'BEING WITH' IN SENSORY THEATRE

WRITTEN BY
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Oily Cart

SPACE TO BE | CREDIT: SUPPLIED BY FAMILIY

PREFACE

This report is written by Dr Jill Goodwin and Ellie Griffiths and was inspired by joint explorations during Jill's time as Researcher-in-Residence with *Oily Cart* (2020-2022). We hope it will be of interest to anyone who works creatively with disabled children and young people who experience the most barriers to access.

Note: In the report we describe and discuss people whose ways of being in the world we cannot experience for ourselves, and we are conscious of the potential for our words to come across as 'othering'. At this point in time, we are yet to discover how to meaningfully apply the guiding maxim 'nothing about us without us' in this context. Our aim in persisting despite these tensions is to move the practice of sensory theatre forwards and to make it more ethical and equitable.

JAMBOREE | CREDIT: SUZI CORKER

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MIRROR MIRROR | CREDIT: NEAL HOUGHTON

SUMMARY

This report comes out of Dr Jill Goodwin's time as Researcher-in-Residence with *Oily Cart*. The residency had a creative strand – which resulted in the 'at home' sensory show *Space to Be*, and a critical strand – in which we invited artists, parents, researchers and practitioners working in the field of inclusive arts, to take part in 'critical conversations' with us. The key themes arising from the residency were:

- **Language and Labelling**
- **Personhood and Agency**
- **The Role of the Supporting Adult**

In our exploration of **Language and Labelling** we discuss the need to be clear (internally and publicly) in the language we use to refer to the individuals we work with. Across our projects, *Oily Cart* have shifted away from using the term 'profound and multiple learning disabilities' (and its abbreviated version, 'PMLD') because it medicalises disability. For *Space to Be* we tested using the term 'sensory being', but in our critical conversations we learnt that this can be seen as a euphemistic term. Professor Melanie Nind suggested that there is a risk of making a whole community of individuals invisible (or even erased) if we use labels that are too vague.

We also discuss the issue of 'presumed competence' (i.e. assuming linguistic understanding in people who do not use verbal language to communicate), which is often seen as a respectful approach. Our critical conversations revealed discreet ableism within this approach as it can unintentionally be disrespectful to a person's non-linguistic way of being. We discuss the challenge of how to show our respect and value for non-linguistic forms of cognition in terms of how we connect *with* and talk about this group.

The Social Model of Disability guides all of *Oily Cart's* work. However, two parents told us it does not match their own experiences because it plays down the impact of their child's medical conditions and barriers to access. Two disabled creatives offered a contrasting view, warning that issues of dependency may mean that the disabled child does not have the same opportunities for rebellion and self-determination. They suggested that parents may risk putting their views onto the child, while a parent pointed out that if they don't advocate for their child, who will? We are committed to seeking ways of talking and writing about the young people we work with that are clear and do not diminish the complexity of the barriers they face. We are seeking terminology that can do this without medicalising their way of being in the world. We take seriously our role in making opportunities where young people's own voices can be appreciated in their own right.

In our second theme, **Personhood and Agency**, we look at the idea of personhood as defined in philosophy. The definition most commonly ascribed to in this field does not acknowledge the personhood of young people who experience the most barriers to access because they have no provable self-awareness, self-determination and capacity for reason. These limited definitions are important to understand because they feed into legislation and affect the status of disabled people. Thankfully there are academics arguing for alternative definitions. For example, in the report we reference researchers who have used an interpretive research approach to show that 'voice' and 'linguistic competence' are not the same thing.

Our audiences cannot always demonstrate agency, independence and progress (as traditionally understood) – aspects that are often classed as essential features of a worthwhile life. The best children's theatre organisations champion agency for their audiences, which can involve focusing on disabled children's reactions and choice-making. However, making choices for some children requires time and relies on the sensitive interpretation of their responses by those who know them well. In these instances, the offer of choice in new settings under time constraints is a meaningless exercise. On the topic of meaning, our critical conversation partner Professor Melanie Nind highlighted how meaning is frequently associated with productivity, even though simply 'being' together (apparently doing nothing) can have real meaning. This notion of moving from 'doing' to 'being' was at the heart of Jill's previous research for her PhD.

In our critical conversation with Professor John Vorhaus, we considered how we might judge the value of being together. He suggested that if we are somehow able to suspend the hierarchy of power and status, then being together can be an equalising experience, which gives it moral value. To create a more 'equalising' encounter was one of the goals of *Space to Be*. John challenged us to clarify what we meant by a shared experience in the context of cognitive difference, and this question led us to discuss what needs to be true if we are to say something is shared?

We also explored whether conceptual understanding is essential in the appreciation of beauty during our critical conversation with Professor John Vorhaus, which led to a discussion about aesthetic experience and affect. Affect can be defined as feelings or instinctual reactions that occur before we are able to (linguistically) articulate more complex and identifiable emotions. Because aesthetic experience works as an embodied response at this affective level, it is equally available to *Oily Cart* audiences regardless of their type of cognition.

In our third theme we explore the important **Role of the Supporting Adult** in sensory work. This became even more pertinent during the pandemic as many of our sensory shows took place in the home, facilitated by parents and carers. *Space to Be* was designed to bring the whole family into a sensory headspace so that they could experience the show on equal terms. This was the first time *Oily Cart* had not focused solely on the experience for the disabled young person, marking a shift in the company's creative approach. Wellbeing was also an important dimension of the *Space to Be* project as the show took place during the second lockdown when many families were shielding, with severely reduced (or even no) care support. Through this project we saw the potential of sensory theatre to bring people out of their heads and into their bodies and the present moment, to be together fully.

