

# Crip Tech & Belonging

Research by Raquel Meseguer Zafe / Uncharted Collective

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*"...I feel like in disabled spaces, digital or physical, there is an acceptance that humans are messy. Disabled spaces welcome the messiness and see value in the 'disruptions.'"*

– Artist interviewed

*"Belonging is the innate human desire to be part of something larger than us. Because this yearning is so primal, we often try to acquire it by fitting in and by seeking approval, which are not only hollow substitutes for belonging, but often barriers to it. Because true belonging only happens when we present our authentic, imperfect selves to the world..."*

– Brené Brown's definition of Belonging

# Context

I am a dis-abled artist whose work straddles theatre, installation, performative conversations and photo-documentary. I am interested in:

1. challenging the norms of public spaces,
2. how to create accessible formats (both process & performance),
3. making space for the unheard stories of disabled people,
4. meaningful co-creation with communities.

In September 2020 I received a PMStudio Future Themes Award to undertake a period of research. In this research I wanted to host conversations with other disabled artists, to find out about their artistic practice and their experiences of disability, in the hope of understanding more nuanced ways to make art more accessible. I was interested in how we go beyond standard access, to enable belonging in our public spaces.

I was lucky enough to interview 6 amazing disabled artists. I spoke to:

a blind musician,

a deaf theatre maker & performer,

a visually impaired dancer & performer,

a visual impaired theatre director, performer & philosopher,

a writer, singer and theatre director with an energy impairment,

and a writer, psychotherapist and artist who is a survivor of trauma and a wheelchair user.

The stories and thoughts they shared with me, I will attribute to us as a collective (rather than as individuals).

# Caveat

I learnt a lot about access doing this research and allowing myself to get things wrong. For example:

I've been working in disability arts for 4 years but I'd never heard of a Palantypist before, and it had to be explained to me that BSL is not every deaf person's first language. For many deaf people English is their first language and for them live captions are a better tool than BSL. I had no idea.

On one occasion I went to visit a visually impaired artist in their home. It was the first time I met them in person and I totally forgot to describe myself. I was in their home and I'd learnt a lot about them just by being there and yet I hadn't disclosed anything about myself. When we next spoke I asked if it would be helpful if I described my appearance. They replied with a hearty 'yes!' That experience made me really aware of the idea of equivalence, and making sure we share equally of ourselves.

I'm sharing this so that you know I'm not an expert and I don't always get it right, but I am really interested in finding out how to do access well and how to get the detail right to signal and enable belonging.

I'm also sharing this so you know when you start to work with access you're going to get things wrong, and that's ok.

# Crip

I feel this term needs some context. Crip is a term used in disability art and activism. It's not an offensive term, it denotes the urge:

*"...to shake things up, to jolt people out of their everyday understandings of bodies and minds, of normalcy and deviance."*

– A. Kafer, *Queer, Feminist, Crip*.

Some of the artists I know use it as a provocation in their work. I use it to remind myself I can do things differently: I can consider how I use the performance space, I can re-imagine the performance format, and I can crip my own ideas of what constitutes 'good performance'. It's a term that has a lot of energy and creativity (and a little mischievousness).

It is also a term used to challenge ableism. Talila A Lewis has a really excellent evolving definition of ableism:

*"A system that places value on people's bodies and minds based on societally constructed ideas of normalcy, intelligence, excellence, and productivity."*

*This form of systemic oppression leads people and society to determine who is valuable and worthy based on a person's appearance and or ability to satisfactorily [re] produce, excel and 'behave'".*

<https://www.talilalewis.com/blog/ableism-2020-an-updated-definition>



# The Research Questions

- 1.** What tech could we, as disabled artists, not live without?
- 2.** How have we crippled tech (analog, digital, space, etc) in life and in art?
- 3.** What technologies or strategies are we using to create meaningful connection in our work?

