

Working it out together: Lessons and insights into inclusive research in an arts context

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Abstract

Background: *I'm Me* is a creative research project co-created between York St John University and Mind the Gap, investigating learning disabled and autistic artists' understandings of identity, representation and voice.

Methods: In this paper, we use Walmsley and Johnson's criteria for inclusive research to reflect on the involvement of people with learning disabilities and autism in *I'm Me*.

Findings: Researchers need to carefully reflect on who benefits from research. Long-term relationships allow genuine allyship and for research design to emerge in an inclusive manner. Taking the time to develop access and clear structures for decision-making can support people with learning disabilities' participation and control over research. Part of access is sharing our findings in accessible ways, in this case, by using plain language and artistic outputs.

Conclusions: Working out *how* people with learning disabilities and autism should be involved in research has involved establishing structures, reflecting and responding to create as much involvement and enable as much decision-making as possible.

KEYWORDS

collaborative practice, ethics, learning (intellectual) disabilities

Accessible Summary

- *I'm Me* is an inclusive research project. As an inclusive research project, people with learning disabilities need to be involved and care about the research. Non-learning disabled researchers need to respect people with learning disabilities.
- We tried to make *I'm Me* inclusive and we learned that:
- Non-learning disabled people need to build long-term working relationships with people with learning disabilities and their support organisations.
- Non-learning disabled people need to think about if the research is serving learning disabled people.
- Understanding access needs takes time and energy. Everyone needs to work on access.

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- Everyone should be clear about how decisions are made. It should be clear when people with learning disabilities are being asked for their opinions and when they are making decisions.
- Sharing what we've learned in different ways makes it easier for more people to understand.
- Having clear ways of working can help people with learning disabilities have control over part of the research.

1 | INTRODUCTION

Since the term was first coined by Jan Walmsley in 2001, 'inclusive research' has come to describe the adoption and adaption of participatory research methodologies to the context of learning disabilities (Walmsley, 2001; Walmsley & Johnson, 2003). Most specifically, inclusive research requires *involving* people with learning disabilities in research about their lives (Carey & Griffiths, 2017). However, while underpinned by core principles, the scope, potential and best practice of what *involving* might entail is far from clear-cut (Nind & Vinha, 2012).

How this fluidity is manifested in practice will be explored in detail in this paper within the context of *I'm Me*, an arts-based investigation into identity, representation and voice with learning disabled and autistic artists. With *I'm Me* 'involving people with learning disabilities' has meant different things at different parts of the process, as we have sought to work out together what inclusive research means for us.

Research in the context of learning disabilities has undergone dramatic shifts in practice over the last 100 years (Iacono & Carling-Jenkins, 2012; Patterson & Block, 2019). The conceptualisation of inclusive research is a direct response to this history, and before discussing our own experiences we first provide a brief narrative of this ethical journey. We then engage directly and deeply with ideas of inclusive research, weaving together conceptual discussion with our own critical self-reflection and insights into *I'm Me* as a way of continuing the evolution of the praxis of inclusive research. In doing so we follow a structure of considering questions of: design and initiation; purpose and allyship; process and access; control; and, outcomes.

2 | NOTE ON AUTHORSHIP AND LANGUAGE

Amongst the various issues that arise in inclusive research are those of authorship and audience, particularly when publishing within academic contexts. Academic authorship requires us to consider who has the capacity, interest and time to write within the particular form required for successful peer review publication. A form that requires significant levels of cultural capital and both tacit and explicit knowledge.

Within this paper, the words 'we' and 'our' describe the three individuals listed as co-authors. The co-authors for this paper are Matthew Reason—an academic researcher without a learning disability; Kelsie Acton—a neurodivergent post-doctoral researcher without a learning disability; Daniel Foulds—a writer and non-academic researcher with a learning disability and without post-16 education. As co-authors we share ownership for the ideas in this paper while also recognising that other individuals from *I'm Me*, both with and without learning disabilities, have been involved in our thinking and learning about the issues discussed.

Language within this context is contested. In this paper we follow a conscious mixing of vocabulary to emphasise specific relationships and values. When talking about broad contexts we use people-first language (people with learning disabilities) as this is often most favoured by individuals themselves and seen as emphasising personhood (Acton, 2024). However, we use identity-first language when talking about specific, outward facing roles within *I'm Me*, where an individual's learning disabled identity is central to that role (learning disabled artist; learning disabled researcher). In this context, identity-first language asserts that learning disability is an inherent part of a person's identity and provides a platform for self-advocacy (Brown, 2011). On our project we have found that using a mixture of these different kinds of languages usefully allows people to think about and focus on different roles at different times in a manner that provides a sense of control and agency.