Later in the report we discuss how, as performers, it can feel challenging to be with someone who appears unresponsive or who doesn't respond in a way we recognise. There can be a tendency to push for recognisable visible responses in order to make our work feel validated. This is compounded when these responses are the only evaluative currency of the work. We question this as a measure of success and discuss other ways to think about impact in this context. We suggest it may be beneficial for artists and performers to 'de-invest' in responses that are recognised through a neurotypical lens. Although positive engagement is a goal we all aim for in our work, we suggest there is a need to reframe 'success' when it comes to more seemingly passive audiences. Jill's provocation during her residency was for *Oily Cart* to become more comfortable with less activity. We ask if it is possible to recalibrate our measure of success in order to recognise the impact the disabled child has on us.

Tensions still exist within each of these ongoing discussions. We will never understand everything from every perspective, and we cannot know what many of our audience members and collaborators think and feel. Our aim is to make sensory theatre better by moving the thinking and discussion in this area forward.

LIGHT SHOW | CREDIT: SUZI CORKER

INTRODUCTION

About the Authors

Dr Jill Goodwin is an Artist/Researcher (www.jillgoodwinphd.wordpress.com) with a background in education. Jill's teaching experience includes working with children and young people who, in the school context, were labelled as having 'profound and multiple learning difficulties'. In her PhD study (Goodwin, 2019) Jill explored the use of a sensorially rich environment, Golden Tent, as an aesthetic space in which staff (who were usually very active and busy around pupils) were invited to stop 'doing' and simply 'be' alongside them. She was interested in whether Golden Tent could offer an 'equalising' environment in which staff could shift to a more embodied awareness in order to experience the sensory present alongside their disabled partners. By promoting the value of simply 'being together' in a more equal way, Jill aimed to subvert hierarchical understandings of education (in which 'competent' teachers train 'incompetent' learners) and move away from the idea that pre-specified learning outcomes (for pupils) should guide all encounters.

THE GOLDEN TENT | CREDIT: JILL GOODWIN

IMAGE OF ELLIE GRIFFITHS | CREDIT: MIHAELA BODIOVIC

Ellie Griffiths is Artistic Director of ***Oily Cart*** (www.oilycart.org.uk), a sensory theatre company that make accessible shows for children of all ages who experience multiple barriers to access. Ellie, along with Executive Director Zoë Lally, took over *Oily Cart* in 2019. When the company was established in 1981 its three founders were pioneers in the field of sensory theatre. Then and now, *Oily Cart* shows aim to engage their audiences with minimal reliance on verbal language by using all other channels of communication, including sound and live music, movement, touch and vibration, light and shadow. They are highly interactive with small audience numbers (typically six young people and their supporting adults) so that the performers can adapt the content to each audience member's preferred way of engaging. Previous *Oily Cart* shows have taken place in hydrotherapy pools, on trampolines, and even with the audience floating up in the air! An *Oily Cart* show celebrates all different ways of being in the world. More companies and artists have now joined *Oily Cart* in creating sensory shows for children and adults, but they still represent a very small part of the global theatre sector.

IMAGES OF PAST OILY CART SHOWS | CREDITS: SUZI CORKER & NEAL HOUGHTON

Background

Oily Cart are always looking to improve their practice by thinking more deeply and critically about their work and the audiences they serve. The Researcher-in-Residence role provides a framework for curiously confronting some of the questions that arise out of their projects alongside people who have different perspectives. This residency had both an artistic and a critical strand. The artistic strand led to *Space to Be*, a show that was directly inspired by Jill's research of 'being with' young people who experience the most barriers to access. The critical strand included a series of 'Critical Conversations' with families, disabled artists, inclusion researchers and a leading sensory specialist that Jill brokered for the company. Both strands of the residency are discussed in this report.

Space to Be

Created during lockdown in the Covid-19 pandemic, *Space to Be* was designed (largely over Zoom) as a touring show that could be delivered to families who were shielding. Families were sent five boxes and instructed to open one a day, so that the story/family experience (connected by audio track) built up over the week.

VISUAL MAP OF SPACE TO BE | CREDIT: ANANYA RAO-MIDDLETON

The show was designed to open up a space where individuals with vastly differing ways of being in the world could share something authentic and meaningful together (in different ways). The creative team sought to establish an artistic equity across this cognitive divide by designing activities that would enable parents and siblings to join their disabled child in a language-free space of 'being' rather than 'doing' (we say more about how we tried to achieve this later). We also attempted to create a show that would mirror the families' own stories back to them rather than imposing a story that might not feel relevant for different families. Each family member was given the name of a fictional star (with its own characteristics and properties), and the central metaphor was that when connections are drawn between the stars, stories emerge from these unique constellations. It was important to the team that each artistic experience placed the disabled young person at the centre of their relational constellation with a view to creating moments of mutual enrichment for all. In this we were following Grace's idea that:

> 'There is much to be gained on both sides from exchanging insight about our experience of life. It is important for Linguistic Beings to remember that sharing insight is a two-way process. We need to spend time sensing as well as showing. If we are resolutely set on trying to teach Sensory Beings to be like us, we squash the value of their lived experience.'
>
> (Grace, 2018:9)

PHOTO OF HANDHELD OBJECT FROM SPACE TO BE | CREDIT: SUZI CORKER

The idea of respecting someone exactly as they are, and the notion of creating a non-hierarchical space for being together in the 'sensory present', were important premises at the heart of *Space to Be*. The show was designed so that Day 1 was a solo experience for the adult, aimed at bringing them into a more sensory headspace. This included an immersive binaural, ASMR (autonomous sensory meridian response) soundtrack played through a set of high-quality headphones, an eye mask and a unique handheld sculpture designed for tactile exploration.