The main things I noticed about our disabled experiences of tech were:

1. The artists I spoke to were careful to define their own relationship to tech.

2. We crip tech and use it for something in opposition to its intended usage.

3. We use tech to be in stealth mode and not have to disclose our disability unless we choose to (big difference!).

**I.**

We all define our relationship to tech to an extent, but the artists I spoke

to had interrogated their relationship to technology.

*“I realised that I was in a significant relationship that I’d never actually consented to going into. If I can’t be in a healthy relationship with my phone, I won’t be in one”*

This artist experimented with having no smart phone and no photo uploads for a year, to question and reset their online identity. They also drew clear boundaries around their online availability with email ‘Golden Rules’ which include an auto reply stating a realistic response time, and an explanation of

brevity on their email signature.

The artists I spoke to also drew boundaries around what they expose themselves to, blocking words and content they find triggering on FB and Twitter. And curating their Instagram feeds with disabled artists & activists, or body positivity content. Maybe the old adage ‘we are what we eat’ applies to our social media feeds too.

They also knew what tech to have to hand, for when they were unwell. For example knowing the short form of Tik Tok or the small challenges of Duo Lingo are perfect

for a fatigue crash. Or having all your analogue tools in one basket at the ready for a flare up. One of the things we talked about is how it gets harder to remember the things that help, the further you get into a pain flare up or a crash. This sounds counter intuitive, but not when you realise that in these states available headspace is shrinking: you become less and less able to make good decisions the more pain, or fatigue you experience.

Other everyday technology we ‘could not live without’ were:

– Siri and Alexa searches

– dictation software and other voice to text software  
– audio versions of articles  
– screen magnification software.

All are valuable energy saving pieces of technology for bodies that need more creativity, time and energy to get ‘normal’ stuff done.

One artist told me the deaf community uses WhatsApp to host support groups. This has been essential during the pandemic because No 10’s briefings still do not include an interpreter (unlike their Welsh & Scottish counterparts). This despite an open

letter to the Prime Minister from the Equality & Human Rights Commission and the #WhereIsTheInterpreter Campaign. BSL interpreters are added by some news broadcasters.

**2.**

Several artists told me about crippling technology and using it for the opposite purpose for which it was designed. Like using a Daysy (fertility monitor) to track their hormone cycle because of how that affects their endometriosis. Or using a Fit Bit to help limit the number of

steps taken in a day and keep their pulse per minute under a known trigger value.

This artist told me the Fit Bit helped them get into the mentality of an athlete and the pacing needed for “the ultra marathon of living with a chronic condition.” The Fit Bit also means they are able to gather data and zoom out to see how they have progressed or discern what their patterns are over time.

I imagine this subverting of technology is because no one is thinking about making tech to support people who live with

endometriosis, or that champion rest or pacing (a quick search on Apps for illness reveals many Apps that help you remember to take your meds, but not many that display a nuanced understanding of disabled experience\*). And I imagine disabled people aren't generally included in data sets used to develop tech, nor are they on the design teams.

To share a case in point, this is what the dictation software on my Mac came up with on my three attempts to dictate ‘anti-ableism’:  
– Buddhism

– auntie able listen  
– auntie able Lizum (Lizum is a ski resort in Austria, where my nemesis auntie able definitely hangs out).

### 3.

One artist told me about the many ways they use accessibility features on their phone to be ‘stealth mode’ and navigate the world without having to constantly disclose their disability or ask for help (although access riders were created to ask an organisation to meet your needs, you out the details of your condition in the process - it's something called

‘enforced intimacy’).

They told me about discreetly taking a photo of the menu or of the departure board and then zooming in to find the info they need. Before the iPhone they would listen in on what someone else ordered or order the same as the person they were dining with (a little awkward on a date or a work meeting). And when they were younger and needed to get the bus, they would listen to the conversations at the bus stop and then get on the bus with the people who'd mentioned the area where they wanted to

go (but it was always a bit of a gamble).

That takes a lot of creativity and energy.

So it's worth applauding the iPhone and celebrating the fact that the iPhone accessibility features and video calls literally changed deaf and visually impaired experiences overnight. It is an access tool and makes many things more independently accessible. But there are still gaps where people are vulnerable, and that is in banking, funding and voting:

1. You cannot FaceTime a bank or a key funding body like

ACE to ask a question if you are deaf.

