

RESEARCH | PEER REVIEWED

Un-Labeling the Language: Exploring Labels, Jargon and Power through Participatory Arts Research with Arts Therapists and People with Learning Disabilities

Nicki Power ^{1,2*}, Emma Millard ^{1,3}, Artists and Activists at The Lawnmowers
Independent Theatre Company ⁴, Catherine Carr ^{1,2}

¹ Queen Mary, University of London, UK

² East London NHS Foundation Trust, UK

³ Croydon Health Services NHS Trust, UK

⁴ unaffiliated, UK

* nicola.power2@nhs.net

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Abstract

People with learning disabilities are often excluded from society. This is changing; however, discrimination persists. Language is one way in which people can be excluded. In healthcare and research, the use of labels and jargon can be a barrier to inclusion. A group of artist-researchers from the UK, some with learning disabilities and some without, wanted to explore power and language in the lives of people with learning disabilities. The group included social change activists The Lawnmowers Independent Theatre Company - who identify as having learning disabilities, and arts therapist researchers working in the National Health Service (NHS). Using arts-based participatory action research methods, we held two co-produced workshops. The first, explore power, jargon and labels for people with learning disabilities and the second, with the arts therapists only, deepened our understanding of exclusion. We used a range of arts-based approaches including improvised performance and music, reflective art making and poetry writing. This article describes the process of working together and how the arts helped us to connect and explore challenging issues. We discuss the different ways labels impact who we are and the power they have to include or exclude people with learning disabilities from healthcare and research. Our participatory approach supported multifaceted knowledge to emerge, which both empowered participants and laid foundations for an ongoing social change partnership. We share our recommendations to make research and healthcare more accessible for people with learning disabilities.

Keywords: participatory action research; arts-based methods; learning disability; arts therapies; inclusion; power; labels

Introduction

This article began when Nicki, an art therapist, emailed Claire, the artistic co-director of The Lawnmowers Independent Theatre Company. She sent a proposal to co-produce a workshop which explored language and power in the lives of people with learning disabilities. Nicki had spent months reading academic art therapy papers dating back to 1980 as part of her PhD research. She wrote in June 2021:

A lot of the language, especially from older papers is shocking, people aren't even seen as human sometimes. I have been thinking about the disability rights movement and disability arts. I want to understand people with a learning disability's perspectives on these types of issues.

Claire replied to say that The Lawnmowers were interested in how the labels and jargon used in health and education settings can be a barrier. Their experience has been that they need to learn the language of the setting, which includes its jargon and labels, before meaningful communication can take place. The name for our workshop: "Un-labelling the Language," was coined by The Lawnmowers. After several telephone calls, securing funding for the project and negotiating the shifting logistics caused by the Covid-19 pandemic, a "pilot project" (to use Nicki's words) or an "R&D - research and development" workshop (to use the language of The Lawnmowers) was arranged.

After this workshop took place, Nicki held a second workshop and invited colleagues, Catherine and Emma (both music therapists and researchers), to come and reflect on the work which took place in "Un-labelling the Language." The workshop was named: "Digesting the Accessible Bread," drawn from a line in a poem written by one of The Lawnmowers (See Box 3).

As part of each of the workshops, we negotiated and agreed on the terms to use in this paper. The Lawnmowers identified most closely with the term learning disabilities to describe this part of their collective identity.

In this paper, we will explore labels, jargon, and power by presenting the two workshops and the processes that unfolded as they happened. Nicki wrote this paper with Catherine and Emma. The Lawnmowers reviewed the paper as a group and sent their edits via email to Nicki. Quotes have been used from the first workshop as headings, to illustrate the themes and bring in the voices from The Lawnmowers throughout.

The Experiences of This Marginalised Group

"That's what really happened"

People with learning disabilities have been on the edge of our communities for a long time (Rickson, 2014). According to a recent survey in the United Kingdom (UK), they are more likely to experience bullying or be the victims of crime than people without learning disabilities (Simmonds et al, 2018). Further, UK data suggests they are more likely to experience loneliness (Sense, 2017) and have a higher prevalence of mental illness than the wider population (Emerson & Baines, 2011). A person with learning disabilities in England dies, on average, twenty years younger than a person who does not have learning disabilities (Glover et al, 2017). They are also more likely to encounter social determinants associated with poor health, such as poverty, lack of access to education and employment, a poor diet, or inadequate housing (Wigham & Emerson, 2015).

History catalogues how labels have been used both to include and to exclude this varied group of people. In the UK, during the Victorian era, people with learning disabilities were confined in asylums and workhouses "not by reason of their social disability, but on their presumed association with poverty, insanity or delinquency" (Gostin, 1986, p.11). The Mental Deficiency Act (1913) was the first time in British history that a law attempted to

categorise this diverse group of people as neither mad nor bad (O’Driscoll, 2009), but a group who may have different needs to other people. The categories of idiot, imbecile, and feeble-minded were defined. This Act was inherently flawed, written in response to social pressure driven by false beliefs that people with learning disabilities were genetically tainting society (Hall, 2008). It effectively denied people their right to citizenship through forced and indefinite detention (Walmsley, 2000). For much of the rest of the twentieth century, the needs and voices of people with learning disabilities were absent from laws and policies in the UK. Despite recognition of the need to improve the lives of people with learning disabilities (Department of Health and Social Security, 1971; Power & Hawtin, 2013) little changed until the 21st century.

The UK Government’s white paper on Valuing People (Department of Health, 2001) ascribed in law the rights of this group of people for the first time, which led to a plethora of policies attempting to rectify the centuries of inequalities (Bull, 2012). It was also the first piece of legislation published in an accessible format (Power & Hawtin, 2013).

Changes in law can bolster changes in society (Healy, 1998), but change at a social level is often a slow process and many inequalities persist. The evolution of both disability rights and disability arts movements have cultivated grass-roots social change. These movements, which seek to redress power imbalances and give voice through political or activist platforms, can be less inclusive of people with learning disabilities (Goodley, 2001; Rickson, 2014). The socially engaged work of organisations such as The Lawnmowers is one approach that captures the resources of people with learning disabilities to contribute to the arts, education, and activism.