3 | THE JOURNEY TO INCLUSIVE RESEARCH

In this section, we argue that the conceptualisation of inclusive research is in explicit response to what has gone before. The development of research ethics features cycles of action and reaction, with the institutions, disciplines and structures within which research today takes place the response to horrific histories of exploitation. As Iacono (2006) writes, "knowingly or not" (p. 173) all research in the context of learning disabilities takes places in the shadow of past practices of abuse and harm. Such histories were the motivation for the international post-war settlement that saw the adoption of widespread human rights legislation including the development of ethical codes of practice (The Nuremberg Code 1947; The Declaration of Helsinki 1964). These enshrined the

importance of informed consent and avoidance of harm which have been the cornerstone of ethics process ever since (Doody, 2018; Iacono & Carling-Jenkins, 2012).

On this grounding, ethics processes and ethical awareness have become increasing formalised, spreading good practice and motivated by good intentions. However, accompanying this growth in ethics professionalism many commentators have observed an increasing conservatism and attitude of protectionism (Boxall & Ralph, 2011; Iacono, 2006; McDonald & Kidney, 2012; McDonald et al., 2013). This is driven by awareness of historic bad practice, a conscious tightening of processes of consent and, perhaps most significantly, the development of a classification of 'vulnerable people' and what Brown (2016) has described as a vulnerability zeitgeist. The uniting of these perceptions is often hardwired into the language of academic ethics processes. The institutional ethics review required for *I'm Me*, for example, included the question 'Does the study involve participants who are potentially vulnerable or unable to give informed consent? In this manner, in the context of learning disabilities, ethics processes structurally construct a presumption of vulnerability and lack of capacity to consent in a mutually reinforcing loop which clearly replicates a deficit model of disability.

As a consequence, positions of protectionism have become embedded within contemporary formal ethics processes, perhaps particularly when combined with risk-aversion within institutional contexts. Boxall and Ralph (2011), for example, write of their concerns "that ethical approval processes in the United Kingdom may be discouraging innovative research with people with profound and multiple learning disabilities" (p. 178). McDonald and Kidney (2012) describe "overly protective expectations" (p. 27), while Clough (2017) describes the potential of discourses about vulnerability "to effect social control and paternalistic intervention in the lives of those classed as vulnerable" (p. 469).

Not coincidentally, formalised ethics processes were developed within institutions that are rooted in systemic ableism (Brown & Leigh, 2020; Price, 2024; Singer & Bacon, 2020). This is enacted on a daily basis through various forms of exclusion, with people with learning disabilities underrepresented and marginalised within higher education, as students or as researchers (Leake & Stodden, 2012; Smith & Stein, 2020). Processes of consent and concepts of vulnerability mirror these practices of exclusion. However, there is increasing awareness that protectionism produces exclusions which are themselves harmful (McDonald & Kidney, 2012; Patterson & Block, 2019).

Exclusion from research is harmful in itself, through removing the possibility of potential benefits from research (Dalton & McVilly, 2004) and through the erasure of the right to self-determination (Iacono, 2006; McDonald & Kidney, 2012). While both important, these two elements have different impacts on research processes. Recognition of the potential benefits of research underpins a call to ensure that any ethical challenges do not cause researchers to avoid learning disability related topics. However, while addressing *what* gets researched this would not necessarily change *how* the research is conducted. Rather than protection *from*

something, recognition of the right to self-determination asserts an inalienable right to choice. In the context of research, these rights have been described in terms of the right to be included (Carey & Griffiths, 2017), the right to self-determination (Iacono, 2006), the right to take and judge risks for oneself (McDonald et al., 2013) and the right to independence and choice (McDonald & Kidney, 2012).