2. If you are blind using your card in public is more vulnerable to misuse.

3. As a blind person you still cannot cast your vote independently in the UK even though the high court ruled this to be illegal in 2019.\*

\*For a low down on the best Apps for illness & wellness visit Grace Quantock's <https://healing-boxes.com/essential-apps-for-chronic-illness-patients-and-carers-part-1/>

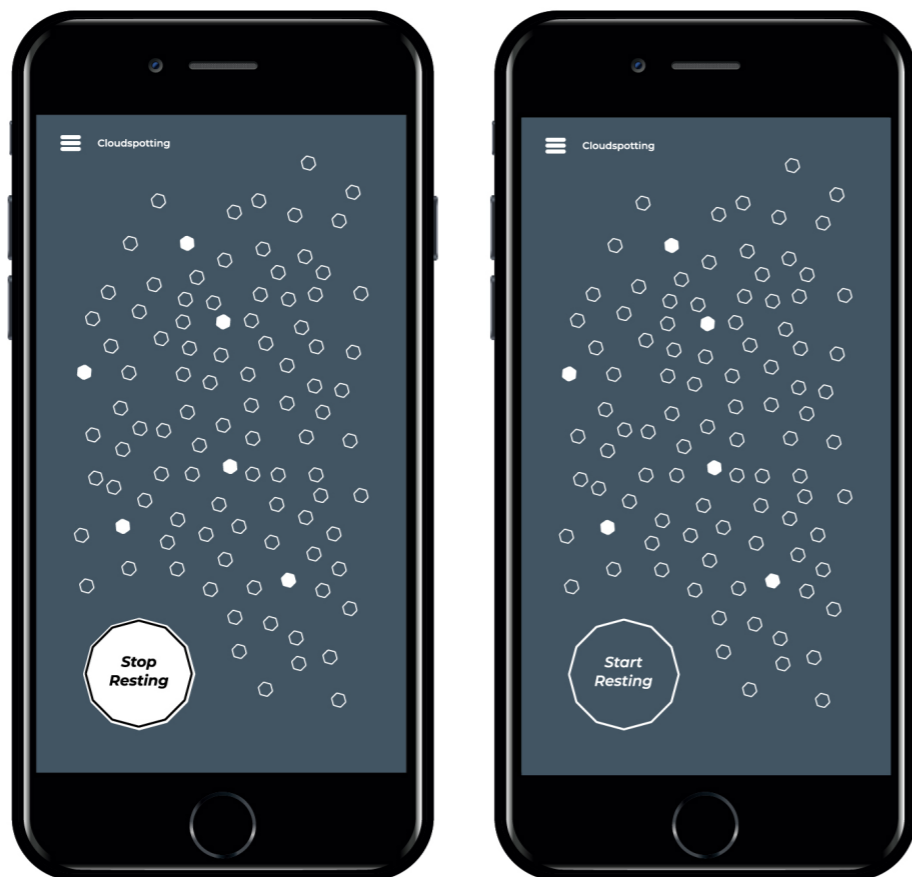
\*BBC Radio 4 podcast In Touch: All about being visually impaired.



**How lived  
experience  
influences our art  
(aka disability as  
creative generator)**



# I. Using tech to translate the lived experience of disability



Many of us tell first person stories about the lived experience of disability. But not all of us, and not all of the time. I'd like to focus here on examples when we:

1. Use tech to translate our lived experience of disability.
2. Interrogate theatrical forms to convey our narratives.

In one of my projects we created an App that allows people with invisible disabilities to communicate their rest in real time with an audience. This translates their live acts of rest into a musical score through the triggering of up to 21 individual loops, triggered via the App (see photo opposite). This communicates how we navigate the world differently and creates an atmosphere in which the audience are invited to rest themselves. It also creates a digital gathering space for audience and resters, and explores the potential for connection across distance, and new modes of togetherness. Quieter modes of being together.