Click the button below to listen to an excerpt from Day 1.

▶

This element of the show received a surge of positive feedback from parents, for example:

> *“I listened to it* [Day 1] *twice and I was so profoundly moved, so deeply moved. Eleven years on this journey, nearly twelve years, and nobody has ever emotionally held me like that, ever (as a professional I mean) and said those things!...it was really moving and very strong and unique. So I want to thank you for thinking about the carer first...”*
>
> Samantha Bowen

As the days went on, the number of family members taking part in each experience expanded, while the number of words contracted. Day 2, for example, was designed for one parent with their disabled child. They were provided with a double-sized deep blue velvet pillow that had a speaker embedded at each end. There was also a velvet blanket embroidered with stars linked into constellations by lines of stitching. The adult was instructed to trace the stitching with their fingers to provide a tactile experience to accompany the sound experience for their child.

PHOTOS OF THE PILLOW AND BLANKET FROM SPACE TO BE | CREDIT: SUZI CORKER

The soundtrack included various voices and accents speaking the words "you and me" in stereo (underneath the participants' heads).

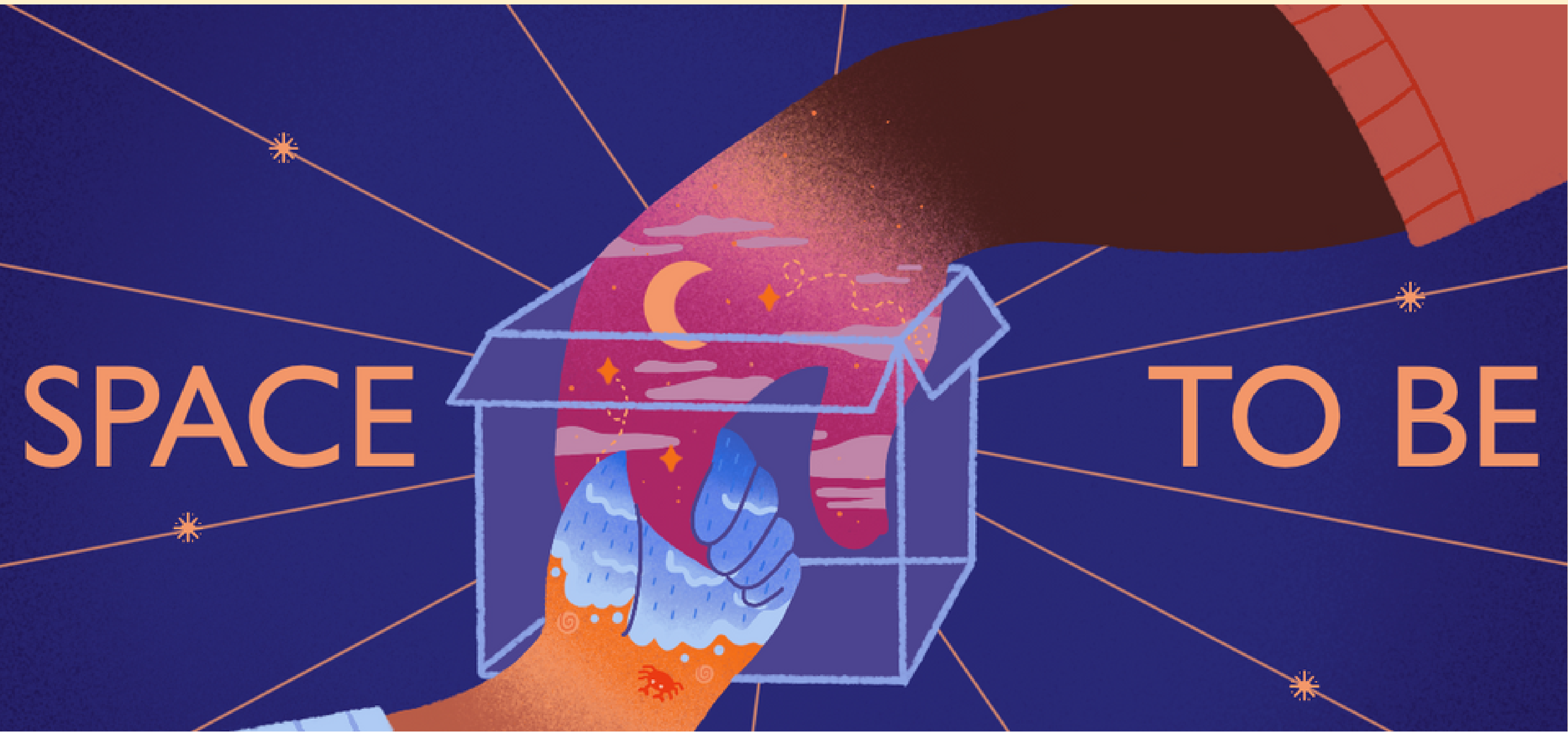
Click the button to the right to listen to an excerpt from Day 2. ▶

This was a powerful experience for some parents:

▶

> *"The individual moments that I felt – I'm gonna get emotional talking about it – but almost like a connection like we were both experiencing this in exactly the same way and getting the same level of enjoyment out of it – I am getting emotional, I apologise now – but it was really moving. It was the bit with the voices they were just going 'First there was you and me...' but it was so powerful but so simple! The words themselves were meaningless to Hugh but the repetition and the rhythm and this... calmness and being in the dark it was just – God I can't believe I'm crying about it, look I was really emotional at the time as well, but it was SO powerful...it was just like this really intense sharing of an experience that's quite difficult to do for those kinds of things. Like, we can share experiences when we, say, go out and we're sat in the wind and we're both feeling the wind in the trees and we're both enjoying that experience (I mean my brain might be racing with twenty different things and Hugh can just sit and enjoy it)...but this was a thing that...it was intense actually. It was amazing, it really was amazing."*
>
> Emma Murphy

MARKETING IMAGE OF SPACE TO BE | CREDIT: ANANYA RAO-MIDDLETON



Days 3 and 4 involved siblings and/or any other members of the family. For Day 3, small tins were provided that contained wrist torches and a tessellated mirror sheet that threw reflected light patterns onto the walls and ceiling. The tins also had individual soundtracks embedded within them that could be played separately, or brought together to form a layered soundscape.

PHOTOS OF OF TIN AND MIRROR SHEET FROM SPACE TO BE | CREDIT: SUZI CORKER

Day 4 involved an audio resonator box designed to be placed on the lap or under the feet of the disabled child. By stretching and pulling on lengths of fabric to create a star shape, the other family members could change the sounds and increase the intensity of the vibrations within the resonator.

PHOTO OF OF THE RESONATOR BOX FROM SPACE TO BE |CREDIT: SUZI CORKER

On Day 5, the family were invited to lie within a mini planetarium tent, projected with a star light and surrounded by a musical soundtrack that included the sound of real stars in the galaxy.[1]

Click the button below to listen to an excerpt from Day 5.

▶

For parent Samantha Bowen, sharing this space with her husband and daughter Lucy was a powerful experience and Lucy really responded to the soundtrack:

▶

> *"But the most magical thing happened when the sounds in the track...there was a baby making babbling noises"* (for clarity, this was actually the sound of a recorded vocalisation of a disabled young person') *"and we'd been really quiet throughout the whole thing, it was very relaxing...we all felt instantly calm, really calm and safe, and this was our little bubble and very connected as a three, as a family... and she was in the middle and she was leading it, which was lovely, and we were the passive ones then, and then she started vocalising when the baby - it's quite emotional talking about it! - when the baby was babbling she vocalised back in a babbly way. I thought, 'My God, this is huge, this is really huge!' So, we did that several times, we kept going back to that".*
>
> Samantha Bowen

SPACE TO BE | CREDIT: IMAGES SUPPLIED BY FAMILIES

Here you can see some of the responses of our audiences of families from across the UK.

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[1] Read musical director Jeremy Harrison's blog about making music with the sound of stars here: https://oilycart.org.uk/resources/jeremy-harrison-the-sound-of-stars/

Critical conversations

As a company whose practice is referred to as 'world-leading' in the sensory theatre sector, *Oily Cart* recognise the importance of critical reflection on their own practices, and the value of feeding the views of people with different specialisms and lived experience into their thinking. It can be hard to prioritise deep and critical reflection in a competitive arts context where there is scarcity of funding, and where artists and organisations feel pushed towards overstating the positive impact of their work. This is a complex field to work in, and one that is still developing, so there is still lots to discover about how to engage and connect with individuals who have extremely different ways of processing, differing levels of awareness and unpredictable responses.

As Researcher-in-Residence with *Oily Cart*, I (Jill) was invited to set up some conversations with people whose different perspectives, interests and knowledge I felt might be valuable for *Oily Cart* to listen to and understand more about. These 'critical conversations' all took place over Zoom and were one hour in length. We acknowledge the limited cultural diversity of our conversation partners, something *Oily Cart* are seeking to address as they embed a more intersectional approach into their working practices. Within the scope of this residency we spoke to:

- **Mandy Redvers-Rowe:** Mandy is a Writer, Performer, Activist and Audio Description Consultant who identifies as blind. The conversation with Mandy highlighted the dominance of the visual sense, and the need to be aware of visual bias when making work for *Oily Cart's* audiences. We talked about how beauty, an idea typically expressed in a visual way, might be expressed from other perspectives and about becoming sensitive to our other senses in order to perceive and understand spaces in a less vision-centric way.

- **Melanie Nind:** Melanie is Professor of Education and Director of the Centre for Research in Inclusion at the University of Southampton. Melanie is probably most well known for her work developing Intensive Interaction (a non-verbal communication technique) in the 1980s, but she has also been at the forefront of work in inclusive research, particularly in relation to learning disabled people. We spoke to Melanie about working inclusively, about language and labelling, and about meaning and evaluation in relation to working with young people with the most barriers to access.

- **John Vorhaus:** John is Professor of Moral and Educational Philosophy at University College London's Institute of Education. John has a particular interest in moral status and disability. In our conversation, we discussed the idea of shared experience with our audiences. John also questioned us, from his perspective as an analytical philosopher, about what we mean when we talk about creating spaces for people to 'just be'.

- **Daryl Beeton:** Daryl is a Theatre-maker, an Advocate for Disabled Artists and an Inclusion Activist. Daryl gave us his perspective on some of our dilemmas around language and labelling. He also shared his views on de-medicalising disability language and shifting ableist viewpoints.

