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RaY

Research at the University of York St John

For more information please contact RaY at ray@yorksj.ac.uk

Cognitive Accessibility, Ethics, and Rights in Research

Matthew Reason, Kelsie Acton, and Daniel Foulds

Introduction

Research ethics describe processes designed to ensure informed consent and the avoidance of harm. In the context of research with people with learning disabilities, these processes are often inaccessible. Ethics processes have also been critiqued for hardwiring a deficit model that makes presumptions of vulnerability or incapacity. Indeed, ethics and learning disability research as a whole has been criticized for being paternalistic and overly protectionist (Boxall and Ralph 2011; McDonald and Kidney 2012). Research ethics, as a result, becomes something done for (or even to) learning disabled people, rather than something that is done with or by them.

Our thread from ethics and accessibility to dramaturgy is rooted in ideas of care. Maaike Bleeker defines the act of doing dramaturgy as an act of responsiveness and, drawing on Donna Haraway (2016, 34), response-ability, "a praxis of care that involves the capacity to attend to and respond within the messy worlds we inhabit and participate in" (Bleeker 2023, 12). This definition aligns with understandings of access as responsive, emergent, and full of care (Prentice, Gotkin, and Lin 2021). Meanwhile Jessica Watkin calls for a disability dramaturgy that "considers care at every point of invitation into the work" (2022, 37). In this paper, we present and critique the ethics processes of a creative research project called I'm Me. We discuss what we have learned about responsiveness and response-ability in making these processes (more) accessible to people with learning disabilities and autism.

In the context of performance, access is often thought of as an adaptation challenge, where content is translated between mediums (e.g., audio description of visual materials or captioning of spoken text, music, and

soundscapes). Elizabeth Ellcessor, however, proposes that *meaningful use*, is a far more significant criterion for access (2016, 6). If adaptations aren't used, this suggests that more fundamental structural changes are required.

In reflecting on our understanding of the intersection of access and ethics, we identified four interlinked elements:

- First, the framing of ethics as being about *rights*. We propose this provides a counternarrative to discourses of vulnerability and incapacity that surround doing research with people with learning disabilities.
- Second, access is about enabling clear understanding. This includes both in the moment understanding and retaining understanding in memory.
- Third, access is about being able to participate and contribute equitably. Following Ellcessor (2016), we describe this in terms of *meaningful participation*.
- Finally, access should always be a responsive process (Jones, Collins, and Zbitnew 2021; Hamraie 2018). It should be actively revisited to ensure that it is genuinely a relational process about the people involved (Konrad 2021).

Often, access is about an end goal, access to something rather than access as a thing in itself. However, we recognize that access is also a value held by and across disability communities. As a value, access includes affective or emotional qualities (Mingus 2011; Ho, Mingus, and Wong 2019) or can be revolutionary and liberatory (Dokumaci 2023, 25).

Given the context of our project, this contribution is primarily focused on what can be termed "cognitive accessibility." This is an under-researched area that encompasses differences in memory, problem-solving, sequencing, attention/awareness, reading, writing, and graphical comprehension (Kärpören 2021; Miesenberg et al. 2019). This is not to disregard other access questions but is in response to the most pressing access needs of the context in which we were working. Our language use also reflects our context. Disability language is complex and changes depending on geography. In other contexts, the artists involved in I'm Me might be variously referred to as neurodivergent artists, cognitively disabled artists, developmentally disabled artists, artists

with intellectual and developmental disabilities, or artists deemed developmentally disabled. Artists use these different language choices to signal their different approaches to understanding disability and ableism. The range of language and thinking behind language in the UK is similarly complex. Here, we use the language that most of the companies involved in I'm Me use, "artists with learning disabilities and autism."

In this paper, we document I'm Me's rights–based approach to informed consent. We then discuss some of our findings from putting these processes into practice across six partner arts organizations. Our discussion includes the delicate balance of time, attention, and repetition to support understanding, memory, and interest. We also examine the evolving nature of artists' understanding and application of their rights in research. First, however, we elaborate further on our particular project and the context in which we are operating.