One artist told me about their research on creating a 'hearing aid' for hearing people. It would

convey their experience of white noise and undifferentiated sound (digital hearing aids quieten background sound and amplify quiet sounds, they also change the tone of voices, like a photo filter alters tone). But growing up using analogue hearing aids they are used to hearing everything loud:

*"If I go in the car the engine is so loud. If I'm on a plane, it's so loud. I have got accustomed to listening to big, big sound....But that's what I thought people heard. Until recently. Until I made the show."*

Their research included the idea of face tracking within the hearing aid: the sound would change depending on whether or not you are looking at someone's face. So if you looked away from the person's face the sound would become very unclear. This conveys the experience of people who lip read, when people turn away from them while speaking.

## 2. Interrogating theatrical form to tell our stories



I am interested in interrogating theatrical conventions in my own work and was curious about how others do this. In my work *A Crash Course in Cloudspotting* we ask the audience to lie down to experience the 45 min audio artwork. We found that words land in the body differently when we are at rest, when we tend to be more open and vulnerable. So the horizontal format is a place of spectatorship with the potential for new forms of storytelling.

One artist spoke of their exploration of the short form of Tik Tok as a platform for new online interactive musical about Chronic Fatigue Syndrome called *Housebound*.

A deaf artist told me they write visually, so when they write plays they spend time in a studio drawing, moving, shouting, interacting with objects. This creates a particular form in their work which they describe as “...very much like easy read text, very direct and powerful.”

So if a scene is about an emotion or an episode, they will speak some text, but also use visuals, colour, objects and movement to tell the story. The form communicates

so clearly, they don't need a BSL interpreter to translate the show. As a form it is also much more accessible for people with cognitive or learning impairments.

At one point in their show *Louder*, there is an 8 min recording of their mum speaking. She speaks very quickly and doesn't use easy language, and it's done very consciously as a moment aimed at hearing parents who have a deaf child. That contrast in the 2 types of language ('easy read' and 'normative') really helps to get the point across.

Another artist told me about their fascination with Audio Description for dance and their research on how to develop movement language hand in hand with a descriptive vocabulary, with the aim to give all audiences a more embodied sense of the movement they watch. Their approach involves creative writing, use of more sensory language, audience walking through the performance area, and audience handling objects to give a sense of weight or structure (see the appendix for an extended discussion on creative AD).

# Fences

Before I talk about how this research has changed my work, I couldn't in good conscience skip over the difficult things I heard from the artists I spoke to about exclusion. If it's taboo and we don't see the fences, then I'm not sure how we change things. So it's in the spirit of opening our minds and hearts to the fences that exist, and to our making a commitment to do what we can to remove them, that I share these extracts (please don't skip them):

*"I remember, I've always had to drive somewhere. If I wanted to speak to someone about something really simple like I don't know a question about a funding application I would have to drive there. I can't pick up the phone.... I've grafted really hard to get what I want because simple things are just not accessible to me."*

*"If you are visually impaired and there is no audio version of an article or a book, then the knowledge cannot reach you."*

*"...you know, over the last 20, 30 years I've been hanging out with them, but I don't really follow a conversation. You know how it is, I just*

*drift off. Find myself talking to myself or going on the phone. Because I don't know what the conversation is. I'm tired of saying, what was that?*

*"There's a huge correlation between people being misunderstood or misjudged, and racism and ableism they all feed into the same phobia... you can't really separate them all out from each other.*

*There's this sense when people are looking down from where they are, like the fences aren't that big, or people aren't trying hard enough to climb the fences... but actually when you get down there, the fences are really bloody high."*



# Belonging & Thriving

I think the opposite of exclusion is not just belonging, but thriving. When we feel safe and we belong, then we can do our best work.

*“You know, I’m probably in a safe space two or three times a year. Maybe through Unlimited. And it’s just wonderful... I’m able to communicate better. I say the best things, sometimes when I’m in a space where they’re all non-disabled, I say the worst stuff because I’m stressed about it. The tension needs to come down. Once the tension is there, everybody’s feeling it...”*

The artists I spoke to felt safer in spaces where they were not the only disabled person, where they felt care was taken to try to meet their access needs, and in cultures that celebrate and perceive value in the ‘disruptions.’