- **Samantha Bowen:** Samantha is a Museum Development Officer who is passionate about inclusion in museums. She is also a parent to Lucy (who was aged 11 at the time of our conversation). Samantha's family experienced *Space to Be* during its tour and she gave feedback on their responses to it as an artistic experience. We also discussed the language and labels that get used to describe Lucy, and Samantha shared some of her views in relation to the social model of disability.

- **Emma Murphy:** Emma is a Teacher for children with profound and multiple learning disabilities (a label she fiercely defends) and a parent to Hugh (who was aged 11 at the time of our conversation). Emma's family experienced *Space to Be* during its tour and she gave feedback on their responses to it as an artistic experience. We also discussed the language and labels that get used to describe Hugh, and Emma shared some of her views around presumed competence and the Social Model of Disability.

- **Joanna Grace:** Joanna is a PhD Researcher, Author, Trainer and Sensory Inclusion Specialist. Jo also reviewed *Space to Be* with her family. In our conversation with Jo we dug into the pervasive power of cognitive ableism and some of its knock-on effects.

In addition to the above conversations, we consulted with Miss Jacqui (who was part of the artistic team for *Space to Be*) to discuss an early draft of this report.

- **Miss Jacqui:** Jacqui is a Poet, Spoken Word Artist and Songwriter. As a disabled black woman, Jacqui aims to challenge people's perceptions through her work, and to help her listeners see the world differently. With Jacqui we discussed some of the issues around disability language and labelling and her feedback contributed to the development of this report.

Each participant was offered payment for their contribution.

Note: all excerpts taken from our critical conversations are written in *italics* within speech marks to signify that they are transcripts of spoken comments.

The key topics of discussion that characterised Jill's time as Researcher-in-Residence can be represented by the following three themes:

- **Language and Labelling**
- **Personhood and Agency**
- **The Role of the Supporting Adult**

We use these three themes to structure this piece of writing, making reference to both the artistic outcome (*Space to Be*) and our critical conversations. However, before we delve into these three topics, we want first to establish the type of child who is at the heart of our thinking throughout.

Who are we talking about?

Khaled is ten years old, has big brown eyes (that really gleam) and a thick mop of dark hair. Khaled's body is still - if you offer him an object he does not reach out and if you place the object in his hand, his fingers do not explore it. Khaled sometimes enjoys it when his body is moved in physical play, like when he is swung in a blanket or slid across a shiny floor on a cloth, and if he's lying on a trampoline, he may smile when he's bounced. Khaled's frequent seizures take a lot out of him, so he can be very sleepy. Khaled is silent although sometimes you can hear his voice in his breathing.

Khaled is the type of child we were thinking about when we worked on Space to Be. He is a fictional character based on children and young people Jill spent time with as a teacher and/or that Oily Cart know from their audiences. By holding children like Khaled at the centre of our thinking we are following Grace's idea of 'Rich Inclusion' (Grace, 2014) whereby, if we meet the needs of those with the most barriers to access we are likely to increase benefits for all. Above we have described some of Khaled's physical features and a few of the things he seems to enjoy, from which you will probably discern that he is a wheelchair user who requires support for all aspects of his daily care. What our description does not indicate is anything about Khaled's cognitive capacity, and for *Space to Be* we imagined Khaled to have minimal or possibly no capacity to process language. This was important because someone whose embodied senses simply exist 'as is' - without translation into words and concepts – has a very different experience of the world compared to someone whose access to the world is processed through language (Grace, 2018). To ignore these differences is potentially to disparage this non-conceptual way of being in the world. If we do not offer artistic engagement in a form that Khaled and others like him can access we are simply adding to the exclusion they consistently experience.

In creating *Space to Be* it was our aim to create artistic experiences that were not only accessible for the disabled child but that brought the whole family together in shared sensory moments. We wanted linguistic and non-linguistic ways of being in the world to not be in a hierarchy or at odds with each other, so that the experiences could be shared in a more equitable way. Now that we have clearly identified the type of child at the centre of our thinking we move on to discuss each of our three themes in turn.

KUBLA KHAN | CREDIT: NEAL HOUGHTON

LANGUAGE AND LABELLING

An unavoidable and consistently challenging issue to navigate in this field is our choice of language and the labels we use to identify and describe people. This is a serious area of consideration because we do not want to participate in discourses that oppress and limit. It is problematic to label any diverse group of individuals according to their perceived difficulties and we want to resist normative bias. Wherever possible it is preferable to check with disabled individuals themselves about how they choose to be identified, and as a basic guideline we want only to use a label in someone's absence that we are equally happy using in front of them. In our critical conversation with artist Daryl Beeton, he encouraged us to not simply accept the most commonly used terms and labels but to rigorously interrogate how we talk about our work, and how we refer to our collaborating artists and our audiences. Daryl encouraged *Oily Cart* (as a company looked to for our specialist work in this area) to be bold in stating clearly what we accept and reject, and to not be afraid of using terms that are different to those used in the mainstream. This is part of how we can advocate for and with disabled people. He also pointed out that, having taken this position, it may take time for our choices to be understood and accepted. To illustrate this point Daryl cited the example of Drake Music who did some consultation about the term 'special' (as in 'special school' and 'special needs'):

> *"...we interviewed and spoke to some disabled artists and practitioners and disabled people that work in the arts, and the resounding thing was that they hate that term because it wasn't a term that was generated or owned by the community it was describing. But... so it was ok for Drake Music as an organisation to put out a statement saying 'we're not using this term any more', you know, 'it doesn't identify what we need to know about the young people we work with', but I would say that's still taken about four or five years for when we communicate with a school that they still know that we're talking about the young people they know, although we're not using the language they understand....So, I think it's a journey and also it's about education and advocacy and that sort of aspect of it as much as it is around the actual language itself."*
>
> Daryl Beeton

LIGHT SHOW | CREDIT: SUZI CORKER

How do we identify our target audience?

