

# Interweaving Accessibility into Theatre: Working with Disabled Creatives for Disabled Audiences as a Disabled Theatre Maker

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## About the Author:

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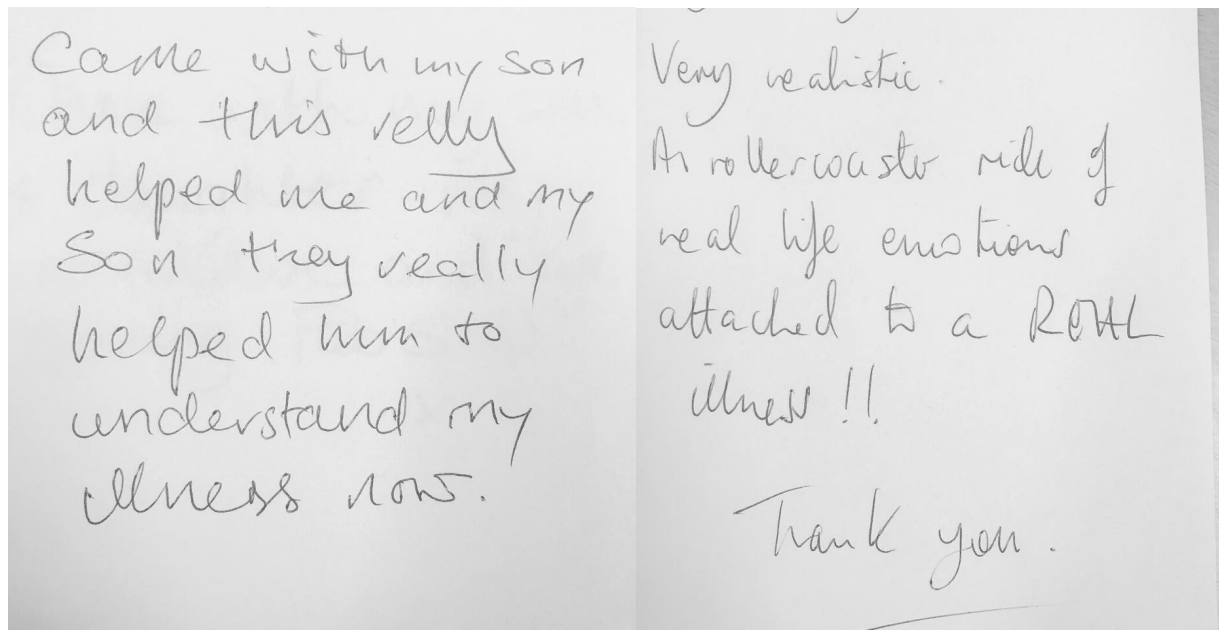
## Introduction

In 2016, while attending a conference, I had an idea for a new creative project. I was heavily pregnant and struggling with mobility problems, and my accessibility needs were unmet or ignored in most public spaces, perhaps because I didn't 'look' disabled. It dawned on me that invisible disabilities were a subject that required investigation through a creative medium. The project I started to formulate would be titled *Living with...* and would produce four different public events, each one exploring a health condition or disorder that isn't visible. The events included a multi-media exhibition, a site-specific performance installation, and interdisciplinary arts workshops. However, in this note from the field, I want to examine and reflect on just one of these events—a performance installation entitled *Living with...FiBrOmYaLgiA* (WordForWord Arts, 2018) that used poetry, verbatim interviews, medical research, video projections, and intricate sound design to explore the painful condition of fibromyalgia. This note from the field is a reflection on how, as a disabled artist, I developed a production with accessibility at the forefront of my practice. This will also include a reflection on how consent and disability, alongside representation, was woven into the production throughout the creative process. Lastly, it will include a discussion with disabled actress Esther Ridgway (who co-devised and performed in the production) on her experience of *Living with...FiBrOmYaLgiA* (WordForWord Arts, 2018) and her experiences of being a disabled performer in the arts industry.

## A Brief Overview of my Long-Term Illness

Fibromyalgia is a somewhat controversial topic. The condition—which I have lived with since 2015—causes symptoms that include chronic fatigue, widespread pain, and anxiety (Goebel et al 2021, 1). It is one of the most common pain conditions that has no cure but is often met with derision. The condition cannot be diagnosed through a medical test, but through a process of elimination—when other conditions are ruled out, you are told you have Fibromyalgia. I have directly experienced skepticism regarding fibromyalgia including one individual who, after I shared my diagnosis with them, responded by asking “isn't that the illness that doesn't exist?” The ferocity of the skeptical lashing out towards this condition and those who endure it cannot be understated. In fact, during my research process for of *Living with...FiBrOmYaLgiA*, I came across a website called fibromyass.com. It is thankfully no longer available, but in 2017 it was a multi-page website dedicated to mocking the condition and those who suffer from it. During the production we heard many anecdotal examples of negative experiences from interviewees and audience members. In fact, the latter had often

brought their family members to see the performance because they didn't take the condition seriously.