Inclusive research emerges within this context. In a historical progression we can see how people with learning disabilities were first perceived as *objects* of research, then more ethically but nonetheless limitingly as *subjects* or potentially participants. The radical challenge of inclusive research is in seeking to go beyond this, with Walmsley and Johnson (2003) describing the requirement for people with learning disabilities to be "more than just subjects of research" (pp. 61–62). This has come to fundamentally define the ethos of inclusive research, which is often defined in terms of seeking to conduct research with people, rather than on them (Nind, 2017), and being participatory and emancipatory (Burch, 2021; Verhage et al., 2024). As a practice, inclusive research incorporates a strongly reflexive sensibility, consistently aware of its own limitations as it considers issues such as recruitment (Carey & Griffiths, 2017), consent (Stickler & Havercamp, 2023) and vulnerability (Clough, 2017). As a practice there is also an inclination to experimentation with methods, particularly the utilisation of arts-based approaches such as those at the heart of *I'm Me*, which enable different forms of inclusive and accessible communication. The radical potential of this restless and evolving praxis is to enact a 'transformative potential' (Verhage et al., 2024) to change how research is conducted. This will change practice in a manner which, in terms of epistemic justice, is arguable as significant as the change which resulted from the post-war adoption of ethical protocols of consent and harm prevention. In the next sections we will explore what this challenge means in practice through the reflexive analysis of our own project *I'm Me*, doing so in a manner that highlights context, practice and insights, recognising both partial achievements and inevitable limitations.

4 | I'M ME AND INCLUSIVE RESEARCH

I'm Me is a collaborative, arts research project between University, core partner Mind the Gap, and a network of six learning disability art organisations—About Face, Confidance, Hijinx, Lung Ha, Open Theatre and Under the Stars. Mind the Gap is a learning disability performance and art company that "exists to enable people with learning disabilities and autism to be part of an arts sector free from discrimination" (Mind the Gap, n.d., para 1). The project uses creative and inclusive research models to explore questions of identity, representation and voice with learning disabled and autistic performing artists. The 2-year project is funded by the AHRC (AH/X003760/1) but the relationships have extended far beyond this.

Researcher reflexivity is a common element of qualitative research, but may be particularly important to developing ethical methods of research with people with learning disabilities

(Walmsley, 1995). Such reflexivity is key to understanding how our intentions with *I'm Me*—to conduct high quality research in an inclusive manner—mapped out through the complex process of doing. In what follows we use Walmsley and Johnson's (2003) five principles for inclusive research as a structure for our reflection:

- The research problem must be one that is owned (not necessarily initiated) by disabled people. [Our subheading: Design and Initiation.]
- It should further the interests of disabled people; non-disabled researchers should be on the side of people with learning disabilities. [Our subheading: Purpose and Allyship.]
- It should be collaborative—people with learning disabilities should be involved in the process of doing the research. [Our subheading: Process and Access.]
- People with learning disabilities should be able to exert some control over process and outcomes. [Our subheading: Control.]
- The outputs and reports must be accessible to people with learning disabilities. [Our subheading: Outputs.]

In the following sections we provide brief summaries of *context*, where we outline what is at stake within this principle; then focus in on *practice*, through a discussion of what we did within *I'm Me*; before broadening out again to explore how what we learnt provides *insights* and implications for inclusive research more widely.

5 | DESIGN AND INITIATION

5.1 | Context

The design, initiation and instigation of research is complex, elusive and yet also vital. Projects often have long and non-linear processes of development as they respond to funding and other windows of opportunity. Having overview of this process brings with it the power to determine what gets researched, what questions are asked, and how they are answered. Typically, both people with learning disabilities, and the organisations which advocate for and support them, are excluded from this process. This provides few opportunities for what Walmsley and Johnson (2003) term 'ownership'. Within this section we discuss how the design and initiation of *I'm Me* sought to open up this process and allow research to develop in a relational and collaborative manner.

5.2 | Practice

I'm Me was developed through a long collaboration between Mind the Gap and Reason, dating back to 2017 and involving multiple points of both formal and informal connection. These included research collaborations (Reason, 2019), funded evaluations, programme validations (Reason & Ward, 2022), undergraduate student placements and post-graduate co-supervision. This long engagement,

tracing far earlier than the project's official start date of May 2023, built relationships of trust and mutual understanding, within which the ownership of ideas becomes fluid. Originally, *I'm Me* grew out of Mind the Gap's interest in supporting the reflective practice of learning disabled artists, with the development of a 'Creative Doodle Book' through a series of collaborative workshops with learning disabled artists in 2019. The social distancing restrictions of Covid-19 shifted the focus of this work, as the resource became a way of supporting remote creative practice (Reason, 2023, 2024).

I'm Me is the next iteration of this relationship, responding to feedback that the open and playful tasks within the Creative Doodle Book provided a space for reflection, engaging with big questions and having difficult conversations in a safe and rewarding manner. Stacey Sampson, of learning disability arts company Under the Stars, for example commented that "We really took the ideas of this book and used them and for us that opened up our space, looking at our surroundings differently" (Reason, 2021, p. 25). The experience of remote working also introduced awareness of the dispersed community of learning disability arts practice and created an improvised network of facilitators and artists working separately on shared questions, challenges and ambitions.