MIRROR MIRROR | CREDIT: NEAL HOUGHTON

The issue of finding consensual terminology is inevitably complicated when the individuals we want to identify cannot participate in conversations about how they are described. For *Space to Be*, we wanted to acknowledge and honour a very specific way of being in the world, but we definitely felt challenged when it came to declaring children like Khaled as our target audience. Within the UK education system, the label 'profound and multiple learning disabilities' (or 'PMLD') is the most commonly used descriptor, but this is a label that *Oily Cart* rejects as a result of the feedback received from disabled people who feel it is not in line with the Social Model of Disability. For many disabled self-advocates, 'PMLD' is a term that medicalises in the sense that it portrays disability as a problem (or tragedy), localised in the individual's body or mind, that medical experts define and provide solutions for. And for Daryl Beeton, *"if you can be reduced to an acronym then there's something wrong"*. In the last three years, *Oily Cart* have consciously shifted towards using language in line with the Social Model of Disability,[2] which importantly came from, and has ownership by, the disabled community. Adopting the Social Model of Disability means recognising that the barriers disabled people face are created by society rather than by an individual's difference to the so-called 'norm'.

For *Space to Be* we tried out the term 'sensory beings' to describe our target audience, alongside the definition, 'A disabled young person who experiences the world in a sensory way'. 'Sensory being' is a term coined by Sensory Engagement Specialist Joanna Grace, and discussed in her 2018 book *Sensory-Being for Sensory Beings*. Grace's distinction between 'sensory beings' and 'linguistic beings' clarifies these significantly different ways of

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[2] For good reads on different models of disability, we recommend Nim Ralph's blog https://www.drakemusic.org/blog/nim-ralph/understanding-disability/ and Withers, A.J. (2012) Disability Politics & Theory

being in the world without rating one as deficit-based compared to the other. However, in our Researcher-in-Residence conversation with Joanna, she acknowledged that the term could be viewed as euphemistic because it avoids direct reference to cognitive capacity, which is a crucial aspect when it comes to suitable provision. This idea also came up in our critical conversation with parent Emma Murphy who commented on the non-specificity of the term 'sensory being':

> *"...it's not enough, because then I think some people think that, oh but my child has, for example, sensory processing difficulties so they're a sensory being, or they always love smelling things... but that's not the same because they are still processing the world with a level of language that Hugh and children like him can't and will never be able to do."*
>
> Emma Murphy

How to market *Space to Be* in a way that clearly identified, and therefore reached, the young people we had in mind was a challenge. As well as trying to ensure full access for cognitively disabled children, we wanted the show to be enjoyed by children whose physical movement is restricted. However, to use the word 'passive' in relation to these children seemed to invite negative associations of a lack of agency. It is rare for children like Khaled, and Emma's son Hugh, to have provision designed specifically for them – so how do we respectfully declare our interest in them as our primary audience? Clearly, we did not want to be asking parents who enquired about the show, "just how disabled is your child?" (and anyway we had no wish to exclude other groups of disabled children) but we did want to positively identify our primary audience for this show. We discussed this with Daryl Beeton:

LIGHT SHOW | CREDIT: SUZI CORKER

“

Jill: *I know in terms of arts provision, the recommended route is simply to really specify what the offering is [rather than the audience],...I get that, and I can see how that could potentially avoid all this labelling because then you're just saying this is what we're offering...but I did feel with Space to Be, well certainly I had a very particular type of audience in mind – and one of the things I'm really interested in is people who are particularly (apparently) passive, physically passive (and obviously we can't know beyond that) and 'passive' seems to be a difficult word as well, as if passive is not ok. And yet that to me was another...that just feels like something really important to clarify and recognise, because you would deliver and offer something very, very different – and to me that's the crucial bit that I'm interested in – than to someone who can very easily uptake an offering and move with it in their own way...*

▶

Daryl: *Yeah, yeah, yeah...*

Jill: *And I want to get at that bit and I don't want to shy away from it...*

Daryl: *But I think again it's always around the context in which it's used. But it's how do you celebrate passiveness? How do you sort of...not reclaim it or regenerate it...but actually place it within the context of... How do you turn that sort of passive reaction into a creative opportunity?*

Jill: *Absolutely, that's exactly the area I think we're in...*

Daryl: *And I think if it's framed within that, then the negative connotations of the word on its own 'passive' start to fall away.*

”

In line with Daryl's comments, our aim was to celebrate these children's unique way of being in the world by framing it as an invitation to others. As Matthews (2013:109) asserts, "Staying still, being apparently passive and allowing experience to come is a profoundly human activity" and with *Space to Be* we wanted this form of engagement to be central for all participants. To move from 'doing' to 'being' in this way is a significant shift, and one that may open up the possibility for a different kind of encounter. Nevertheless, our hesitancy around choice of language for marketing *Space to Be* prompted us to ask - why does it feel so uncomfortable to be explicit about the children the show was designed for? We also discussed this in our conversation with Joanna Grace:

> *"With cognitive impairment there's a sort of taboo isn't there? It's like the worst thing you could say or the worst thing you could be, is somebody who isn't cognitively able, so we almost...we shouldn't mention it...and I think that if it was accepted as a valid form of lived experience (because there is, totally, value in that experience)...I think the problem with it is the word impairment, isn't it? What you need is to replace that word impairment – which suggests that your experiences are 'lesser than' – you need a word that describes a type of cognition in relation to another type of cognition, so that you're saying that these are different but not giving them a rating."*
>
> Joanna Grace

It was clear that our dilemmas over language were reflecting prevailing prejudice and taboo around physical and cognitive disability. In addition to the issue of how we speak about cognitively disabled people, how we speak to them can also be a contentious issue. We introduced Khaled as someone who accesses and experiences the world non-linguistically. How then should we use and think about our own use of language when we want to connect with him?