*Anonymous feedback from audience members.*

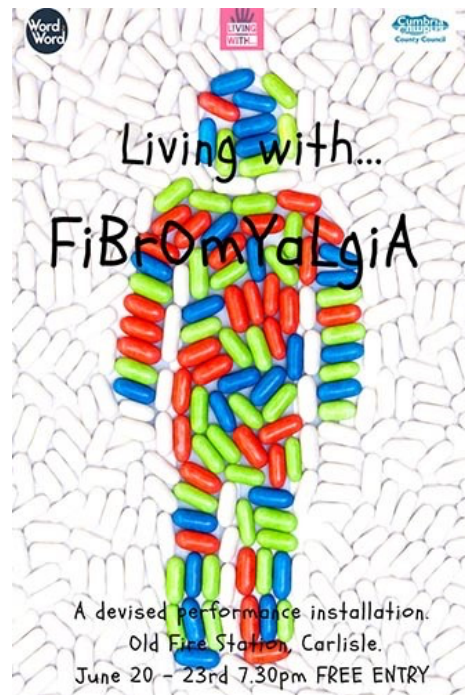
In 2021 a new study at King's College in London showed ground-breaking evidence that fibromyalgia is caused by antibodies that affect pain-sensing nerves (Goebal et al 2021, 7), although whether this scientific discovery will alter the public perception of the condition is yet to be seen.

There have been previous projects that investigated the value of theatre to those who experience Fibromyalgia, such as research studies examining the impact of dramatherapy on Fibromyalgia patients (Horwitz, Kowalski and Anderberg 2010, 13-19). The focus of these projects has been on improving the wellbeing of those with Fibromyalgia, while *Living with...FiBrOmYaLgiA* was focused on offering a platform to sufferers and having a direct impact on audience members regarding awareness and perception of the condition.

### **The Project**

The show was performed in 2018 at The Old Fire Station in Carlisle, Cumbria in the United Kingdom. It was conceptualized as an embodiment of life with Fibromyalgia, exploring the physical symptoms, the negative perceptions of the condition, the trauma of navigating the UK's disability benefit system, the loss of identity felt by sufferers, and the frustration of a medical system that struggles to help Fibromyalgia patients. It wasn't quite a manifesto. It made no demands other than for the illness to be taken seriously and for the experiences of

those who live with it to be seen as valid. It was a plea for the simple dignity of acknowledgement.



*Poster design for the production.*

The show was a thirty-minute performance that was performed three times per evening across four evenings. There was a thirty-minute break in between each performance and an informal aesthetic to the event—there was no backstage area, and the technical aspects of the show were very visible. The cast and crew relaxed on the set or audience seats during the break. The performance was created collaboratively with a group of ten actors with poetry, medical information, and interviews with Fibromyalgia patients used as devising materials. Some excerpts of text found on the now-defunct fibromyass.com were even incorporated, showing the vitriol Fibromyalgia sufferers can receive from others. The production was interdisciplinary and included physical theatre, choral work, and a movement sequence choreographed to an intricately designed soundscape by Finn Drude. It also included live streamed video of actor Aimee Irwin's face from a go-pro camera onto one of the performance space walls.



The set was made of duvets, blankets, cushions and pillows, and the cast were dressed in their own pajamas. Approximately 50% of the cast and production team had a disability of some kind, including 25% who live with Fibromyalgia.



*During rehearsals*

The verbatim content initiated some interesting discussions among the cast as the interviewees' answers occasionally showed hypocrisy or contained opinions that cast members didn't agree with. For the able-bodied members of the cast, it appeared to be revelatory that disabled people can be flawed, judgemental and even unpleasant at times; this helped us to recognize the ways in which ableism creates monolithic images of those with disabilities, often casting disabled people as either monsters or martyrs. As well as negative ableist views towards people with disabilities, well-intentioned infantilisations are also prevalent in society (Robey et al 2006). The contradictory sections of verbatim text, when used in performance, established truthfully flawed and multifaceted individuals; this made the use of verbatim text vital to offering nuanced, authentic representations of the experience of living with Fibromyalgia.