*“... it’s all the tiny pieces of technology: a line in an email,*

*knowing the lighting has been considered, a choice of seating, that lets you know you’re welcome”*

As a culture or quality it might be described as ‘friendliness’. The root word of friend is the old English verb *fræond* which means to love, to like, to honour, to set free. Which I understand as the difference between conceptually knowing someone’s needs, and embracing them.

It’s the difference between providing a mat for me, and suggesting we both lie down to have a horizontal conversation because you know it’s much less painful for me.

It’s the difference between just booking a BSL interpreter, and asking everyone to modify how they participate in a workshop to make it more accessible i.e. can people please put their hand up when they speak, and speak more slowly.

It’s the difference between letting someone take sole responsibility for managing their energy levels and taking on some responsibility by knowing their exit plan in advance (remember the more fatigue the less good our decision making). Or better still embracing the way someone navigates the world as part of the adventure:

*“...he kept checking in, asking where my Fitbit was at, on how many steps we’d done... to figure out how far we could get on the next bit. To have someone take a little bit of responsibility ...that was really really nice.”*

# How my work changed through this research & guiding principles

## I.

To be guided by a principle of equivalence when considering different formats and ways to make work inclusive.

## 2.

Whenever possible, to integrate accessibility into the making of the work from the beginning.

## 3.

To be guided by a principle of 'friendliness'.

## 4.

To refer to the case study on the next page and use it as an evolving prompt. To let it be a live and living thing (and not a checklist).



I thought a good way to bring all this learning together, would be to apply it to two integrated dance workshops I will run with Arnolfini in 2021. For these workshops I aim to:

**a.**

Begin with a 'soft start' (a relaxed start time and the ability to join later).

**b.**

Have the option to move fluidly in and out of participating (and have a resting space to facilitate this).

**c.**

Consider the lighting (people who lip read or who are visually impaired often need consistent light or brighter light, whilst neurodiverse people often need non bright stimulus). Learn how to negotiate the lighting between the participants, throughout the workshop.

**d.**

Have 2 BSL interpreters present for the session.

**e.**

Ask people to put their hand up when

they speak, and ask everyone to speak more slowly.

**f.**

To create exercises where we practice audio describing for one another, so we begin to flex that muscle. For example if working in partners we might describe what part of the body we are moving from, or describe what other dancers in the room are doing.

**g.**

Use forms of dance like contact improvisation where touch is the method of

communication.

**h.**

Have a resting space both in the workshop space, and a separate quiet room. The space would have options to lie down, sit, bean bags, etc.

**i.**

Communicate on channels disabled people use and include an audio flyer (a great thing about smart phones is we can make decent audio content so easily now).

**j.**

Have budget to cover

disabled participants' travel expenses and be transparent about what access really costs to the hosting venue.

**k.**

Experiment with more friendly language i.e. 'how can we make you comfortable in this space' or 'how can we welcome you and prepare you to be in this space?'



# Uncomfortable Truths

Again, I can't in good conscience skip over the things I noticed during the pandemic (and I ask that you don't skip over them either).

There was a moment in the UK's first lockdown when we thought our hospitals would be overwhelmed and Do Not Resuscitate forms were sent to disabled people in the post. That moment sent a very clear message about whose life would be accorded less value medically, culturally, and systemically, when and if we have to make the really hard choice about who gets the ventilator.

One artist told me about attending a 'Devoted & Disgruntled' event (this is a space created by the theatre industry for blue sky thinking.) The event was about recovery in the arts and the future of theatre. In the open space\* part of the event, the artist created a room to talk about access and only two people attended. Two people in over a hundred.

I note these to point out how we continue to write disability out of our futures. Again, if we don't see it, we can't gauge whether we are moving towards or away from more equitable futures.