TUBE | CREDIT: JACK TIZARD

The issue of 'presumed competence'

As practitioners working with children who experience the most barriers to access, we have to tread a difficult line at times. We know that children who express themselves in ways other than through verbal language may understand much more than they can show us. Within the education sector, an important distinction is sometimes made between profound and multiple learning disabilities (PMLD) and profound and multiple barriers to learning (PMBL). This distinction seeks to recognise what might be hugely differing cognitive capacities contained within similarly disabled bodies. In our work we may have no opportunity to discover the cognitive capacity of an audience member, and in these circumstances to 'presume competence' is often viewed as the most respectful approach to take. To presume competence means to assume linguistic understanding in people who do not use verbal language to communicate.

It could be said, however, that hidden within this approach is an assumed superiority of intellectual competence – we are trying to avoid the 'insult' of treating someone as if they have this stigmatized type of cognition. Parent Emma Murphy made this point about presumed competence:

> *"...and it's that presuming competence and a level of cognition and then that's so offensive in some ways because actually you're saying that that's the only important way of understanding – and it's not, it's not the only way of connecting...so presuming competence then really undermines his experiences of the world, which are just as valid, but different..."*
>
> Emma Murphy

LIGHT SHOW | CREDIT: SUZI CORKER

So for Emma, presuming competence with her son Hugh feels like disrespecting his non-linguistic way of being. Conversely, with *Space to Be*, one parent questioned our use of the term 'sensory being' on our marketing, protesting that her daughter was only ever given opportunities to access sensory activities because people made assumptions about her cognitive capacity based upon her physical disabilities. This mother felt that her daughter was being denied access to certain experiences because of other people's limited assumptions about her capabilities. So does being explicit about cognitive differences demonstrate increased levels of respect?

And how do we avoid a ‘them and us’ mentality? For Professor Melanie Nind it is really important that we make the community of individuals we are talking about clearly identifiable:

> *“I’m not sure about that assumption [that there is something wrong with the idea of ‘them and us’] because breaking it down...the danger in breaking it down, is that we none of us have a label and then in some ways we can’t talk about the people we mean and people become either invisible, or worse still actually erased. For me it would be less about getting rid of ‘them and us’ and more about ensuring the communications are respectful and that we’re self-critical when we use those terms."*
>
> Melanie Nind

Parent Emma Murphy agrees. She told us how it was initially very painful for her to accept the label ‘profound and multiple learning disabilities’ for her son Hugh, but now she is fiercely protective of the term as an important identifier for him:

> *“Now, I feel like it’s an appropriate description, and I feel like anything less than that almost belittles the challenges he faces. So if you say, if I just use the word, for example, 'disabled', that’s so huge nobody could possibly understand the level of cognitive impairment that he has. The cognitive and physical impairment is so significant that words like ‘disabled’ or even ‘differently-abled’ it really, really doesn’t...and I think – it’s not about pointing out all the things he can’t do, but if I don’t, then you won’t know how to adapt what you’re doing, or how you’re behaving to enable him to be able to access it. There’s no point going up and having a conversation with him and expecting him to understand everything you’re saying, but that doesn’t mean don’t have a conversation with him – it’s about changing your expectations of what his understanding is and taking time to interact with him in a slightly different way.”*
>
> Emma Murphy

So for Emma, being explicit about the nature of Hugh's access is really important. For *Space to Be* we chose the term 'sensory being' to identify this distinction between sensory and linguistic modes of access but our discussions continue in relation to finding terminology that is explicit enough to make the barriers this group face clear, without the adoption of a medical lens.

Disability as a social construct

There is no doubt that the Social Model of Disability has been (and remains) a fundamentally important development in relation to the empowerment and personal identities of disabled people. By identifying the disabling barriers that obstruct and oppress as the problem (rather than 'impaired' individuals who fall short of a norm), expectations and responsibility shift towards a society that fails to accommodate difference. To understand disability as a social construct unites many disabled people in a common cause against the social structures that exclude them – a political stance *Oily Cart* wholeheartedly supports.

However, as parents Samantha and Emma told us:

▶

> *"I haven't met a parent yet who either understands or really believes in the Social Model of Disability I'm afraid, because it kind of almost downplays the literal day-to-day challenges of having a severe disability or profound disability, which are numerous. It kind of washes that down, and so I think there's a tension there. The reality is it's the medical model we're living every day as a parent/carer."*
>
> Samantha Bowen

▶

> *"There are things that can be put in place I think, socially, that would make life easier, more accessible, but that won't make Hugh, or children like him any less disabled. Sometimes, with the Social Model of Disability I think it seems like it could be an easy fix, and it could be about making sure there's ramps and that doorways are widened and that everybody has an understanding of neurodivergence, but whilst things are improving (and I think people are certainly more aware of autism and neurological differences in that respect) I think when you meet a child like Hugh, who has such profound disabilities and medical needs as well, I don't really think any method of applying of the Social Model of Disability makes a real difference."*
>
> Emma Murphy