I'm Me was developed through the learning from this experience and the hundreds of learning disabled artists who engaged with the Creative Doodle Book. This again included close collaboration with Mind the Gap, with learning disabled artists consulted on the formation of accessible research questions.

5.3 | Insights

This narrative is long and nuanced, describing open-ended collaboration. It involves sustained interpersonal connections that generate relationships of trust. Genuine research collaborations are, "a complex and unpredictable swirl of power relations, and of constantly changing selves" (Hollingsworth et al., 1997, p. 56). These human and intricate processes also have the multiple points of connection so that rather than relationships ending when individual projects end, they continue in different forms. With *I'm Me*, the research design was *emergent*—meaning it was generated through the relationships themselves, rather than having a singular or external stimulus or starting point. There was no other way *I'm Me* could have happened except through the precise narrative of relationships described here. Inclusive research design, in other words, is research design which is emergent within (rather than external to) inclusive environments, relationships and practices.

6 | PURPOSE AND ALLYSHIP

6.1 | Context

Walmsley and Johnson's (2003) second key principle of inclusive research states that research 'should further the interests of disabled

people; non-disabled researchers should be on the side of people with learning disabilities' (p. 64). The two clear elements to this statement provide our focus for this section. The first is about *purpose* and intentions; the second about what has been most systematically defined as *allyship*.

6.2 | Practice

All funded research projects are required to articulate their objectives and beneficiaries. With *I'm Me* this included: challenging perceptions; providing resources for training and education; and evidencing the value of engaging learning disabled and autistic voices in research, public discourse and policy. Exploring how people with learning disabilities understand their own identities, their representation in broader society, and what they want to say is a vital first step to building a more inclusive society. Through these objectives, *I'm Me* manifests not just the principle of furthering the interests of people with learning disabilities, but of developing and broadening capacity for self-advocacy, enabling both the partner organisations and individual artists involved to create change within their own communities.

Even with enhanced capacity for self-advocacy people with learning disabilities still need allies. Originating in the context of queer politics (McKinnon, 2017) ideas of allyship have a strong presence in disability politics and disability arts (Hadley, 2019, 2020) and can be defined as, "the lifelong, positive, and conscious actions undertaken to promote the inclusion of marginalised populations" (McDonald et al., 2023, p. 398). It is a term that has strong currency within Mind the Gap, regularly used by both learning disabled artists and non-learning disabled producers and facilitators. Yet for Hadley it remains an under theorised concept which limits its ability to help develop truly inclusive practices (2020: 179). Hadley draws on literature of a variety of sources, beyond disability, to explore how well-intentioned allyship can be corroded into purely instrumental or even exploitative relationships, with descriptions of transactional, optical, performative, pseudo or even gaslighting allyship. Hadley coins the phrase 'ally of convenience', defined as "the non-disabled supporter who secures funding for programmes, then sets the aims, methods, and outcomes to benefit themselves as much if more than disabled participants" (2020, p. 181).

Self-reflexivity is particularly challenging here, we all like to believe we are operating with the best of intentions and are 'true' allies. There are, however, clear potential parallels with research contexts, where ally of convenience might describe a relationship that enables a researcher to meet their own professional ambitions but lacks substantive engagement, lasting collaboration or positive outcomes for people with disabilities themselves. Here through *I'm Me* we have posed, including within workshops with learning disabled and autistic artists and research assistants, a series of questions. These have included: What is the relationship between payment and allyship? Whose voices and names will be most prominent in outputs?

What are the tensions between facilitators being conscious of safeguarding, and potential over-protectionism? Who does the work of championing access? Are we doing enough to challenge ableist academic structures?

6.3 | Insights

The simple articulation of positive purpose or allyship, therefore, is in itself not enough. The truism that good intentions do not always make good consequences applies to the context of learning disabilities as much as it does any other. Instead models of reflexive practice usefully transform allyship from potentially performative statements into meaningful relationships. A useful structure is McDonald et al's (2023) presentation of four actionable ideas to foster allyship in intellectual disability research, including (1) learning from long-term relationships with intellectually disabled people; (2) amplifying the voices of intellectually disabled people; (3) infusing anti-ableists frameworks into research processes; (4) embodying a career-long commitment to disability rights. Within these frameworks it is clear that researcher-as-ally describes an attitude and actions that sits not only with the design and operation of an individual research project, but within and throughout a researcher's whole career in a long-term and conscious manner. This long-term commitment mirrors the nuanced design process of *I'm Me* and again points to the need for multiple points of contact that avoid relationships ending as projects or funding ends.