Introducing the Artist-Researchers

“That’s who I am, take me as I am”

Although The Lawnmowers and arts therapists have many intersecting aspects to their identities, we have chosen the term: artist-researchers (Wang et al, 2017) to refer to our collective group members, placing the use of the arts in this research at the core of our collective identity. The artist-researchers who co-produced the workshop series were both experts with lived experience and experts by training (Black et al, 2019).

The experts with lived experience were The Lawnmowers Independent Theatre Company, based in Newcastle-upon-Tyne. They are a social change company of artists and actors, run by and for people with learning disabilities. They believe that people with learning disabilities should be active citizens, agents of social change, and visible artists. Their company has over thirty years of experience in devising forum theatre based on Augusto Boal’s premise that “We are all actors: being a citizen is not living in society, it is changing it” (Baol, 2009). Forum theatre uses interaction between the actors and the audience to create opportunities for “empowerment through participation” (Brandon & Keyes, 2013, p.169). More recently, The Lawnmowers have been working in partnership with higher education institutes through simulation training (Abma et al, 2019; Brandon & Keyes, 2013; Campbell, 2014) and providing consultation on inclusive research (NIHR, 2020).

The experts by training were an art therapist (Nicki) and two music therapists (Catherine and Emma). They work in the National Health Service (NHS) in England. They provide group and individual therapy both in community and inpatient settings in mental health services and are also active researchers. Their professional training in the arts therapies, combines psychotherapy with an arts modality. All three experts by training locate themselves within recovery-orientated approaches to both research and clinical practice (Carr et al, 2021; Millard et al, 2021; Critchley et al, 2019). In their clinical practice, they draw on Leamy et al’s (2011) processes of recovery in mental health (connectedness, hope and optimism, identity, meaning, and empowerment). They work collaboratively with

people who use NHS services to focus on their strengths and capacities through the creative arts (McCaffrey et al, 2018), as well as the challenges they face. They do not have learning disabilities.

The Barriers to Accessible Academia

“My advice is try harder”

In research that is co-produced, the co-participants “work together, sharing power and responsibility from the start to the end of the project, including the generation of knowledge” (NIHR, Involve, 2018, p.4). This is how the artist-researchers conceptualised the series of workshops described in this paper.

The ethos of co-production is that the people who use a public service are “hidden resources, not drains on the system” (Boyle & Harris, 2009, p.11). Through harnessing their unique skills and experience, in equal partnership with professionals or service providers, change programmes can develop more responsive and effective services (Farr, 2018). When working collaboratively in this way, power is shared and there is an emphasis on the development of relationships between researchers. While the prior relationship between the experts with lived experience and the experts by training was not located in a specific public service, both groups of artist-researchers understood the inherent power structures within each other’s contexts and had experience of working in “culturally safe” ways (Stuart & Shay, 2018).

Although our workshops were fully co-produced, this paper is not. The Lawnmowers consulted on the contents of this paper and edited a draft version, but the main body of the writing was completed by the experts by training (arts therapists). Miles, Renado and Marston (2021, p.5), in their exploration of authorship when co-producing, refer to “academic publications [as] a specific and inflexible output.” Despite our best efforts to be inclusive, this paper will not be accessible to many people with learning disabilities who are impacted by lack of access to technology (Sheehan & Hassiotis, 2017) and who may not have the required literacy. We have created an easy-read summary of the article, which will widen access to the main aims and findings of the project.

Theoretical Position and Methodology

“Not art for art’s sake”

Rooted within social justice theory (Jost & Kay, 2010), the artist-researchers employed anti-oppressive practice (Baines, 2013; Rickson, 2014; Sakamoto & Pitner, 2005) through the lens of critical disability theory (Goodley, 2001; Pickard, 2020), focussing on emerging affirmative arts therapies voices (Pickard et al, 2020; Rickson, 2014; Yi & Hyland Moon, 2020), acknowledging critical arts therapy voices (Baines, 2021; Eastwood, 2021), and making use of participatory action research (PAR) methods.

PAR is not a particular research method, but rather a diversity of approaches that include three elements: “participation (or collaboration), action (or social change), and research (generation of knowledge)” (Spaniol, 2005, p.87). Kemmis and McTaggart (2007) describe PAR as a “social process of collaborative learning” (p.277). This is akin to co-production, where change occurs between people when social practices involve shared power. Just as co-production seeks to overcome traditional power imbalances, PAR has an ethical commitment to challenge social hierarchies (Askins & Pain, 2011). Both approaches, PAR and co-production, seek beneficial outcomes for the communities at the centre of the research, and both focus on resources, not deficits.

Our arts-based approach used a combination of art forms (visual, literary, performance, and music) to explore and understand the issues of power and language (Hunt, 2005;

Ledger & McCaffrey, 2015; McCaffrey & Edwards, 2015; Wang et al, 2017). We also planned to use music and movement in both of our workshops, but were unable to do so in the first workshop with The Lawnmowers due to challenges because of the Covid-19 pandemic. The arts as a tool to communicate and engage were familiar to all the participants in their professional lives. Here, we chose arts-based methods because of their capacity to include “overlooked, ignored or not conceptualised [issues and to] generate valuable community knowledge to inform” (Majid & Kandasamy, 2021, p.266).

The combination of these methods was congruent with both the arts therapists’ recovery-based model of practice and The Lawnmowers’ use of forum theatre. The Lawnmowers call this “*not art for arts’ sake*”; the arts therapists consider this approach to be transformative co-production (Needham & Carr, 2009): socially engaged arts-based research which leads to radical system change.

Aims of our Artist-Researcher Collaborations

“Artistic Bounce”

The overarching aim of this piece of work was to explore the potential for an ongoing collaborative relationship between The Lawnmowers and Nicki. She was keen to include people with learning disabilities in her PhD research as active partners throughout all stages of the research process. Nicki had past experience as a service manager supporting the development of an arts-based wing of a recovery college (Critchley et al, 2019) and as a clinician co-producing with experts with lived experience in secondary mental health services (Critchley et al, 2017). This meant that she had a good understanding of the additional time required to negotiate boundaries, of the need to sit with uncertainty in the co-production process, and of ethical considerations around power-sharing and financial remuneration for experts with experience. The Lawnmowers were interested in expanding the reach of their social justice work, geographically (beyond the North-East of England) and professionally (into mental health research), therefore this collaboration had potential benefits for both groups.