Our Context

I'm Me is an Arts and Humanities Research Council–funded collaboration between Mind the Gap, one of the leading learning disability performance companies in the UK, and York St John University. The project uses creative methods to work with artists with learning disabilities and autism in order to explore the themes of identity, representation, and voice. It does so in partnership with a network of six further learning disability performing arts companies across the UK (About Face, Confidance, Hijinx, Lung-ha, Open Theatre, and Under the Stars). I'm Me is an example of inclusive research. Jan Walmsley and Karen Johnson (2003) define inclusive research as research that:

- engages with topics of interest to people with learning disabilities;
- may ultimately lead to better lives for them;
- must represent the "views and experiences" of people with learning disabilities;
- is conducted with respect toward people with learning disabilities.

Inclusive research usually strives to involve people with learning disabilities, particularly as researchers (Carey and Griffiths 2017). I'm Me has involved people with learning disabilities and autism at all stages, from design to

delivery to analysis. The authorship of this paper reflects this commitment. Matthew Reason is an academic researcher without a learning disability; Kelsie Acton is a neurodivergent post-doctoral researcher without a learning disability; and Daniel Foulds is a writer and nonacademic researcher with a learning disability and without post-secondary education. In addition, all the participating companies have involved lead artists with learning disabilities in the planning and delivering of the research sessions in each of their companies. I'm Me has also benefitted from the involvement of three research assistants with learning disabilities: Daniel Foulds, Alison Colburne, and Zara Mallinson. (For further discussion of I'm Me's approach to inclusive research, see Reason, Acton, and Foulds [2024].)

In the context of learning disabilities, the themes of identity, representation, and voice can be seen as "sensitive" topics as they can spark discussions of disability and discrimination. Within the context of university ethics processes, people with learning disabilities are deemed "vulnerable populations." This requires particular scrutiny of questions of risk, harm, and capacity to give consent. However, it also requires reflection on what the label "vulnerability" produces. Karen Brown notes that vulnerability is a way of framing the relationship between people belonging to particular groups and the state or organizations (in this case, universities). "Vulnerable" indicates a relationship that can offer particular supports but is also marked by an "intensification of social control" (2016, 319). This social control is often marked by a language of deficit and lack. University ethics processes implicitly assume that people who are vulnerable are less able to freely consent to participate in research (Boxall and Ralph 2011). Research with people who have learning disabilities is subject to a higher level of institutional risk assessment than research with other populations. While this level of scrutiny is justified by the horrific abuses of past research (Iancono 2006), it also risks stifling research into topics of urgent concern or promoting research through proxies such as parents, caregivers, teachers, and therapists. Either outcome denies people with learning disabilities a voice in matters that concern them. The result is that ethics processes become a form of "social control and paternalistic intervention in the lives of those classed as vulnerable" (Clough 2017, 469).

If we think of access as a purely adaptive process, then it does not necessarily challenge these structures. However, understanding access as a *value* and way of working begins to do something much more radical. Access as value is implicit to the social model of disability, which strongly resonates with the practice of the arts organizations collaborating with I'm Me. The social model proposes that disability is not an individual fault located in the body or mind of the individual to be cured by medical intervention or overcome by great effort. Rather, disability is located in inaccessible environments, policies, and attitudes that exclude disabled people from participation in the full range of human experience. Access expands disabled people's choices while inaccessibility limits them. In essence, people are disabled by the world around them (Shakespeare 2006). Implicit in this is that without inaccessible environments, policies, and attitudes, disability would not exist. Although the idea that access can eliminate disability has been critiqued, particularly by people with pain and fatigue (Wendell 1989), access is central to disability cultures and disability arts, a deeply held value and way of being with one another. In the next sections, we shift from this broad setting of context and value to the pragmatics of our approach to ethics in I'm Me and reflection on how this operated in practice.