\* Open Space is a method used to facilitate conversations at big events. People pose questions in different spaces and you 'vote with your feet', you go to the question that most excites you. A key premise of the Open Space method is that you leave a conversation as soon as you are no longer interested. Once you are not excited you are no longer needed at that conversation, but you might be needed elsewhere.

# New Normal / New Futures

I'd like to leave you with a final thought about our 'new normal'. The pandemic has normalised some aspects of disability experience: we all now live with precarity & the need to change plans quickly, we talk more openly about our mental health needs, many of us have pivoted to deliver aspects of our work online or 'cripped' our practice in other ways.

And during the pandemic remote art and events have been more accessible to a lot of disabled people. A visually impaired colleague of mine now talks about "going to the Royal Opera House," because they can access events using magnification software on their screen at home.

And there WAS a moment when we were all questioning how much we wanted to go back to a 'normal' that didn't work for so many people, especially people of colour, LGBTQ+ and disabled communities. That moment seems to have lost some of its traction. Which is a shame. But we can all begin to work with accessibility and uphold accessibility in our own practice (to the best of our ability).

So please let's continue to:

- explore the potential of live streaming and remote events,
- explore online and hybrid forms of being together,
- create welcoming and integrated spaces (digital & physical).

**Thank you.**



# A huge thank you to

Jo Bannon

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Thank you to all my cripp friends, colleagues, fellow artists and activists.

## **Appendix: On Creative Audio Description for Dance with Holly Thomas**

*“there’s almost two schools of description: people being really creative and experimental and artistic, and then there’s people using the traditional form. And I don’t think that they’re brought together successfully very well, very often.”*

Audio Description is the art of describing visual art or live performance, in words. Originally created so visually impaired people could experience visual art forms, there is increasing interest in how to integrate AD for all audience, and in making it an integrated part of the creative process, rather than something added on at the end (but we’ll get to that).

The traditional components for Audio Describing a live show include:

1. Programme notes sent in audio and text format ahead of the show. This enables the audience member to dive into the world of the show (the set, costumes and colours). It makes sure the visually impaired audience have the same information about the set and world as a sighted audience.

*“... and then with the sight I do have, I can really make sense of what is going on. It fills in the gaps.”*

2. A touch tour shows visually impaired audience around the set ahead of show time. It usually includes the chance to meet the performers, and might include the opportunity to try on the costumes.

3. A pre-show workshop is a more in-depth introduction to the movement and visual language of the show. It might include playing parts of the soundtrack and describing key moments in the show; it might link musical motifs with characters; the performers may dance the movements close to the participants so they can hear and sense the movements; moments of hands on touch to follow the movements of the dancers may be facilitated; key movement language may be taught to the workshop participants.

4. And finally the Audio Description is delivered live through headsets during the show (the audio describer is normally in a booth up by

the lighting box, or in a separate room with a monitor and a live feed). Bone conducting headphones allow you to simultaneously hear the sound in the room (but are not always available).

Traditional AD will describe the key things that make it possible to access the show: the set, the costumes, the performers and where they are on stage, their movements, gait and facial expressions (in as much detail as possible within the time allowed by the pace of the show).

\* Shape Arts created a really good doc on Audio Description for Art you can access here: <https://www.shapearts.org.uk/news/ways-of-seeing-art-booklet>

## **Our experiments in Creative Audio Description**

Working on the AD for Lost Dog's Juliet + Romeo we discovered that audio describing dance is a process of translation from a non-verbal language (that often resists words) into a verbal language. We also discovered it cannot be objective: we have to choose which movements to describe, and in choosing to describe one, I miss the next three.

I found that I wasn't necessarily describing the movements I felt to be most important, but those I could describe in words. And I felt limited by the lack of adequate vocabulary: I can say a 'turn' but there are infinite qualities and tempos. I often felt unable to communicate the nuances of the movement.

### **Sensory Language**

Holly is interested in whether more sensory AD language, is capable of connecting the audience to the feeling of the movement and to the liveness of it.