Starting with Nicki’s theme of wanting to explore power and language, Nicki and the Lawnmowers designed and participated in a workshop, or as the Lawnmowers called it, an “*artistic bounce*”: a shared creative experiment, valuable as a standalone piece of work, but providing core ingredients for future creative output. This workshop was called “Un-labelling the Language.” This was followed by a second workshop, called “Digesting the Accessible Bread,” involving Nicki, Emma, and Catherine. We used art and music to reflect on our felt response, as people without learning disabilities, to the data produced in the first workshop. This enabled us to distil core themes from the large volume of data, whilst maintaining the richness of the creative process and the individual stories within. We were able to expand our understanding, through making our own connections to the ways people with learning disabilities might feel in response to discrimination and exclusion. Nicki had negotiated with The Lawnmowers during “Un-labelling the Language,” that they did not want to be intensively involved in further analysis, or in the writing up of the paper, due to their other commitments. Furthermore, they recognised that one of the benefits of the co-production relationship with the arts therapists was their expertise in academic writing, which had the potential for their social justice work to reach a wider audience. The themes from all of the workshops were collated by Nicki, who then shared them with Catherine and Emma to write the first draft of this paper. The Lawnmowers held a group session to review this draft version and Claire returned comments, further ideas, and reflections to Nicki via email.

Originally, we had planned to have all artist-researchers at “Un-labelling the Language,” but this was not possible due to the increased risks of Covid-19 for people with learning

disabilities (Public Health England, 2020). Risk management required that external visitors to The Lawnmowers be limited to just one person. Nicki was the first external person to visit The Lawnmowers in-person since the start of the pandemic in 2020. We then planned to use video-conferencing to include Emma and Catherine in the workshop, but Covid-19 again thwarted this plan as we had to re-arrange Nicki's visit to Newcastle due to the legal requirement to isolate after testing positive for the virus. Emma and Catherine were introduced to The Lawnmowers via photographs shared on a projector.

Ethical Practice in Co-Production

Our workshops were a collaboration between two professional groups – the arts therapists and The Lawnmowers. The Lawnmowers are a professional group whose job it is to use their lived experience to actively engage with other professionals, particularly those without learning disabilities, and the arts therapists are a professional group who often work with people who have learning disabilities to offer them psychological support using creative arts mediums. Our collaboration does not fall under the definition of formal research (Health Research Authority, 2020), and so we did not seek ethical approval for this work. We did, however, act ethically throughout the collaborative process. This included minimising the potential for harm, such as emotional distress, through clear communication in advance of the workshop themes, an informed consent process, and voluntary participation with people encouraged to share only what they wished and to take breaks as needed during the workshops.

The artist-researchers in both workshops were collaborators and not research participants. We began each session by exploring an informed consent process, to ensure that everyone present understood what was planned and what would happen to their data if they chose to participate. There was an easy-read, illustrated consent form for people to sign which sought consent to use our words, art, and work to write this paper and develop future resources. Each section of the form was discussed by the groups at both workshops. Members of The Lawnmowers were offered support around understanding and completion by Nicki or Claire.

Acknowledging that historically, input from such groups has often been taken for free, which may be exploitative (Needham & Carr, 2009), we secured appropriate funding to pay The Lawnmowers for their professional skills and expertise from East London NHS Foundation Trust. It is important to recognise the ethical challenges of paying people who may be less empowered to give their views. They may feel pressurised to commit or seek to placate the party with more power through acquiescence (Beail & Williams, 2014; Farmer & McLeod, 2011; McVilly et al, 2008; Nind, 2008). However, in this context, members of The Lawnmowers were paid for their time, advice, and expertise, as this is their job.

Objectives of the Co-Produced Workshops

The objectives of the two-day “Un-labelling the Language” workshop (Nicki & The Lawnmowers) were to:

- Identify labels for people with learning disabilities and think about their meaning
- Explore the power of words to include or exclude people with learning disabilities
- Understand the importance of context (the place or setting) when we use jargon
- Develop suggestions to help researchers and healthcare providers to be more inclusive and to shift power in relationships

The objectives of the “Digesting the Accessible Bread” workshop (the arts therapists) were to:

- Process the emotional impact of social change research with a marginalised group
- Continue to distil the outputs from the first workshop

Workshop Format

Each workshop had a guiding frame, within which there was scope to shift in response to where the artist-researchers wanted to go on the day (see boxes 1 & 2). To enable an equal space for all voices and expressions to be heard, we drew upon the concepts of:

- Making a “communicative space” (Habermans as cited in Abma et al, 2019). This is a space where we can all share, talk, or make together, which builds a mutual inquiry.
- Through relational interplay, in the form of dialogue and in this case, making use of the arts, the group reaches intersubjective agreement and understanding as a form of “unified consensus” (Kemmis & McTaggart, 2007).
- Using the spectrum of the arts, we made the process an “immersive embodied experience” (Kelemen & Hamilton, 2015), enabling all to be there together using our voices and bodies to deepen understanding.
- To further increase inclusivity, we broadened our communication tools (Royal College of Speech and Language Therapists, 2013), making use of gesture-based communication and accessible printed information, such as the Communi-cards pack (Figure 1).



Figure 1. Communi-cards to support accessibility in verbal spaces.

A skeleton plan for “Un-labelling the Language” was developed by Nicki and Claire with topics for exploration such as: Labels, Jargon, Power. Specific content was not defined at the outset, as we drew on the expertise of the group to co-produce the session. For example, on the morning of day one, the plan consisted of completing the consent agreement and doing a warm-up activity together. The Lawnmowers decided and led this activity on the day and added a second activity which explored misunderstood words using a jargon relay race. Each activity was structured using Kemmis and McTaggart’s (2007) action research repeated cycles of: Plan, Act and Observe, Reflect. This model was replicated for “Digesting the Accessible Bread” with Nicki offering a skeleton plan, the contents of which was shaped by the arts therapist collaborators. The final detailed workshop programme for both workshops, assembled after the workshops had taken place, is shown in Appendix.