Finally, we want to acknowledge how feminist critiques of vulnerability and autonomy (Davy, 2015) propose that all human beings should be understood as inherently in need of support—and consequently in need of supporters, of allies. Allyship within the context of inclusive research, therefore, can be understood as relational networks of enduring support, understanding and care.

7 | PROCESS AND ACCESS

7.1 | Context

Walmsley and Johnson (2003) state that in inclusive research, "people with learning disabilities should be involved in the process of doing the research" (p. 64). There is a deliberate openness in this statement, to reflect the complexity of research processes and of working with people with learning disabilities. The openness is a recognition that what constitutes 'involved' must flex to the day-to-day operation of doing research and the diverse needs and objectives of each individual. Inclusive research will always involve multiple people, both with and without learning disabilities, working together as allies to do the research. In this section we discuss how involvement is indivisible from *access*, as to genuinely involve somebody we must also provide the support and tools necessary for them to contribute fully and meaningfully.

7.2 | Practice

I'm Me's core planning team is drawn from York St John University and Mind the Gap. It consists of two researchers (Reason and Acton), a producer (Jess Boyes), two learning disabled researchers (Foulds and Zara Mallinson), joined when appropriate by two facilitators (Vicky Ackroyd and Bee Skivington). This planning team is responsible for the overall direction and delivery of the project and is the primary decision-making forum. Within this group different members have a different focus, such as research (Reason, Acton, Foulds), facilitation of research and development workshops (Ackroyd, Skivington, Mallinson), delivery (Acton, Boyes). Also deeply involved are Mind the Gap's ensemble of learning disabled artists (with some variation this includes Bairstow, Clay, Colborne, Colborne, Davies, Evans-Thirlwell, Gray, Haines, Jones, Reed and Riley). Some of these artists were also involved in the original development of the Creative Doodle Book in 2018, and therefore have a long-term relationship with the project.

In addition, *I'm Me* operates with a network of six learning disabled arts organisations, each of who has assigned a lead facilitator and a learning disabled lead artist to the project. Together their role is to deliver creative research workshops within their respective organisations, doing so with a significant degree of freedom. As the project works across theatre, music and dance, practice within the companies varies widely. The facilitators and lead artists are also the contact point for data collection, sharing creative responses and observations from their workshops with the core planning team. Clearly this all describes multiple different kinds of involvement, with different degrees of intensity, control, responsibility, capacity and interest. Throughout all of this are questions of access and the need to responsively engage with what individuals need in terms of support and adaptation to enable them to perform their role within the overall process and project.

One example of this has been in the operation of meetings. Here, under the instigation of Acton, we have evolved a practice that supports access needs and promotes equity of engagement. This has included using a 'talking stick' to ensure no cross-talking and to slow the speed of conversation along with structures such as speaking in turns around the table so everybody has an opportunity to contribute. At other times we have incorporated Easy Read agendas and summaries of items along with visualisation aides. At the same time, we have consistently struggled with the sheer volume of things that need discussing. Working with multiple diaries, including with freelancers and part time staff, means that meetings when everybody is available are often long. This, however, has made it difficult for some to participate and process, resulting in overload and burnout. In a reflective conversations, both project research assistants have talked about challenges of thinking on their feet, knowing their role and how to contribute within meetings (Acton, Foulds & Mallinson, forthcoming).

7.3 | Insights

Amongst our conclusions would be that research processes are often their most inclusive and accessible when they are slow and considered. When things are rushed, or when clear structures are circumvented or do not exist, then the accessibility of these processes is lessened. Time is essential, not to just to allow for processing but also to understand each other's contexts and ways of working. At the same time, we were aware that responses such as removing items from meetings to make them shorter could result in key points being decided elsewhere with less transparent and accessible processes, returning us to the pressure of attempting to cover everything within limited time.

Crucially, access is an ongoing process. As Dolmage (2017) argues, access needs to be responsive, providing not just commitments but mechanisms for correction when the promised access is not implemented or other kinds of access are needed. This process of revising taken-for-granted ways of doing things (such as meetings) takes time and invites access friction. Access friction exists when disability and access remakes our ways of doing things, rather than smoothly incorporating disabled people into non-disabled ways of doing (Hamraie, 2016). A key question is who is responsible for maintaining access, particularly as it is a responsibility that can generate friction and produces emotional labour. It is important this responsibility is shared. For non-disabled researchers without lived experience of access challenges, there is valuable emotional and empathetic learning in actively engaging with the labour required to consistently push for access. Change is hard and working through access friction takes time. Ultimately, inclusive research requires an ongoing commitment to a process of experimenting and refining access, in which everybody takes on responsibility for in a relational network.