*"I do think there is a role for traditional AD, it's just I don't want that to be my starting point when I'm trying to find the language and trying to find the ways to connect [with the audience]."*

Holly has experimented with how you might develop AD alongside creating movement. This involved setting movement improvisation tasks, followed by written tasks. She asked the dancers to describe their internal experience of the movement; to write about what they were imagining or what came into their mind; anything they remembered or saw of the other dancers. This created many different types of text to play with.

This resonated with me, as my main take away from the Lost Dog creative AD project was that I wished I'd involved the dancers sooner - they have so much more information and knowledge about how the movement feels from the inside. And this is so different to describing it from the outside, the difference between what a movement feels like and what it looks like.

Holly quoted the playwright Bryony Lavery who in an NT workshop said "every piece of good writing is about writing from all of the senses."

\* You can access a free online workshop with Bryony Lavery here <https://www.youtube.com/watch?v=Qfzv4NqTRgQ>

## **Touch**

Holly wanders if starting from sensory language and touch, can connect the audience to the movement in a more embodied way:

*"[one of the dancers]...was thinking a lot about weight and bones, and about a bird...this idea of taking flight or levity...and I was like, what is it if you have the description of the weight of an animal...the textural and physical qualities of that...what if you were to lift that animal and hold it...all the weight of it's bones...the dimensions of it's body..."*

*If you're experiencing it, not from seeing it but from holding it and feeling it...does that take your audience into a place where they're becoming more attuned to their own body and physicality.*

*So then when you're using description and language, are they more directly connected to that, through being awakened in their own body?"*

Holly talked about seeing a performance where the dancers worked with small spheres. After the show the producer, knowing her to

be visually impaired, invited Holly to hold the spheres. One of them was made from a really dense metal, it was really heavy, and the other one was much lighter:

*“As soon as you held them you understood how their movements were working...all these counterbalances they were creating with these two differently weighed balls.*

*Actually, the whole of the audience would have benefited from being able to pick them up before the show...because then you have that felt sense, that knowledge of all the properties of that object.”*

### **Tenses**

Holly also plays with the tense of description:

*“I think there’s something really interesting... if you’re trying to describe the movement as it’s happening it can dictate the speed of the movement...what happens if you change the tense?... if you don’t have to describe at the point the movement is actually happening”.*

I find this idea really exciting. It makes me think of the possibility to explode moments, to repeat

and reconstruct movement, to describe it from different angles. It makes me think of a form that loops and weaves in on itself: that keeps returning to a moment, that loops within a moment before carrying on.

### **A new way of experiencing dance**

*“...at the very core of it, what I’d like to do next is to make something that is about revealing what is unseen within a dance performance, in it’s widest context...and then audio description and description just become an essential tool in making that happen.*

*... literally a different way of experiencing dance, by revealing what’s unseen... so even if you’re seeing it, you might begin to see it differently.”*