Methods in Workshop 1: “Un-labelling the Language”

Setting: Arts Centre, Pelaw in Gateshead, Newcastle. The home of The Lawnmowers Independent Theatre Company.

Participants: 14 adults with and without learning disabilities. (1 paid carer; 2 ciswomen without learning disabilities; 11 people who identify as having learning disabilities). One person joined via Zoom (video conferencing) on the second day.

Design: The workshop lasted two days with a series of activities drawn from both the professional and lived experience of the participants.

Claire facilitated the workshops through managing time and technology, but different artist-researchers led segments based on emerging aspects of the co-production process. All artist-researchers had lunch together in a shared space.

Data Collection: Multiple sources and methods were used to collect data:

- Audio recordings were made of conversations for sense-checking later.
- Nicki kept contemporaneous ethnographically informed field notes (Wolcott, 1995).
- Visual data included: reflective postcards (Figures 3 & 4) made by artist-researchers at the end of each day, post-it notes, DVD segments of The Lawnmowers past performances played live in session and photos on the walls of the Arts Centre past performance events.
- Literary data included: poetry written by members of the group, a book on people with learning disabilities’ experiences of parenting (Cooper & Flower, 2020)

Box 1. Methods used in “Un-labelling the Language”.

Methods in Workshop 2: “Digesting the Accessible Bread”

Setting: Lecture Theatre at the Unit for Social and Community Psychiatry, Newham Centre for Mental Health, London. The office base of the arts therapists.

Participants: Three ciswomen arts therapists (one art therapist and two music therapists) who are also researchers in mental health. They do not have learning disabilities.

Design: A half-day arts-based reflective workshop which made use of response art (Fish, 2012) as well as the data and creative outputs of “Un-labelling the Language” as the basis for further creative inquiry.

Nicki facilitated the session through managing time, technology, and resources. With Nicki, Catherine and Emma co-produced the arts-based activities used in the workshop.

Data Collection: Multiple sources and methods were used to collect data:

- Nicki kept contemporaneous ethnographically informed field notes (Wolcott, 1995) on the group process (including music and art making) and group discussions.
- Visual data included: art journal and mixed-media response art, two-dimensional art images made in session, photos of images and the space; video recording of the temporary three-dimensional art installations made.
- Music was improvised during the workshop, but no sound recordings were made. Discussions and reflections on the music-making process were recorded by Nicki in field notes as above.

Box 2. Methods used in “Digesting the Accessible Bread”.

Workshop Process and Key Findings

Within the scope of this paper, we will focus on three key findings from our PAR. In line with the participatory and flexible nature the workshops, we have presented these findings with a narrative context of how they evolved across different activities. The first and second findings emerged from “Un-labelling the Language.” These focus on the use of labels and jargon, where dynamics of power are woven throughout our words and the arts. The third, developed within “Digesting the Accessible Bread,” centres on the role of arts-based methods in exploring complex social inequalities.

1. Labels of Learning Disability

“Tins of food have labels, but people have identities”

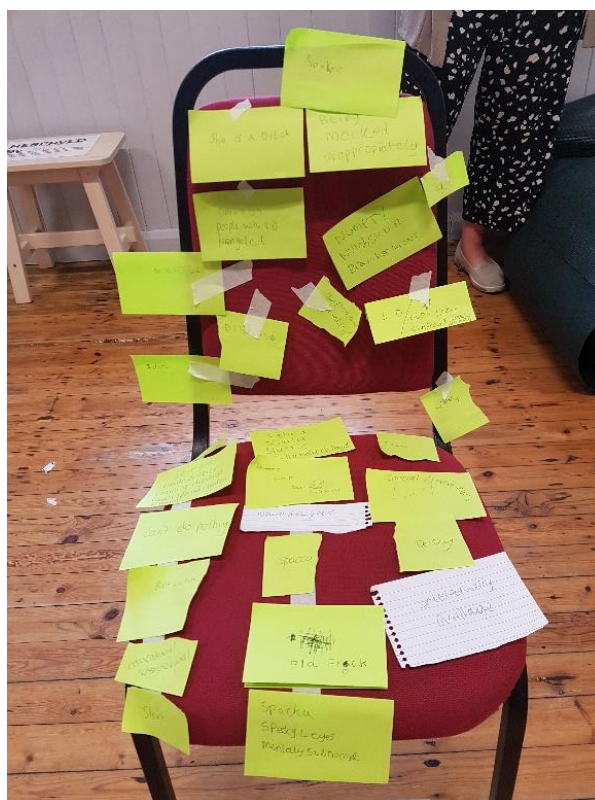
Together, projected onto the wall of the Arts Centre, with tinny speakers and dimmed lights, we watched a scene from the live filming of “Walk the Walk” (2003), a piece of theatre made in response to Valuing People (Department of Health, 2001). In the clip we see Andy, playing the role of the asylum warden. He is encouraging everyone to join a sing-song – audience and actors together. The actors, in striped overalls, have large labels hung around their necks: playing the roles of idiot, imbecile, feeble minded, and moral imbecile. The melody is that of the Anglican hymn “All things bright and beautiful,” composed by William Henry Monk, with Cecil Francis Alexander’s words adapted to reflect the social thinking from which the Mental Deficiency Act (1913) emerged.

All things slow and handicapped
are safe within these walls.
All things bright and beautiful
you won’t find here at all.

The idiots and cretins,
the moral imbeciles;
Are lucky to be getting
their dress, their beds and meals.

All things slow and handicapped
are safe within these walls.
All things bright and beautiful
you won’t find here at all.

This is Nicki’s introduction to the work of The Lawnmowers. The labels from this Act led us into a discussion of the labels which have been put upon members of the group. We began to talk about the names that people had been called in their lives or had heard about from the past. We decided to make post-it labels with all of these names written on. We thought about sticking these labels to a person in the room, but thought better of it; we didn’t want to label any one person with the weight of history and discrimination. Instead, we chose an empty red chair and filled it with brightly coloured words (Figure 2).



- Spaker
- Numpty
- Numbskull
- Brainless no one
- God's little children
- Mongoloid
- Retard
- Disabled
- Spastic
- Nonse
- Bitch
- Idiot
- Intellectually disabled
- Mentally subnormal
- Backward
- Slow
- Bootlicker
- Can't do nothing
- Imbecile
- Thicko
- Neurodivergent

Figure 2. The labels of learning disability.