Rights–Based Approach

The development of a rights-based model of disability, as exemplified in the UN Convention on the Rights of Persons with Disabilities, seeks to counter deficit-based perceptions of disability through asserting the inalienable right to human dignity (Degener 2016). This is particularly the case in the context of ethics, where the language and principles of research rights provides a powerful counterbalance to narratives of protectionism and vulnerability. While these have often resulted in exclusion from research, a rights–based approach emphasizes inclusion. This can be seen in literature around research rights in the context of learning disability, which asserts the right to be included (Carey and Griffiths 2017); the right to self–determination (Iacono 2006); the right to take and judge risks for oneself (McDonald, Kidney, and Patka 2013); and the right to independence and choice (McDonald and Kidney 2012).

As Lombard–Vance and colleagues point out, accessibility is a general principle of a rights–based approach, as it forms a "precondition for the enjoyment of all human rights" (2023). For I'm Me, we wanted to utilize rights–based approaches as our philosophical underpinning, asserting fundamental positive rights, but adapt them to our specific context in terms of accessibility and ethos. A specific inspiration for our particular practical approach came from education, and the development by Tim Moore and colleagues (2008) of a charter of twelve rights in research for children and young people. A little like an Easy Read document, which is a form of more accessible communication designed for people with learning disabilities (Inclusion Europe, n.d.), each right is presented by a short piece of text and an anchoring image or icon.

This charter was introduced to the I'm Me planning team, including learning disabled research assistants Foulds and Mallinson. It was discussed and the rights were reviewed within the context of research with people with learning disabilities and autism. Key decisions made in response included the need to reduce the number from twelve in order to be accessible, not just in the moment but also in memory. The result was a set of five rights in research. This was accompanied by a consent process that focused not just on informing artists with learning disabilities of potential risks, but framed research engagement in terms of agency, support and benefits. We believe this develops standard ethics approaches to embrace a strong assertion of the right to inclusion within research that emphasizes agency and access. The I'm Me five rights in research are detailed in the table below:

Image and Description	Right	Explanation of Right
\n\nImage description: A brightly coloured drawing of a person speaking into a loudhailer or megaphone.	1. You have the right to have your say.	Everybody has the right to be heard about issues that affect them.

Image and Description	Right	Explanation of Right
Image description: A brightly coloured drawing. On the left a person wearing a headscarf rests her hand comfortingly on the shoulder of a person in a plaid shirt.	2. You have the right to support.	You have the right to the support you need to enable you to contribute the best you can.
Image description: A drawing of a person with a cane asking a person with long blue hair something. The person with blue hair holds up their hand as if to say no.	3. You have the right to feel safe and say no.	During the research, you have the right to stop, to take a break, to talk to somebody you trust.

Image and Description	Right	Explanation of Right
Image description: A person raises his hand toward us as if to say no. His face is pixelated so we cannot see his identity.	4. You have the right to privacy.	Privacy is about whether your name is used in the work we create together.
Image description: A person with ear defenders holds a sign saying "Change" in large capital letters over their head. To the right another person jumps for joy.	5. You have the right for it to feel worthwhile.	Being involved should feel valuable and important to you.

Figure 1. I'm Me rights in research.

Informed Consent as Access

While a rights-based approach counters the assumption of deficits, researchers cannot presume competence without providing adequate support for people with learning disabilities and autism to fully understand those rights. Informed consent is therefore indivisible from questions of access.

Researchers working with people with learning disabilities often employ alternative methods to establish informed consent. These can range from interviews (Goldsmith and Skirton 2015) to workshops (Cook and Inglish 2009) as well as plain language or Easy Read documents. However, Klaus Miesenberg and colleagues (2019) emphasize that cognitive accessibility cannot stop with plain language and Easy Read. Given the diversity of cognitive impairments, approaches to cognitive accessibility need to be specific and personalized. Katherine E. McDonald and Colleen A. Kidney describe how researchers agree there is a responsibility to promote comprehension, including by "tailoring approaches to fit individuals' strengths and weaknesses" (2012, 35). These approaches might include the following:

> Presenting information in relationship to familiar situations and experiences and using simple, jargon-free language, symbols, concrete visual aids, and multiformat practical demonstrations, repeating information, providing information in person verbally with nonverbal communication signals, and allowing participants increased time to make decisions (35).

Mary Bottomley and colleagues (2024) identify similar approaches and add the important point of adapting explanations to suit individual participants.