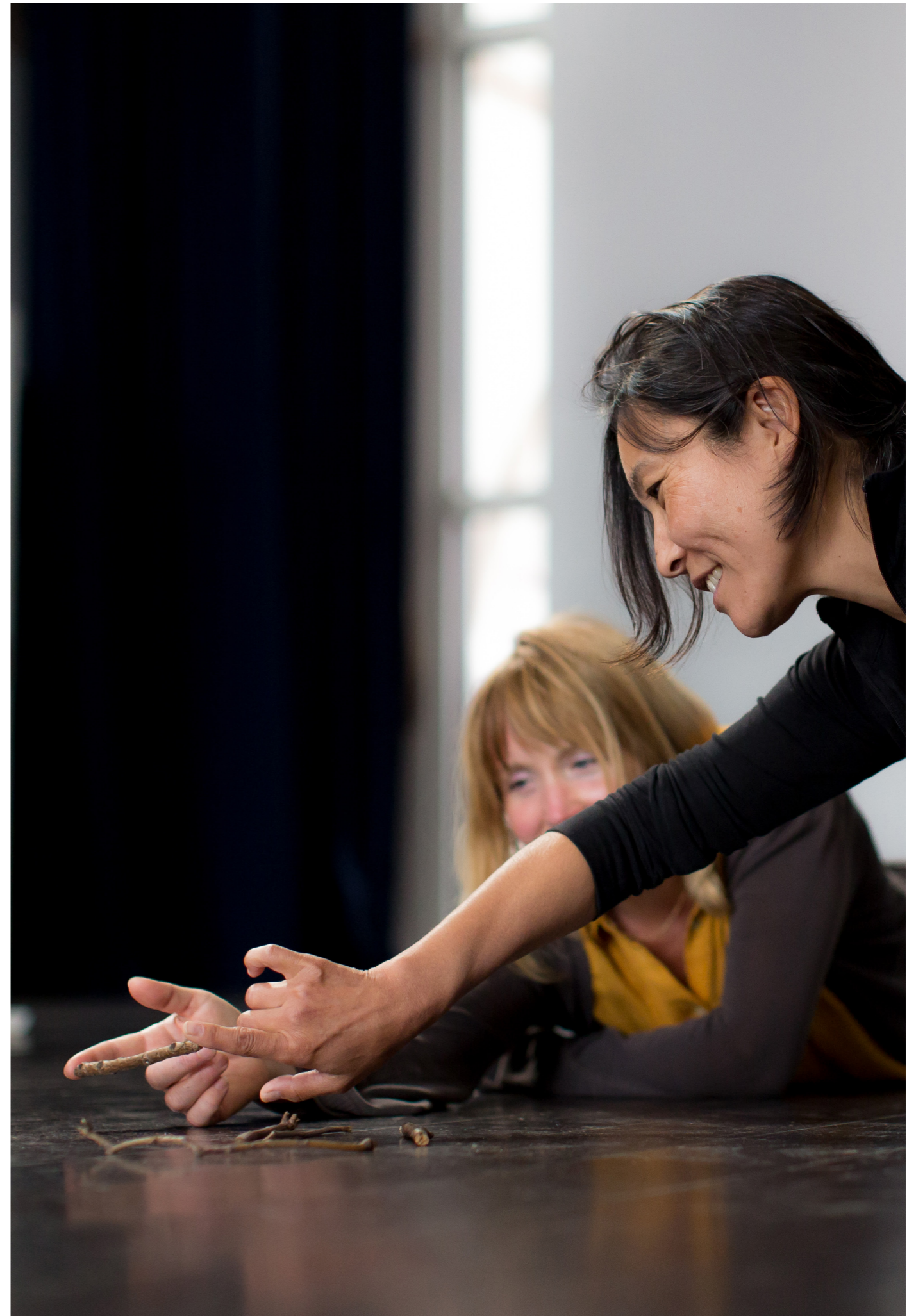
After this conversation with Holly I wrote down this list to remind me of all the layers that could contribute to AD: sensory language, textural qualities, touch, embodied perception, time & tense.

I wrote this along with a reminder NOT to forget the key elements that ensure the description still creates the opportunity for someone who is visually impaired to experience the show,

with as much equity of experience as possible. Without that it's creative text, but it's no longer access.

We also talked about beginning an evolving list of language and ways to describe dance. A sort of open source document. If we're able to start this, I'll post about it on my website.

Thank you.





## References

Jo Bannon

<https://www.jobannon.co.uk>

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Jonny Cotsen

<https://www.otherroomtheatre.com/en/about/team1/jonny-cotsen/>

Stephanie Kempson

<http://www.stephaniekempson.co.uk>

Holly Thomas

<https://hollythomasdance.wordpress.com>

Grace Quantock

<http://gracequantock.com>

## The following organisations were mentioned in the document:

Unlimited is an arts commissioning programme that enables new work by disabled artists to reach UK and International audiences.

<https://weareunlimited.org.uk>

I have Jos Boys at the DisOrdinary Architecture Project to thank for the phrase “Disability as a creative generator”.

<http://disordinaryarchitecture.co.uk>

Brené Brown’s definition of belonging is from her book The Gifts of Imperfection.

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