After this, we talked together about people’s lived experiences behind these single words. A woman, remembering her childhood, spoke about her mother being told she’d: *“never amount to anything”* and needed to go to a local residential school. She was labelled as either *“abnormal or subnormal.”* A man spoke about being an inpatient in the 1990s, a health professional labelled him: *“you’re an animal, who should never have been born.”* A young man spoke about being bullied in school, called a *“boot-licker”* and having his lunch money taken every day. Nicki said what an outdated discriminatory term this was to still be in use today. An older man spoke about different generations using terms that were once viewed as politically correct, referring to his father saying: *“he goes to his handicapped group.”*

The people in the room shared the history of people with learning disabilities, firmly anchoring it in their lived experience, in our society. One person noted: *“Labels are powerful, they hurt you. Can start feeling that it’s true.”* Although Nicki had worked as an art therapist with people with learning disabilities for over a decade, she had never heard the story of this group of people told in their own words in such a complete narrative, through their experiences and those of their families. She cried.

Andrew Mc suggested that: *“Tins of food have labels, people have identities.”* We thought about how naming a group, can identify them as different in society, suggesting that each member of that group is the same – like the tins of beans. Debs added: *“Everyone’s identity is different; depends where you’re at.”* We concluded that: *“Labels are a way to try to understand a person, but not the whole person.”*

When we set about defining our identity as a group, in preparation for writing this paper, Claire asked the group: *“Do you put the disability before the artist or the artist before the learning disability?”* She gave the examples: *“I work at a theatre company for people with learning disabilities.”* Followed by: *“I work at a theatre company. My actors have learning disabilities.”*

Through these two phrases, the artist-researchers witnessed how meaning can be profoundly altered when we speak. By locating an impairment (the cognitive impairment for people with learning disabilities) at the core of someone's identity in the former or as part of a much richer, more complex whole person, in the latter (Goodley et al, 2021).

2. Locating Jargon to Aid Understanding

“That went over me head”

“Ginger Beard” (aka Andrew Robson) recounts his monologue from a recent production entitled: “Retake, Remake” (2021). This production sees The Lawnmowers reclaim roles in films and TV which have been played by actors who do not have learning disabilities. For this speech, he stood. His body managed to tense whilst at the same time growing larger in stature. His voice changed timbre, now slower, deeper. He commanded the space. We listened. He played the role of prominent eugenicist and playwright, George Bernard Shaw:

“ ‘I never know exactly how to make my opinions clear,
Because, I object to all punishment whatsoever, I don't want to punish anybody.
But there are an extraordinary number of people who I want to kill.
Nothing of the unkind or capable of spirit, but it must be evident to all of you;
You should all know, apart from certain people at least
Who are no use in this world, who are more trouble than they are worth.
And I think it would be a good thing to make everybody come before a properly
appointed board, just as you might come before the income tax commissioners.
And say every 5 years or every 7 years;
Just put them there and say:
sir or madam, now will you be kind enough to produce your evidence.
If you can't produce your evidence
If you're not pulling your weight in the thought of the group
If you're not producing as much as you consume or perhaps a little more
Then clearly, we cannot use, the big organisation of our society for the purpose of
keeping you alive,
Because your life does not benefit us and can't be of very much use to you.'
That's the speech I say in the play.”

Pulling us from the early 20th century right back to the room, Andy said: *“the jargon word for all this is eugenics. We know what it's all about, but it's a meaningless word.”* The discussion moved on to other complex words, at first too difficult to understand. Scott said: *“once you've had the experience you can understand the context and meaning.”* There's more talk as a group about locating words in a time and place (their context). Then, there was a realisation that The Lawnmowers needed to explain some of their language to Nicki. Kindly, Claire said: *“outsiders help reflect on practice.”*

Astutely, one artist-researcher said: *“Every setting has jargon.”* The Lawnmowers moved on to talk about: *“jargon is the e-numbers and preservatives...we've had to eat the inaccessible bread in the NHS to understand what they mean.”* Claire referred to: *“the language we've had to adopt...in order to go into that world,”* when talking about delivering simulation training to healthcare trainees. There's a sense of shared space and negotiating a common tongue to be able to make this work that changes people.

Andrew Mc commented: *“A simple language is not a childish language...a simple language is a good thing; we need to understand.”* This reflection highlights the difference between infantilisation, which comes from a place where one knows better than the other, moving communication to a place of understanding between people.

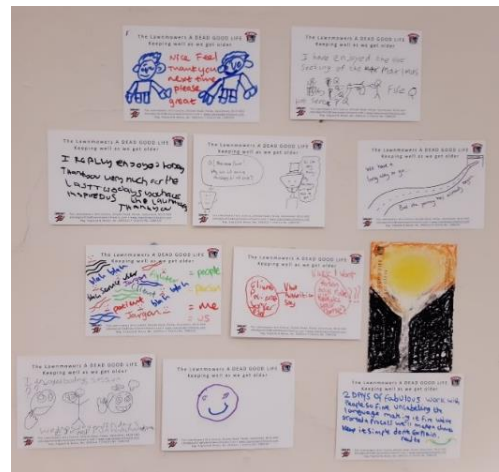


Figure 3. (left) and Figure 4. (right): Reflective postcards from day 1 and day 2 of “Un-labelling the Language”.

***UNLABELLING THE LANGUAGE**

Unlabelling the language declassifying the jargon simplifying understanding of what we don't know purifying simplicity making words make sence giving words a meaning back giving words a life.

Unlocking our understanding on things to understand making real intentions true and proud and grand

Levelling out the bull crap reinventing the mad turning words and phrases into something glad.

Mixing up the jargon cupboard boiling up the wordy soup scooping out a lovley treat of accessible bread so good to eat spread it with our non jargon butter add a little touch of proper respect and dignity pride and love we have voices to be heard keep accessible

keep real plain simple language don't need to explain see the people hear us clear you know now we are here we exist we live.

Poem from Andrew Mc

On a journey we went.

The labels put upon us.
A mirror reflection.
Working as a team.
We signed our consent.