These descriptions resonate with the approaches we've taken with I'm Me, where engagement with informed consent has offered information in multiple forms. We have also sought to support repeated engagement with the informed consent process in order to make the process more cognitively accessible. The variety of approaches is perhaps as important as each individual element, providing opportunities for repetition and double-checking. Under the Stars noted this, commenting that what worked for them

was "repetition through different forms: through acting out, through watching the video, through then going through the doodle book [and] really considered language that was made for us to use" (Under the Stars).

In the following short sections, we discuss specific examples of approaches to communicating ethics and informed consent in I'm Me. First the development of a rights in research video; then a resource or scenario pack that we provided our partner companies. Finally, we discuss an unanticipated development, when one company developed their own rights in research movement gestures.

Rights in Research Video
The use of a video as an effective form of communication for people with learning disabilities is well established, particularly in the context of education (Evmenova and Behrmann 2014). Among a variety of benefits, video enables the combining of audio and visual processing, the bringing together of spoken and caption text, and the use of eye and body language. Additionally, video can also be paused, replayed, and revisited in an endless manner. For I'm Me, an additional benefit of video is its ability to be used across a geographically dispersed research network.

Within a four-minute running time, the video includes a short introduction and then states each of the five rights and gives an example of what this might mean. For example.

> **Daniel:** We believe that everyone should be able to be heard and be able to share their feeling. Zara, what does it mean to you to be a part, to have your say?
> **Zara:** It means that I want to get my voice heard and make my experiences understood. How about you?
> **Daniel:** It's to be able to share my thoughts. Part of the reason why I'm a part of I'm Me is so that learning disabled voice and stories can be heard.

As can be seen, the video has a consciously conversational, first-person tone between the two presenters, Daniel Foulds and Zara Mallinson, learning disabled research assistants on I'm Me. Crucially, Foulds and Mallinson did not

just appear in the video, they also scripted it with Reason, ensuring that the language used was understandable and that the examples and understandings were authentic and relatable.

Figure 2. Screenshot from rights in research video.
(https://www.youtube.com/watch?v=3kPZAkSfS_Y)

Image description: Seated in a bank of theatre seats, Daniel Foulds—a tall, broad white man with curly hair, wearing glasses and a check shirt—looks into the camera. To his right, Zara Mallinson—a white woman with straight blond hair and a multi-coloured shirt—turns away so only the back of her head is visible. The subtitle reads, "Why are you facing away Zara?"

Not mentioned by McDonald and Kidney (2012), but something that emerges in our experience, is the value of giving this kind of opportunity for ethics to be articulated from and by learning disabled people themselves. A recurring theme of our research has been the impact of artists with learning disabilities talking to other artists with learning disabilities about topics like identity. Similarly, within this video. Foulds and Mallinson's involvement may have created interest and investment in the rights in research process that might not otherwise have existed.

Alongside the exchange between Foulds and Mallinson, the video also uses a small number of visual anchors (such as the illustrations reproduced in figure 1) and also performative elements. When explaining anonymity, which was

possibly the most difficult idea to convey, Mallinson turns her face away from the camera while Foulds faces toward the viewer, physically illustrating the range of options available to artists on the project.

The video was universally appreciated by the companies. A facilitator from Mind the Gap said, "[The video] felt like it had the most [and] biggest response. And there were a lot of participants who had said that, you know what, I've never had sort of rights in research presented to me so clearly." Hijinx worked with a number of different groups spread across Wales. After observing the response to the video in the first rights in research session they delivered, their lead facilitator and lead artists decided to open subsequent rights in research sessions with the video.

Rights in Research Scenarios

As previously discussed, researchers have found that providing concrete examples for otherwise abstract rights can be vital in ensuring accessibility for people with learning disabilities (Bottomley et al. 2024; McDonald and Kidney 2012). Recognizing this, with I'm Me, we produced a short booklet for our partner organizations that examined each right through a scenario or series of questions.