8 | CONTROL

8.1 | Context

In their definition of inclusive research, Walmsley and Johnson (2003) write that "people with learning disabilities should be able to exert some control over process and outcomes" (p. 64). Here the involvement of people with learning disabilities, discussed in the previous section, shifts to consider the significance of that involvement. As Bigby and Frawley (2010) suggest we need to ask questions about "ownership and control, genuineness of involvement" (p. 53) and provide honest accounts of these in practice. The issue of control within inclusive research also strongly reflects the wider movement for self-determinism, and the importance of controlling decisions and decision-making processes (McDonald et al., 2013).

In terms of control, the qualifier in Walmsley and Johnson's (2003) formulation is important, "some control" (p. 64) is recognition that within any research project there will be a multitude of decision-making moments, big and small, within which no individual

has a veto or absolute control. This is both necessary and right within a collaborative process, which would grind to a halt if it was dependent on outright consensus. However, this makes it even more vital to ask whether the decisions being made are meaningful, with structural and holistic impact, or are they more limited and tokenistic. This is recognition that forms of 'empty participation' often provide apparent choices that do little to change overall outcomes. Or, as Foulds puts it reflecting on his own experiences, it was important that he felt he could make meaningful contributions to meetings and wasn't just 'another body in the room' (Reason, Acton, et al., 2024).

8.2 | Practice

In *I'm Me*, there were clear moments when people with learning disabilities had both influence and some control over decision making. Learning disabled artists were involved in the development of the grant that funded this project; Foulds and Mallinson have been involved as learning disabled researchers in planning meetings from the beginning of the funded period and have been key in facilitating sessions with artists and collecting data; Foulds has also been deeply involved in developing this article and planning other ways to share the results of the research, such as publications in non-academic journals and podcast episodes. The project's end-point will be a creative arts festival, and people with learning disabilities will be involved in the programming and curatorial processes for this. Certainly, therefore, learning disabled researchers and artists have been involved in all stages of this project and have, therefore, had *some* control over how the research is conducted and how it is shared. However, it is also important to acknowledge not all elements of a process are decision making moments, and not all involvement is control. Being explicit and transparent about those relationships is important in order not to raise false expectations or to mislead.

The exact mechanisms of 'some control' is elusive, often located in specific moments of decision making. To illustrate this further we will look in detail at the decision-making processes of one element of the project. As part of *I'm Me* we are developing three Creative Doodle Books that structure our creative cycles of enquiry into the themes of identity, representation and voice. Each book is created through a 2-month period of research and development with learning disabled artists at Company 1 and their content determines the questions asked and nature of enquiry across the whole *I'm Me* Research Network. Therefore, what is included and what isn't has significant consequences. The following is a schematic mapping of the process of this decision making and reflection on moments of ownership and control.

Planning: *I'm Me's* planning group develops proposals for a series of participatory workshops designed to unpack questions relating to the core theme. Within this process learning disabled researchers contribute ideas, choices, opinions. Control is shared collectively within the group.

Participatory exploration: Mind the Gap's facilitators lead workshops with the company's ensemble of learning disabled artists.

These are designed to test initial ideas, gather a sense of how enquiries will work in practice and gain feedback from the artists. This is not a decision-making moment, but one of consultation and information gathering.

Post-workshop debriefs: Incorporating learning disabled researchers, a pre-set observation structure is used to share insights from each workshop in debriefs. This includes collating a series of potential Doodle Book pages to take to the planning group. While this is not a formal moment of decision making, what does or doesn't get recorded here is significant.

Execution: The planning group reviews discussions and a series of pages are developed in collaboration with a designer. There are multiple drafts and review moments. This is the ultimate decision-making moment, again involving learning disabled researchers.

Structurally, in macro-terms, the above describes a clear and transparent process, with instances of inclusive and shared control and others of participation and consultation. However, we have become aware as the project unfolds that the execution of artists' ideas from workshops depends on them being noted in the post-workshop debriefs and brought forward to the next stage of the process. If the volume of ideas is too great or ideas are considered unpractical, it can be that they are removed or simply not recorded. In other words, this informal or micro-moment actually determines what ideas are available to members of the formal decision-making team to consider.