Like boats on the water, on a journey we went.

Tins of food have labels, people have identities.

A smile. I feel happy.
Welcome anytime.

*(a group poem made
line by line from
our day 1 postcards)*

Blah, blah, blah.

Blah, blah, blah.

Jargon can get in the way.

We've started a process.

We'll make a change.

Blah, blah, blah.

Keep it simple.

People, person, us me.

What's your name?

Blah, blah, blah.

Hold on to the person.

In the professional. In you and in me.

We're all human here.

**original format and spelling preserved*

Box 3. Poetry from “Un-labelling the Language”.

3. Digesting the Accessible Bread

“Your art put voice to those experiences”

We met, a trio of arts therapists, in the yellow-walled, shiny-floored, lecture space at the Academic Unit. Tables were laden with produce from the “Un-labelling the Language” workshop, held the month before. One spread with the resources gifted to Nicki; a book about parenting experiences for people with learning disabilities (Cooper & Flower, 2020); a CD made by The Lawnmowers: Beat This! percussion group; the Communi-cards pack and DVDs of past theatre productions. Another table held the labels of learning disability and reflective postcards; experiences captured in time; images and words holding the story. The third table held Nicki’s response art (Fish, 2012). Socially distanced chairs formed a sort of circle around the art materials and musical instruments tentatively occupying the central floorspace.

We had planned to play the DVD of the Mental Deficiency Act sketch from “Walk the Walk” (2003) and the video of an improvised role play (see Appendix: Table 1, section VI) by The Lawnmowers. The computer in the room was broken and so we were left without the images and voices of The Lawnmowers there with us for “Digesting the Accessible Bread.”



Figure 5. Table-top tour by Catherine and Emma.

Together, the arts therapists used multi-modal, arts-based methods to deepen our understanding of the work which had emerged (Box 4). We continued to make sense of the wealth of material which Nicki had carried back from Newcastle. Through witnessing the story of the workshop in objects and words, Catherine and Emma were able to offer new perspectives (Figure 5). The data from “Un-labelling the language” evoked a strong emotional response from Catherine and Emma. Catherine described the post-it note labels of learning disability as: *“Stabs. Even on a chair it would have felt hard.”* Emma saw these labels as being *“located in you [as a person].”* Labels applied by a non-disabled society and with the potential to dominate a person’s identity. We were struck by there being: *“so little representation, we so rarely hear these stories”*; the silent voices of people with learning disabilities.



Figure 6. Holding it all together.



Figure 7. Ghosts of the past.



Figure 8. Ribbon tying, fire pages burning.



Figure 9. The windhorse.

The zither was out of tune. It still made sound. Next, the chime bar. A pitch that hung in the air. Hands reaching across edges; horror and humanity; holding it all together. Eyes that see the other, being seen. Finding connection and wanting to give voice. (Figure 6)

The xylophone made a tinkly tune. Could it be a nursery rhyme? Ghosts of the past captured in pastel. A family story connecting to the history of many. (Figure 7)

A lack of resonance in the sounds the instruments made. A wish for that deep connection. My voice crackly and thin. I couldn't go deep with the instruments here.

We could sense bodies in the space. Our own and others. Breathing, stepping, moving.

A string and a yellow ribbon draped across the room. They tied the disparate objects to the people in the room. Now we're all touching. Tied together.

Pages, red and orange torn; making an explosion. Wanting to make a mess, but the materials are too tidy. Dry and safe. The zither places nearby. Connecting again. Glad we're together. (Figure 8) Later, a thick blue ribbon reached across the space, above eye level. Along it were strung torn and punctured pages. A processional route. Each of your Lawnmowers here today. (Figure 9)

The surprise of looking up from making and finding the prayerflag hanging above.

The guitar, singing bowls, humming together. Vulnerable but less fragile. Using my voice was grounding, powerful. It's you. Your essence. An authentic resonance. A connection with self and others. Humming together. Another nursery song. A lullaby. Sense of the maternal.

Leftover blue paper. A black oil pastel. Listening, eyes closed to the sounds. Making marks. Wanting to let the black smear the floor. I didn't let myself.

Box 4. Digesting the Accessible Bread” the process of making and sharing written by Nicki through fusing her words with words shared in the workshop.

The co-created processes of music and art making within “Digesting the Accessible Bread” gave us new insight. There was a *“blunted quality, a lack of weight”* to the sound we created. The art materials were *“dry, contained, limited; when I wanted mess.”* Together as arts therapists, the limitations of the setting, and the tools we had, left us unable to fully express the *“well of emotion”* we felt in this work. For us, this feeling of being unable to communicate through the art materials as fully as we wanted to enabled us to make connections to the ways people with learning disabilities might feel in response to the discrimination and exclusion they face. A sense of being hidden, where society places limits on a person’s identity, hiding their true self and inhibiting the potentials they could realise. It highlighted the necessity for active change agents, like The Lawnmowers.

In preparing this paper, the arts therapists reflected that the value of having the second workshop was not immediately clear before it happened. We knew that Nicki needed to be able to “digest” the material from “Un-labelling the Language” and that Catherine and Emma needed immersion in the data to support their understanding of the experiences of this group of people with learning disabilities. As a group, we made a multi-modal response before talking together. Through the shared actions of making and hearing a sounded response in music, and making and seeing a tactile response in art, we were able to externalise the impact of this experience on us and make sense of our individual responses. The creation of a safe space, set apart from our daily work-life, and the use of the arts enabled a full creative exploration of the data.

Afterwards

After both workshops, participants continued to express their creativity and process the work. Some of this was shared between the artist-researchers (Box 3). After the “Digesting the Accessible Bread” workshop, Nicki wrote this poem. Some of the words are those spoken in the workshop.

Windhorse

Ghosts of the past; our struggle to deal with difference.
Treading over art materials, like walking on egg-shells.
We so rarely hear these stories: the ordinariness of living.
We are tied as one, by the human condition.
Each of your Lawnmowers here today in paper and ribbon.
A windhorse reaching across the space. Join our procession.
Connecting. Having a voice. I’m glad we’re together.

PAR required all artist-researchers to hold uncertainty. Could we create new relationships? Would we be able to do the work we set out to? Could we produce anything at all from the workshops? And if we did, would it be any good?