The format of scenarios and questions gave artists the chance to *practise making choices*, emphasizing their agency and decision-making power around their involvement in I'm Me. The booklet ended with the informed consent form. The booklets were not meant to be worked through individually, but were a basis for group sessions. We believe the booklets supported memory and communication by giving artists something they could keep and possibly show to families, caregivers, or other people in their lives.
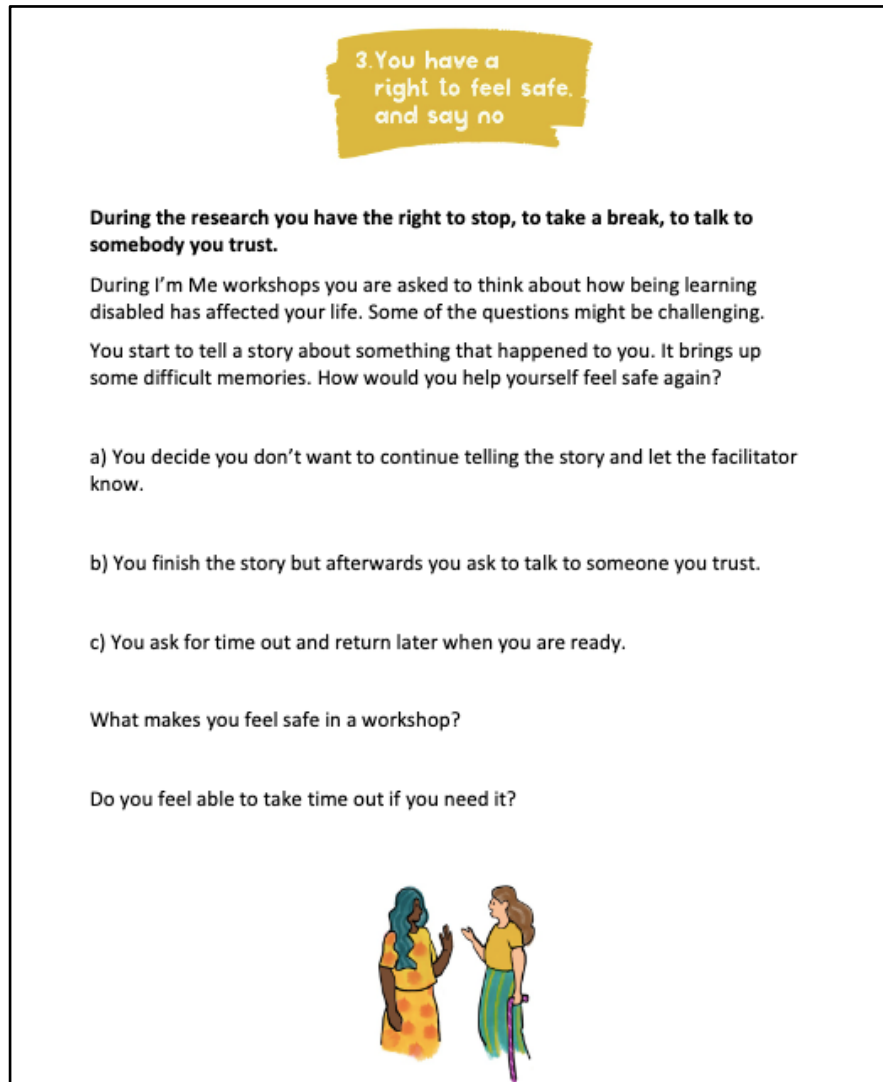
Figure 3. Example page from scenario booklet.

Image description: At the top, on a yellow swish is the title: 3. You have a right to feel safe and say no. Underneath, the page reads: During the research you have the right to stop, to take a break, to talk to somebody you trust. During I'm Me workshops, you are asked to think about how being learning disabled has affected your life. Some of the questions might be challenging. You start to tell a story about something that happened to you. It brings up some difficult memories. How would you help yourself feel safe again? a) You decide you don't want to continue telling the story and let the facilitator know. b) You finish the story but afterwards you ask to talk to someone you trust. c) You ask for time out and return later when you are ready. What makes you feel safe in a workshop? Do you feel able to take time out if you need it? At the bottom there is a drawing of a person with a cane asking a person with long blue hair something. The person with blue hair holds us their hand as if to say no.