It might also be legitimate to ask why the involvement of learning disabled artists is consultative, rather than decision making. Why aren't they given more control and involved in directly selecting the content of each Creative Doodle Book? There are number of reasons for this. From the artists' perspective these include levels of interest and availability; while for the project it recognises the challenge of managing decision making with a large group of people. Most crucially, it also recognises that to be meaningful involvement needs to be supported, unsupported involvement in decision making can be counterproductive and even tokenistic. Instead it is through the learning disabled researchers that the project provides access to decision making and control, with these individuals provided with access support and time to make that role both possible and meaningful.

8.3 | Insights

In synthesising our experiences, we would suggest that inclusive research design needs to aim for transparency about the nature of involvement. For us this has included being clear about the difference between consultation and decision making, recognising that people have different roles within a project, and ensuring that moments of decision making are structural and supported. We have also thought about how this is more transparent within explicit structures or macro process than during more improvised micro processes. There are, therefore, two questions about control which are worth asking:

- Macro processes—are learning disabled people *structurally* integral to decision making, development and planning processes?

- Micro processes—is there ability to capture and revisit *improvised* moments of decision making to ensure that these structural processes are operating in practice?

One of our lessons from this experience is that the former are much easier to keep track of and monitor, while the latter—those smaller but often very significant in-the-moment decisions—can be more elusive.

9 | OUTPUTS

9.1 | Context

In their final principle of inclusive research, Walmsley and Johnson (2003) describe how reports and outputs should be accessible to people with learning disabilities. Walmsley and Johnson (2003) carefully explore the tensions between a commitment to accessibility and developing research that explores the complex, nuanced realities of people with learning disabilities' lives. Disability research broadly, however, has been critiqued for being exploitative, particularly for producing inaccessible outputs that produce little or no change for the communities who have given to the research (Kitchin, 2000). Producing outputs that are accessible to the people involved provides a measure of accountability for researchers and guards against misrepresentation (Kitchin, 2000). Part of the desired impact of inclusive research is to ensure that the knowledge generated through research and crucially, the research skills, which include communicating results, remain within learning disability communities (Walmsley & Johnson, 2003).

9.2 | Practice

I'm Me addresses this through having multiple kinds of outputs for different audiences and contexts, including performances, art works, exhibition, podcast, comics and video. Indeed, one of the primarily structural elements of *I'm Me* is that it will use the creative outputs authored by learning disabled and autistic artists to communicate and record understandings and critiques of their own identity and representation. As all the participants in *I'm Me* are artists, they come to the project with considerable expertise in expressing themselves through their own artistic medium, particularly dance, music and theatre. In this element, *I'm Me's* creative methodology ensures that ways of sharing research outputs are not just accessible, but are also ones that all the learning disabled artists involved in the project have considerable familiarity and experience with.

This is not the case with publications such as this, and alongside the variety of creative and accessible participant authored outputs, we remain committed to producing academic articles which will focus on methodologies, the development of theoretical frameworks and strategies of practice. Walmsley and Johnson (2003) note:

Many researchers struggle to resolve the tensions that exist between research which is academically rigorous, acceptable to funding organisations and publishable, and research which is of use to the people who are subject to it [...] A resolution of this tension is probably not possible. (p. 9)

Indeed, of all the outputs *I'm Me* produces, the traditional academic article will likely seem the most remote to all our collaborators and participants. As many of the artists and companies involved in *I'm Me* are unfamiliar with academic research it can be a struggle to communicate how their stories and art might be shared through academic publications like this one. Anne Denby, who manages the drama programme at Under the Stars, reflected:

The tricky bit for me is knowing, do people have a full understanding of what academic research means? People are happy to be part of the project and take part in their workshop, but I'm not feeling a hundred percent comfortable that people know their experience might be written about and where it might end up.

With these questions in mind, it is vital that we take considerable time and care to ensure that everybody involved within the process could give fully informed consent, and we discuss our approach to this in developing a model of Rights in Research elsewhere (Reason et al., 2025). That includes doing what we can to ensure that even academic publications such as this have a transparency of process and are as accessible as possible.

In the spirit of imperfectly practicing for a more equitable future we have written a plain language summary of this article and circulated this to our partners. Plain language is “communication your audience can understand the first time they read or hear it” (Plain Language Action and Information Network, n.d., para 1). Plain language is imagined to provide access for a wide range of audiences, including some people with learning disabilities. It does not, however, guarantee access. We will need to engage in further conversations and thinking together to ensure than everyone who is interested in this work understands it. Nor does it address the multitude of other barriers that prevent people with learning disabilities from accessing academic discourses about themselves or exercising authority within them.