We also discussed the responsibility required when using others' sensitive experiences in generating public performance; because the verbatim text had been sourced from arguably vulnerable individuals, we questioned established practices related to verbatim text, reflecting upon the ethics of using other peoples' stories. Were the standard consent forms provided and signed before the interviews sufficient to protect interviewees? There is ongoing debate about how consent and disability intersect. While infantilisation is egregious, exploiting those with a disability is harmful and can be easily done without intent. Unspoken power imbalances between disabled and able-bodied individuals can be felt consciously or subconsciously by a

disabled person, making consent difficult to navigate (Boettcher et al 2022, 5). Mia Mingus writes that “disabled people get told we must shrink ourselves and our desires to settle for living in the wake of an able-bodied parade” (2017), conveying the pressure disabled people may feel to please or to conform to expectations so they will be included. This pressure could be felt by an interviewee who is keen to please the interviewer and give the answers they suspect the interviewer wants. Noting these complicating factors, we determined that it was important to ensure that interviewees for this project could withdraw their interviews and statements at any time, and that these materials were used respectfully in a performance crafted by those with shared lived experience.

### **Inclusivity in Practice, Not Just Principle**

Inclusivity was a priority throughout our production process, informing all decision-making. The devising process was designed to be collaborative, with open discussion about the topics and how they were being communicated to an audience. With this in mind, I sought to a cast and production team (technicians, designers, and a dramaturg) who could bring different perspectives and lived experience with disability to the rehearsal room. While this choice was important for representation, the inclusion of disabled creatives added complexities with consent that needed to be navigated. Chelsea Pace and Laura Rikard write “when an actor doesn’t know how a director will feel about them establishing clear boundaries, with their reputation potentially on the line, they will say yes, knowing that ‘yes, and’ is the safest choice” (Pace and Rikard 2020, 8). If this is true of able-bodied actors, then disabled actors may feel further compelled to agree to staging, dialogue and choreography that they aren’t comfortable performing. In 2020, 95% of disabled characters were played by able-bodied actors (Kataja 2020) and the scarcity of employment for disabled actors may cause them to prioritise pleasing directors, producers, and fellow actors over their own well-being for the reasons established by Pace and Rikard. We chose to combat this during our production; consent was promoted through all actors having autonomy regarding their movement choices on stage. We collectively created a vocabulary of physical actions to use during the movement sequence that could be used in whatever order and speed the individual performer chose.



*Actors Chloe Lobley and Esther Ridgway exploring their movement vocabulary.*

There was no requirement for synchronization with the rest of the cast or for maintaining the same pattern of movement from one performance to the next. The performers' choices did not impact other cast members or the meaning of the production, eliminating pressure. Creatively, the use of a shared movement vocabulary added a sense of commonality within the cast, demonstrating a shared physical language that inferred the similar experiences of those with Fibromyalgia. At the same time, the lack of uniformity and synchronization also visually illustrated individuality and variety in relationships with the condition. Through enabling the cast to alter their delivery of the movements for each performance, it also allowed the production to evolve creatively. From a practical, consent-minded perspective, this approach allowed those with disabilities in the cast to decide where their level of discomfort or 'acceptable risk' (Rikard and Villarreal 2023) was during each performance. From my own personal experience, I was acutely aware of that level varying from one day to the next, as conditions like fibromyalgia can have 'flare ups' in which the severity of symptoms increases. Removing the demand to replicate exact choreography for each performance made the actors' participation in the production physically and emotionally more accessible, displayed trust in their creative choices as craftspeople, and also allowed them to push themselves when and how they wanted to.

The set and costumes were selected to represent the large amount of time that many Fibromyalgia sufferers spend in bed due to their symptoms. For costume, cast (and crew) could

wear their favourite pajamas. The looseness of most pajamas facilitated movement, and—similarly to the movement sequence—established a shared theme and a sense of commonality while also featuring individuality.

The set, composed of bedding and blankets, was also partly supplied by the cast so there was a sense of genuine comfort when lying down in the performance space. The padding offered by a set created of bedding also served the access needs of actors with health issues such as joint pain by transforming hard floors into surfaces upon which they could sit, kneel or lie as needed during each performance, prompting rest when needed and increasing comfort.

The design team also maintained creative autonomy throughout our process, developing the sound and projection designs after discussions and research. The devising of sequences, and my direction of them, was responsive to the sound and production design rather than dictatorial. While discussions about tone and theme were key in unifying the production, the creative output of the production team informed and developed the content of the sequences. My aim was to encourage the production team to feel comfortable to voice opinions, assert boundaries if needed, and feel confident that their work would be respected.

During the logistical planning of the production, accessibility was built into decisions regarding the length of the show, the performance times, the venue, and the cost to attend. The performances were free, enabling those who may struggle to work due to health issues an opportunity to engage with theatre without the cost being a concern. The venue that was chosen had been renovated recently and met accessibility standards. The performances were devised to be a maximum of thirty minutes long, as longer than this would potentially be painful for someone with a condition such as Fibromyalgia to sit. By repeating the performance three times per evening with thirty-minute gaps in between, we created flexibility for those attending. Leaving the house to arrive at a specific time can be stressful, painful, and simply impossible for many disabilities including chronic pain conditions. We offered free hot drinks in between performances so if someone was late for one performance they can have a cup of tea or coffee while they wait for the next one. This also gave audiences the opportunity to reflect on the production after viewing a performance, offer feedback, and even wait to watch the next performance if they wish. Even with these alterations, some potential audience members (including some interviewees) were too unwell to attend any of the performances. To provide access to these individuals (and those situated far from the venue location), we livestreamed the final performance on our social media pages, receiving almost two thousand views.