Facilitators used the booklets and scenarios as a starting point for sessions. Here Hijinx offers an example of how they worked with the scenarios to encourage artists to physicalize their decisions and actively reflect on why they made the decisions they did:

> We decided we wanted to explore it physically, just because most of our actors tend to be up in a workshop, so as a starting point, we set up the room. So, we used your document and then we kind of [viewed] the different examples that you've laid out and said, OK, so if you feel you fit in A, go to this side of the room; [and] if you're B, stay here; and if you're C, down here. And then Victoria [lead artist] did a wonderful job, then, kind of going around [to] each group and picking a few people or asking people to explain why they chose and why they've fallen into those categories. (Hijinx)

Other facilitators drew analogies between the scenarios and situations the group had encountered while working on past performance projects. Workshops also offered the advantage of groups of artists working together to understand the concepts.
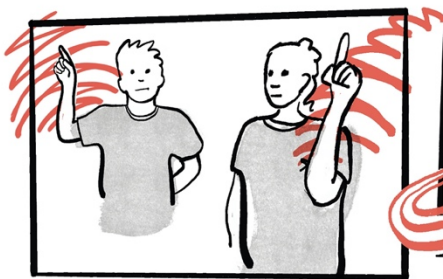
Movement Gestures
Physicalizing the rights in research was a common way the facilitators worked with the scenarios. Confidance, the one dance company working on I'm Me, also created a gesture for each right. Artists in that company collaborated to decide on how to embody each right. This meant artists had to think about what each right meant in order to develop the gestures. In addition, the gestures served as a short, physical reminder of the rights that the company could repeat at the start of each session.
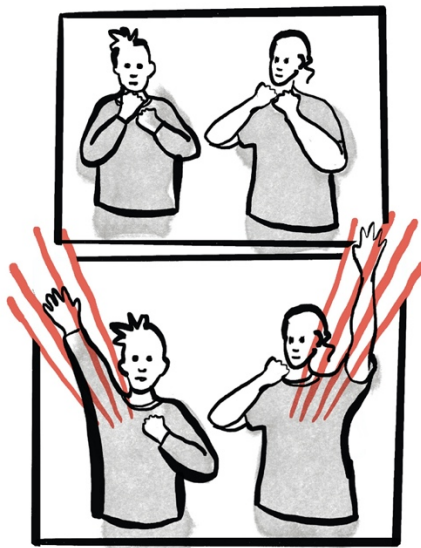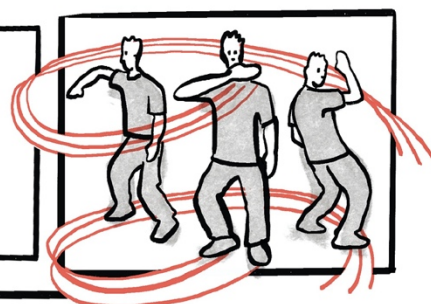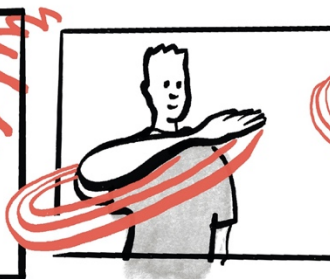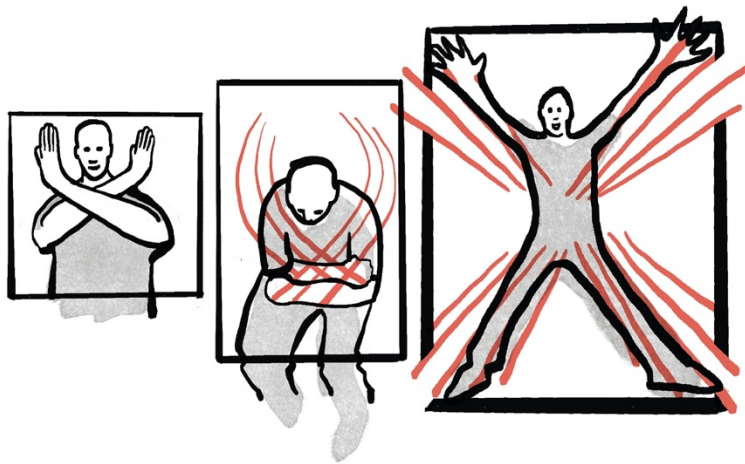
1. The right to have your say
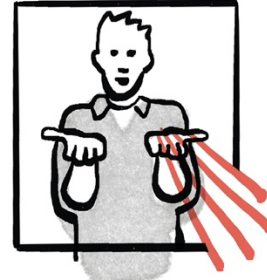
2. The right to support

