wider research team. Particularly when the research itself is about learning disabilities. Historically there has been little to no representation of people with learning disabilities in research, although this is starting to change, particular in areas such as the arts, including through projects such as I'm Me. One very clear thing I feel like I have been able to contribute to the wider research team has been the ability to voice an honest and authentic perspective of someone with a learning disability. This is across the board from planning meetings, to sessions, to data collection interviews, and how to make information as clear and plain language in summaries of publications we have been doing.

This has caused a few questions to arise as a result, I have questioned whether I am there as a member of the learning disabled community, an insider as it were, or someone who has stepped outside of our community and wants to observe it, an outsider. I believe however that I can and am doing both by bringing in a focus of shared experience of being both a researcher and a person with a learning disability. This has though caused some personal issues as a result and made me feel like I belong in neither the learning disabled community nor the non learning disabled community. For example, in data collection interviews I often felt like I could ask good questions and resonance with the lead artist because we are both learning disabled artists. But when we were updating the companies about the project, especially when talking about writing papers with Matthew and Kelsie or about data collection, I felt like there was a lack of interest or understanding. Being a learning disabled artist who loves words and research sometimes makes me feel like an outsider. I am however content that hopefully the way I work gives meaningful and true representation of learning disabled people in academia.

Closing Reflections

One of the unique things about I'm Me has been that I have spent a lot of time working closely with the research team. This is not an experience I've had before. I've found that there isn't the expectation that I should know it all. I'm learning new things about research. The research team have worked hard to make this kind of work accessible to me. This means as well as me learning, they're learning about access from me, as well as a different perspective from someone with a learning disability. I hope this helps them work in more accessible ways in future and helps make universities and research teams work in close collaboration with other people with learning disabilities.

With the I'm Me project having the opportunity to explore themes of Identity, Representation and Voice has been a brilliant and very rare opportunity. It's not just a project looking for themes about a group of people that deal with epistemic injustice regularly, it is also very important to remember that these are what fundamentally make us not just people with a learning disability but human.

I've personally and professionally changed my outlook about being a researcher with a learning disability and I think it's both been a challenging and exciting experience. Through learning a lot of new skills as a researcher and being able to look and adapt my practice around my access needs. I would encourage anyone to always look at their access as well as others because if you can’t do the best job in your environment when something isn’t working how can you expect anyone else to? The journey may be long, but it is one that makes us all better versions of ourselves.

One piece of advice I would give to researchers interested in working with someone with a learning disability is simply this; keep having open and honest communication about how things are going both well and what they find challenging and make sure to do this from the beginning of a project all the way through to the end.