### A Reflection with Esther Ridgway

When writing this reflection, I consulted one of the cast members from *Living with...FiBrOmYaLgiA*, Esther Ridgway. Esther was born with Noonan Syndrome and Periventricular Leukomalacia, and she provided incredibly valuable insight during the production process. I asked her for her reflections on the production and her thoughts on being a disabled actor. The following is a transcript of our reflection during this conversation.

**Grace Thomas:** Six years on, what are your thoughts on *Living with...FiBrOmYaLgiA*?

**Esther Ridgway:** It was a great show to bring people awareness of what life with a hidden disability looks like. Even though, at the time, my disability was hidden - I didn't need to use crutches or sticks as I do now - I felt like a fraud if I said that I had a disability.

This show lets people realise the hardships that people who don't look disabled but have long-term health conditions go through. I felt that working on this show gave me that sense of belonging as well that I could work with a theatre company and express the needs I had during rehearsals but also for the show, making sure that I had extra blankets and pillows, so I didn't hurt myself. The show and everyone working on it gave me that voice so I can say what is working for me and my body and what isn't, which is crucial for me.

**Grace Thomas:** So, does having a disability sometimes affect how you behave in the rehearsal room? Do you feel like consent and saying "no" is impaired?

**Esther Ridgway:** We are now hearing in both the theatre and film and TV world how intimacy coordinators help make the actors feel safe when doing things due to incidents in the past with #MeToo. I think things like intimacy coordinators need to exist with disabled actors, especially if they work with a director that has never worked with people with disabilities before. That way people can say what is working for them, what isn't, and see if they can work around it. Especially as we know what our bodies are like and what we can handle, and most of the time, we can handle a lot.

**Grace Thomas:** Do you worry about employability as a disabled actress?

**Esther Ridgway:** Years ago, I never classed myself as a disabled actress because even though I had a disability, it was never really an issue. I was fit and healthy, and I was able to walk long distances and go running without any issue to my body. But as I got older, things changed. I noticed years ago that when I applied for roles and I'd say I'm a disabled actress, I rarely received a response for an audition. When I removed that

information, I was asked to audition. However, this is changing. For example, DANC (Disabled Artists Networking Community) has been excellent. They bring together people from all over the UK to network with casting directors, directors, theatre companies, producers, writers etc.

**Grace Thomas:** So, in your opinion, is there an improvement in disabled representation?

**Esther Ridgway:** Ten years ago, if there was a disabled character on TV, it was more than likely a non-disabled actor playing that role. It's improving but only slightly. There have been actors who have said, "I don't see the problem because it's called acting, and that's what we do." But it's one less role that someone with a disability is missing out on!

**Grace Thomas:** And adaptations can be easily made to include disabled performers and crew members, surely?

**Esther Ridgway:** My first TV role was in *Doctors* on the BBC where I played a character who had a disability. The crew and director were terrific. They made sure I was ok. When I got the part, I told my agents what my needs were, and I said that if there were long times waiting around, I needed a chair to sit. I had that. The minibus taking me to the location was easy to get in and out of and my dressing room was downstairs, so I didn't need to worry about climbing loads of stairs.

**Grace Thomas:** That's wonderful. Are there any particularly negative experiences you've had as a disabled actor?

**Esther Ridgway:** One negative experience I had was when I was training at university. I was the only student who had a disability, and I loved to dance. But my tutors didn't want to help me adapt the dances, they expected me to do them as choreographed. I'm not a natural dancer or a choreographer. I couldn't get the lines or shapes right, my arms weren't straight, and I felt like I was in a losing battle every time I was in the dance room.

But I feel and hope that there is now more support in place in higher education facilities when it comes to the arts, both with physical and hidden disabilities but also with people who are neurodivergent.

**Grace Thomas:** Still a long way to go! Thank you for sharing with me, Esther.

## Conclusion

When reflecting on my own practice during this production and listening to Esther, I become frustrated with the on-going battle for accessibility and inclusion within the arts. When

creating this production, the adjustments and adaptations made increased the accessibility of the production for those making it and performing it, and for audiences watching it. However, it also enriched and informed the content, structure, and aesthetic of the production, offering new insights and complexities to my initial concept. Inclusivity and accessibility should be a consideration for every theatre maker because, as well as offering meaningful creative experiences to everyone, the theatre maker broadens their creative possibilities. Through working with disabled creatives and making theatre for disabled audiences, our view of the world broadens.

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