3. The right to say no

4. The right to privacy

5. The right for it to feel worthwhile

Figure 4. Movement gestures representing the rights in research. Developed by dancers at Confidance. Illustrated by Brian Hartley.

Image description: The rights to research are illustrated through a sequence of comicbook panels, with black borders. Each panel features figures drawn in a loose and open style, clothing drawn in a uniform watercolour grey wash. The panels include movement lines drawn in a bold and distinct red. The first two panels are captioned 1. The right to have your say. The first panel shows two figures with arms held close to their chest. In the second panel, each figure lifts an arm dynamically into the air. 2. The right to support is illustrated in four panels arranged in a square. The top two show a single figure lifting first their right hand and then their left so it is facing palm up in front of them, as if supporting something. The bottom two panels again show first the right hand and then the left being lifted into the air in a pointing gesture. 3. The right to say no is illustrated in a single panel showing two figures. Both have stern expressions on their faces and one arm raised in the air with finger pointed, movement lines indicate the finger being firmly shaken from side to side. 4. The right to privacy is illustrated across three panels. In the first, a single figure swipes an arm diagonally across their chest. The second panel pulls back to show three figures, turning in a circular motion on the spot with one arm held diagonally in front of them. The final panel again features one figure, with both arms crossed in an X in front of their body. The final page features right number 5, the right for it to feel worthwhile. Three panels are drawn in increasing size. The first and smallest shows a figure with arms crossed in front of their body. In the second panel, movement lines indicate the figure

crouching with their arms held closed across their stomach. The final and largest panel shows the figure jumping into an x–shape, fingers spread and toes pointed, with movement lines radiating out from the centre of their body like an explosion.

What Remained a Challenge: Time and Complexity

I'm Me used multiple ways of engaging artists with learning disabilities and autism in their rights in research. While this multifaceted approach to informed consent is promising, we also experienced significant challenges around the complexity of the material.

Facilitators highlighted two challenges they faced when approaching rights in research processes. First, explaining rights in research, even with the support of multiple visual tools and skilled facilitators, is inevitably content heavy. Facilitators were faced with decisions about how much time to spend talking about each right to ensure understanding. Under the Stars explained: "But inevitably there was a lot of talking and thinking in one day. So we did have a bit of overwhelm creeping by the afternoon. Which was demonstrated sort of by a couple of people saying, 'I don't know if I can sign this now. I feel a bit there's been too many words'" (Under the Stars).

Second, and compounding the first factor, artists struggled with the decision they were presented between anonymity and recognition. The presumption of blanket anonymity has the benefit of absolute clarity, even if we would strongly argue it has its own significant limitations. Artists take justifiable pride in their art and typically want their names associated with the work they create. We therefore wanted to enable active choice about when and whether to be named or not named. However, offering nuance produces complexity. One facilitator noted: "I think there was a little bit, it took a little while to understand the concept of choosing if you'd be happy to be named in the different scenarios" (Hijinx). It became apparent that artists had a strong understanding of how, if sharing art, their name would be attached to the art they created. Academic writing was less familiar, so understanding where and when people's names would be shared was more confusing. As one facilitator noted, the discussion started to have "so many kinds of subclauses, and it's not something that they might have thought about very much" (Under the Stars).

If we refuse the equation that access equals simplification (here perhaps in the assumption of anonymization), then it would seem that adequate time is an essential factor in access. However, we cannot simply say that taking *more* time to make things clear is the answer. More time can become boring and lead to disengagement or people answering simply to get it over with, none of which is good access or good dramaturgy of care. What the facilitators are striving for is a delicate balance between the time necessary to make sure artists understand what they're consenting to and taking so much time that the process becomes too long and laborious.