At the end of day two with The Lawnmowers, Nicki looked at the reflective postcards and realised that “making sense of experience takes time; must take its own time” (Edwards, 1997, p.55). One of The Lawnmower’s postcards on that day read: *“I felt it went amazing because it was different. Worked hard. Working as a team.”* This level of co-production was new for both The Lawnmowers and the arts therapists. This paper represents our “foregrounding work” (Eisenstadt & McLellan, 2020), the careful preparation of common ground, which will ensure the longevity of our collaborative partnership.

Claire had said, about the influence of The Lawnmowers’ work with higher education: *“...[it] builds a legacy in the area, the students they’ve taught, it goes out with them.”* This is the kind of alternative impact (Pain et al, 2016) we have been able to grow. Since the workshops, we have secured funding to work in partnership for the next three years. We have made initial links with arts therapy university programmes to broaden The

Lawnmowers simulation training and we are continuing the creative dialogue that founded our artist-researcher collaboration. Our next planned PAR workshop will take place in Summer 2022, building on the findings in this paper, to identify factors that contribute to the powerful impact of arts-based work.

Discussion

Through these workshops, the two groups of artist-researchers explored and developed their thoughts about the impact and use of labels and jargon in different contexts. It was understood that all contexts have jargon and sometimes this is necessary. Nicki had to learn some of The Lawnmowers' terminology, and they had to learn some of the terms used by the arts therapists. In order to find a common language, we need to be aware of the jargon we use and how that might prevent others from understanding information and accessing certain settings. Simplifying language can be a helpful way to include as many people as possible and does not need to be seen as childish or "not academic."

In both workshops, the artist-researchers agreed that labels are powerful. They can hurt and exclude people. In contrast, they can also be helpful. Labels can be a way to understand some aspects of who that person is, but they cannot encompass the full richness of that person's identity. Even when someone does have a label which helps to understand something about them, it is essential to think about the whole person and to get to know them. Treating everyone with humanity and being curious about their experiences are good starting points to do this. It is crucial that there are ongoing discussions about what is right for different people, at different times and in their specific context.

It seemed that everyone had something to say about the labels experienced by people with learning disabilities. In the "Un-Labeling the Language" workshop there was a particular salience to the painful past experiences of The Lawnmowers. Many of them had been called derogatory names, implying that they were worth less than others or that they had little to offer. The arts-based methods allowed these experiences to become visible and for the group to step back and look at them with some distance. Some members of the group may have been left with ongoing emotional distress from those past encounters, which highlights the challenges that people with learning disabilities experience throughout their lives (Wigham & Emerson, 2015). When The Lawnmowers reviewed this paper, they reflected that the mistreatment, bullying, and inequality they face as individuals, and that so many people with learning disabilities are confronted with, is the core motive for their involvement with theatre for change (Denzin, 2018) as a social justice collective.

The various art forms used in both workshops were employed as the primary method of exploring and understanding labels and language for people with learning disabilities. These are sensitive and challenging topics, which have the capacity to elicit strong emotional responses, including past trauma. The arts offered a way for the artist-researchers, in each workshop, to connect with each other and explore these difficult topics, both individually and as a collective group (Chilton & Leavy, 2014). The Lawnmowers already had an "arts-based" connection through their theatre work and were already a cohesive group (Goldstraw, et al, 2020), and the arts therapists had a different type of connection through their academic work. These arts-focussed skills were developed further during the workshops, and it seemed that a deeper understanding of the topics was facilitated through the arts-based methods than may have been possible through verbal communication alone (such as semi-structured interviews). It has been suggested that the arts can offer a "container" for difficult topics (Gerber et al, 2018). The Lawnmowers could get straight into these challenging conversations and explore the range of labels they had experienced. When preparing this paper, they reflected that they believe this is possible because:

“the data is very rich in a creative process and so much more richer due to knowledge from past shows. We can have beautiful discussions, deep conversations. We do more than an advocacy group.”

This highlights that the arts are the vehicle that enables The Lawnmowers’ social change work to happen. The combination of shared group purpose and the use of the arts as the primary communication tool facilitates imaginative ways of being, alternative possible futures (van der Vaart et al, 2018), and shifts from advocacy into activism (Spaniol, 2005).

The PAR approach we used in both workshops supported multifaceted knowledge to emerge (van der Vaart et al, 2018). This meant that workshops were accessible to everyone involved, empowering participants, and laying foundations for an ongoing social change partnership. Across both workshops, we came together as people and explored all aspects of life and society. Both arts-based research and PAR require delving into the issues relevant to a particular marginalised group (Majid & Kandasamy, 2021), which is exactly what we did. People with learning disabilities may need additional support in some areas of their lives, which can mean that personal and private experiences are regularly shared with others. This may be welcomed, or it may feel intrusive. They do not always have as much control over some aspects of their life as they would like (Power et al, 2021). People with learning disabilities have the same needs, desires, wishes, and hopes for their lives as everyone else (Haigh et al, 2013), but our society does not always support the realisation of these.

This partnership (between The Lawnmowers and the arts therapists) has already been mutually beneficial. The Lawnmowers have increased their allyship to include the arts therapists, and future mental health-related research will carry their voices. The skills of The Lawnmowers were acknowledged financially, and future readers of this paper will become aware of both the inequalities and abilities of people with learning disabilities. Thus, their social justice cause has been strengthened. The Lawnmowers believe that one of the benefits offered to healthcare researchers through partnership with a social change theatre company, is that groups like theirs can:

“...offer research richer debate due to archives, past shows and the work we have already done when working on show material and other R&D process. Also, when disseminating data from research we can offer a creative response that other groups wouldn’t in the form of a rap, theatre piece, film etc. This then gives more accessibility, representation and reach that an [academic] paper might not. This is why other researchers in the region are interested in doing work with the Lawnmowers.”