Equally important is the involvement of Foulds as a co-author of this paper, which has prompted a valuable process of figuring out what it means to write together accessibly. While this is still very much an ongoing learning, this has involved: meetings talking through the paper; dedicated co-writing time; and demystifying many of the conventions of academic writing. We've also acted as a collaborative peer review team for a journal article on inclusive theatre, thereby further developing Foulds' academic capital and understanding. In turn, Foulds has brought his lived experiences, including that of someone with a learning disability who has been involved as a

participant in a number of research projects but is now for the first time engaging in analysis and authorship. This again represents a sharing and pooling of different forms of capital that is stronger and more powerful as a result.

9.3 | Insights

We have experienced the tensions Walmsley and Jonson's (2003) describe between producing research outputs that are accessible to most of the artists and facilitators we are working with and outputs like this one, which is not. We have opted to work with a variety of outputs that convey our findings in multiple ways. In doing so, we hope to acknowledge the diversity of people that *I'm Me* engages with, both as collaborators and as potential audiences and to meet their access requirements. Crucially, however, we would consider *I'm Me*'s main output not to be papers such as this, but the concluding arts festival featuring public facing creations by learning disabled artists.

10 | CONCLUSION

We have titled this paper working it out together, as that captures two elements of our inclusive research journey. First, the importance of collaboration, including over extended periods of time, in which mutually constructive relationships and genuine allyship can evolve. Working together also includes recognising the different skills that individuals bring to the project and the different access needs required to enable people to contribute the best work they can.

Second, working it out together recognises that this is a process of discovery. Very little of the detail discussed here—beyond the overriding ethos and some key structural elements—was known in advance. Walmsley and Johnson (2003) capture this aspect of discovery well, writing:

We believe it is important to recognize that while the goals of inclusive research should be involvement, participation, empowerment of all those taking part in it, these will not always be present for all parties at all times during the research. Rather they may emerge slowly. We have found that the researcher is often the last to learn and the most astonished by the learning. (p. 82)

In the two decades since Walmsley and Johnson (2003) coined inclusive research, the approach has become very much defined as a praxis—that is, it discovers what it is through its doing or what Nind (2017) terms 'practical wisdom'. In this vein, researchers report inclusive research as being characterised by feelings of not quite getting it right, and of "competing ethical demands and tensions" (McDonald et al., 2013, p. 217). For Nind, the praxis of inclusive

research means it is responding to what should be done in particular, local and contingent settings, but that by sharing this practice in an open and reflexive manner we can generate a "collective wisdom on doing research inclusively" (2017, p. 284). This paper seeks to contribute and extend this collective wisdom, doing so by layering our practice and learning against Walmsley and Johnson's key principles and current scholarship in inclusive research.

Reflecting on our insights described in this paper, there seems to be a recurring balance between establishing overarching structures and responsiveness to circumstance. Structures are crucial in ensuring the consistent, meaningful and supportive involvement of people with learning disabilities in all aspects of the research process. Responsiveness recognises that structures do not always guarantee access or meaningful involvement, and it is vital to remain alert to the moments where there are gaps and intervene.

In many ways our work to establish structures and then respond to their unforeseen failures mirrors the historical trajectory of research with people with learning disabilities. The importance of informed consent and the avoidance of harm are embedded within ethics, process, but increasingly we are becoming cautious of the exclusionary potential of processes that predetermine the vulnerability of whole demographic groups. We would suggest, however, that we should also be cautious about an end point that celebrates autonomy above all else. Unqualified autonomy does not recognise the genuine support needs of people with learning disabilities, and the access necessary for them to engage with research in a meaningful manner. Moreover, autonomy atomises society into individuals, rather than recognising the value of a research community consisting of diverse experiences and expertise. With *I'm Me*, one thing we have started to recognise is the value of thinking not of individual contributions but of being invested in and belonging to a collective enquiry. Within this collective enquiry the authority of the project is greater than the individual contributions, coming as it does from sharing different forms of capital, including knowledge, experience and creativity. We suggest that inclusive research is defined by complicated and reflexive processes of mutual support, collaboration, trust and control. Part of inclusive research is being in the mess and working it out together in a manner that is equally empowering for everybody involved.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request. Data available on request from authors and will be deposited in university data repository at end of project (<https://yorks.figshare.com/>).

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