Consent as Not Just Ongoing, but Evolving and Expanding

Facilitators also needed to consider memory when making decisions about how long to spend on the consent process and how often they should remind artists of their rights in research. Memory and time were key enablers and constraints to artists understanding their rights in research. Within I'm Me, facilitators could not assume that artists would remember their rights each week, and even more so across gaps for holidays or other breaks. This understanding that informed consent is not a one-off undertaking but an ongoing process is widely understood and echoed (Klykken 2022; Miller and Bell 2012). However, it becomes even more crucial in spaces where people's memories work differently from the way normative informed consent processes assume. In our interviews, the facilitators demonstrated awareness of this:

> I think we've set the foundations for [consent]. But I think, I think we just have to keep going back to it. Just keep checking that that is what people want. (About Face)

> What we have been doing is reinforcing them as we go. (Confidance)

> [We've] reiterated at the beginning of every session, you know, that if anyone doesn't want to speak at any point, then it's OK. If anyone feels anything, it's fine to feel things. And yeah it's just created a very safe and open rehearsal space. (Lung-ha)

To make informed consent both meaningful and accessible, facilitators built ways to regularly remind artists about their rights in research. This might include reminders at the start of each session (for example through the

previously described movement gestures) or at crucial decision–making moments (such as whether a piece of work should be authored, anonymised, or excluded). These moments of returning to the rights in research offer an important illustration of how ongoing consent needs to be active and structured, rather than presumed and passive.

What is less frequently discussed is that when ongoing consent is active, it will almost certainly also evolve, become more complex, and begin to morph beyond its original context. About Face, for example, reported how when they returned to reiterate the rights in the first workshop back after a Christmas break, they thought the process would be quicker because it was familiar. Instead, they found it took much longer, as the level of understanding had increased. Elsewhere, we have witnessed artists across several companies spontaneously thinking about their rights in relation to the wider world. As one facilitator notes, "And then there was later a discussion on, well, do I have these rights anyway? In life? Which led to a deeper discussion about, yes, you do" (Mind the Gap). In other instances, companies have reported their artists using their rights elsewhere in the organization, outside the I'm Me sessions. This included, ironically but appropriately, in one instance, someone arguing that they would rather prioritize developing the play they had been working on and spend less time on I'm Me. Another makes the link between the right to support and their shared living accommodation.

To us, this adoption and spontaneous use indicates that the artists have been thinking deeply about their rights each time they are invited to remember and discuss them and the contexts in which they are thinking about rights are continually expanding. This is exciting, as they should have all these rights everywhere. Yet it is also a reminder that, in practice, we know these rights are not always delivered or stood up for.

Conclusion

That participating artists spontaneously and independently applied their rights in research in new contexts is a powerful marker of understanding. In this paper, we have identified a number of crucial factors that perhaps enabled this to happen.

- First, the articulation of *rights*—rather than protections, deficits, vulnerabilities and so forth—is crucial to their adoption.

We believe that framing them as rights made them more likely to be internalized, to be owned and exercised. Accessibility is in part about the accessibility of the concepts, but also about their resonance and appeal—do they speak to their audiences in a meaningful and significant manner?

- Second, we enabled and produced *multiple different points of access*—textual, visual, video, dialogical, embodied, and more.

This has multiple benefits, from supporting different ways of cognitive understanding to allowing variety so as to re-enforce memory in a nonrepetitious manner. Both these responses—to the access needs of the artists we work with, and to broader societal contexts that frame them as vulnerable and in need of control—aimed to enable artists to exercise their rights. By taking access as a value in this process, we succeeded (at least in some instances) in expanding the choices available to the artists.

As a final thought, it is worth reflecting on what the consequences or rewards of this access are. The immediate result is clear: The access supported and enabled understanding of the rights in research. The demonstration of this understanding, this ability to consent, in turn enables access to research. Access to research enables the ability to have one's voice heard, to shape knowledge, and thereby to produce change. For individuals and populations who have at times been excluded from research due to reasons of access, these developments are particularly important and likely to provide positive impact over time.

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