We entered into the PAR without knowing what the outcomes would be. This meant all artist-researchers were in the same place of “not knowing,” which balanced some of the potential power imbalances. Through this type of work, flattening traditional hierarchies offers potential to empower the marginalised group (van der Vaart et al, 2018), ensuring that the process and products are representative of people’s lived experiences (Pain et al, 2016). However, it must be acknowledged that this paper has been written largely by the arts therapists. Although The Lawnmowers have reviewed our words, the contents may not fully represent their views. Jones and Hunt (2022), in their co-authored paper by a researcher and patient partner, reflect on “the dance of academia” (p.5) when collaborating throughout Jones’ PhD. They refer to the carefully negotiated roles within co-production relationships in healthcare research as being like parts of a dance, some steps you observe, some you learn, and others you don’t. This pilot with The Lawnmowers might be considered the first dance class with Nicki. We entered the lesson with “collaborating with consideration” (2022, p.7) in mind and left feeling connected and energised. Chapman-Hoult et al. (2020) note the “slow violence” that writing up can do to the richness of gesture and interaction fostered through our encounters. We have sought

to rebalance this through inclusion of arts-based responses, including poetry and written words. We also encourage the reader to explore the wider artistic and filmed work of the Lawnmowers as a means of broadening and deepening meaning from this paper (<https://lawnmowerstheatre.com/>)

This carefully negotiated co-production process enabled the artist-researchers to think about intersectional roles and identities. As arts therapists, we meet people with learning disabilities as whole people and consider multiple dimensions of their identity in order to support them in expressing their experiences and feelings. As experts with lived experience, a component of The Lawnmowers' job is to use parts of their life story in their social change work. This work can be challenging. The artist-researchers agreed that having a shared passion and being part of a team maintains motivation when there are systemic or organisational blocks. Coming together under a collective identity also increases a sense of individual safety when addressing issues of discrimination and marginalisation.

Recommendations

Our suggestions to maximise accessibility of academic processes and products are:

- Provision of pictorial summaries or video abstracts make publications more accessible to non-readers than having a lay summary alone.
- Use of simple language where possible when writing for publication expands the potential reach of your work.
- When labels and jargon have to be used, provide explanations of these in simple terms and check that people outside of your field of expertise can understand what you have written.

Conclusion

All participants in this project were able to have difficult conversations, at great depth, firmly grounded in the creative arts and strengthened by the use of participatory action research. Together we used words, art, music, and acting to explore language and power in healthcare and in society. The variety of our lived and professional experience meant that these discussions could go beyond policy or process, sharing our stories to make sense and deepen understanding.

This pilot successfully acted as a proof of concept between The Lawnmowers and Nicki. Both partners want to continue to work together in the future to ensure that future research is accessible, relevant, and meaningful for people with learning disabilities.

The ripple effects of our co-production are much larger than the few days we spent together; already we have expanded research and creative networks and linked with higher education settings. We are continuing to build platforms for people with learning disabilities to be active citizens and change agents.

This group of co-researchers know that we should cut down on jargon and labels. We want to continue to push the boundaries of what inclusive research can look like. We want to work toward a more representative society. Most importantly, we want to do this together.

After the "Un-labelling the Language" workshop, Andrew Mc wrote:

ODE4Nicky

Nicky you have the Power
To make a change help make
language an engaging thing. To look
at accessibility make words count
For all of those who need some help.

To understand the words we don't, to make a
language raise a toast to a more inclusive
Society a one where we can all be free.
We breathe the air as everyone does we all
Deserve respect and love to understand
And be understood. This is our
Challenge, The fight goes on.

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The Lawnmowers Independent Theatre Company preferred to appear as a collective in the authorship of this paper. Where individual Lawnmowers are quoted or their creative work is represented, Nicki agreed with them to use their preferred name. The individual members who contributed to this research were: Debbie Bell, Dan Brunskill, George Copeland, Matthew Dennis, Nick Hernon, Louis Huckle, Claire Hills-Wilson (artistic director), Andrew McLeod, Chris Moules, Stephanie Nicholas, Philip Overbury (support staff), Andrew Robson (aka Ginger Beard), Scott Rowe, Andy Stafford.

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Conflict of Interest

The authors have no known conflicts of interest to declare. There is no financial interest to report.

About the Authors

Nicki Power is an art therapist and doctoral fellow at Queen Mary University of London, supported by Barts Charity. As an early career researcher, she is interested in collaborative and inclusive research with people with a learning disability and arts therapists. Previously she was Head of Arts Therapies for Bedfordshire Adult Mental Health & Learning Disability Services, part of East London NHS Foundation Trust. She is a coordinator of the British Association of Art Therapy Learning Disability Professional Support Group. She is a member of the editorial board for the *Irish Journal of Creative Arts Therapies: Polyphony*. She is the art therapy representative for the Learning Disability National Professional Senate in the UK. Nicki has taught on several art therapy training courses and has an active art practice.

Dr. Emma Millard is a music therapist and researcher. She works as part of the Indigo children's bereavement team at Croydon Health Services NHS Trust. She also works on inpatient wards in adult mental health at Central and North-West London NHS Trust. Her doctoral work, based at the Unit for Social and Community Psychiatry, Queen Mary University of London, focused on the role of patient preferences in the arts therapies. Emma is an Editor of the *British Journal of Music Therapy* and teaches on the research module for the Music Therapy MA at the Guildhall School for Music and Drama.

The Lawnmowers Independent Theatre Company are a producing-arts organisation focussed on social change through the use of forum theatre. They believe the arts can unlock the talents and capacity of people with learning disabilities to take charge of their lives, as active citizens, visible artists, and agents of change. They operate in Gateshead, Newcastle-Upon-Tyne and surrounding areas. The Lawnmowers are a registered charity. They are run by and for people with learning disabilities.

Dr. Catherine Carr is a music therapist and researcher based at the Unit for Social and Community Psychiatry which is jointly part of Queen Mary University of London and East London NHS Foundation Trust. She works on inpatient wards for older adults' mental health. Her research focuses upon the development and evaluation of group arts therapies in different mental health contexts, with a strong emphasis upon mixed methods and placing the voice of those who use arts therapies at the centre. Alongside Triona McAffrey and Hans Petter Solli, she is a co-founding member of the Alliance for Recovery Research in Music Therapy – an international collaboration dedicated to furthering co-production of knowledge between service users, carers, music therapists, and wider stakeholders. Catherine has taught on a number of music therapy training courses and, as a musician, she continues to play and record with contemporary composers and artists.

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