These comments illustrate the view that, for some, the Social Model of Disability plays down the impact of multiple medical conditions and barriers to access on daily life for some disabled people. In fact, many disability activists and supporters of the social model want to make it more nuanced for those whose bodies bring day-to-day challenges in addition to the oppression of societal barriers and prejudice, and more inclusive for those who cannot self-advocate. Disabled artist Miss Jacqui commented on how discussions around models of disability are often binary (i.e. medical v social) and do not consider other models, such as the radical model.[3] What we heard during our critical conversations illustrated some of the ways in which the views of disabled self-advocates can differ from the perspectives of parents of children with multiple barriers to access. For example, Jacqui was surprised to read Samantha and Emma's comments about the Social Model of Disabilityand made these comments in response:

> *"So I respect the parents who feel like that, because I'm not a parent, one, and I'm not in their situation, so to read that perspective really made me... check-in with myself and go – are you as open as you think you are? And I think that's really important that the text challenges us individually like how we use language and how we use terms and why we use them and what is the intention behind it...you come to a conversation with all of your life experiences that will shape why you feel a certain way about a certain thing."*
>
> Miss Jacqui

As well as differing perspectives on the relevance of the Social Model of Disability for our primary audience within our (admittedly very small) pool of conversation partners, potentially conflicting views were evidenced in other areas too. For example, disabled writer and performer Mandy Redvers-Rowe commented on how parenting relationships are complicated by issues of dependency and on-going care. She noted that the disabled child may not have the same opportunities for rebellion and self-determination as a non-disabled peer:

> *"...that thing for those young people, is they are trapped, if they don't get treated in the way they'd like to be by the people that care for them...that fight against their parents, which non-disabled kids have all the time (do you know what I mean?) becomes loaded with somebody who then has to take you to the toilet and put you to bed, you know, it's loaded and very emotional..."*
>
> Mandy Redvers-Rowe

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[3] For a good definition of this model see Withers, 2012.

Both Jacqui, and Mandy Redvers-Rowe cautioned against taking the views of supporting adults as fully representative of the young people they speak for, because the life experiences of each are so different:

> *"But I think it's important for adults who support young people to understand that they can't put their prejudices and how they feel about something on children and young people, and try to explore as much as they can what that means for each person..."*
>
> Miss Jacqui

For parent Emma Murphy, the issue is that if she doesn't speak up on behalf of her son Hugh, who will?:

> *"...self-advocacy is great and it's brilliant and it's brought about a lot of changes, but the people that get forgotten are the people that can't advocate for themselves. And sometimes parents are forced out of that discussion because it's not a parent's place to advocate for their child, but actually Hugh is never going to be able to advocate for himself and so the only person who can do that is me and parents like me."*
>
> Emma Murphy

We acknowledge the tension of our own position in discussing these differing views. As practitioners, we rely upon the knowledge of support partners and we respect their vital role as advocates for children like Khaled. Equally *Oily Cart* rely on and respect the perspectives of disabled artists and activists who are linguistic beings. In our work with the arts we want to try and find new, creative ways in which the agency and missing 'voices' of children with the greatest barriers to access to can be witnessed in their own right.

In this section we have discussed some of the issues around disability language and labelling in relation to marketing *Space to Be*, particularly the challenges around being explicit. We referred to the stigmatisation of the cognitively disabled and the issue of presumed competence. How do we demonstrate respect and achieve inclusivity in the light of these issues? We acknowledged the importance of the Social Model of Disabilityand represented the views of two parents who feel the model is not representative of their lives with their disabled children. The apparently opposing view of parents advocating for their disabled children compared to self-advocating disabled adults reminds us of the need to be open to all viewpoints, as well as to create opportunities whereby disabled children are seen and heard in their own right – an important role for the arts. We move on now to the next topic arising out of our Researcher-in-Residency discussions, the notion of personhood and agency in relation to children like Khaled.

PERSONHOOD AND AGENCY

> 'To be with Sesha is to enter her orbit, to gain a glimpse of the world as she constructs it...In one who can scarcely move a muscle, a glint in the eye at a strain of familiar music establishes her personhood.'
>
> (Kittay, 2001 in Vorhaus, 2006:319)

Personhood as defined in philosophy

As part of our Researcher-in-Residence conversations we discussed the notion of personhood as defined in philosophical debates regarding the moral status of cognitively disabled people – an upsetting and difficult area at times. Within this field, people like Khaled are viewed as not possessing the psychological qualities that warrant 'personhood' status, specifically those of self-awareness, self-determination and the capacity for reason, i.e. the qualities said to set people apart from non-human animals. Such a selective notion of personhood will likely seem both bizarre and offensive to most people reading this, who take it for granted that Khaled deserves the same status and respect as any other human being, regardless of any assumed lack of self-awareness, self-determination and capacity for reason. However, within the philosophical literature, the idea that individuals like Khaled lack personhood is a mainstream view, and this matters greatly because:

> '...philosophical views do trickle out from the academy and into society, through popular books, or because philosophers sit on ethical advisory panels...'
>
> (Curtis & Vehmas, 2021:187)

Definitions of personhood are also important because they have ramifications in terms of the rights, entitlements and treatment of people like Khaled, and because they affect the status and value given to certain lives. Sadly, these negative implications are evidenced in the shocking health inequalities widely experienced by people with learning disabilities, such as the blanket 'do not resuscitate' notices given to individuals who are learning disabled during the pandemic. As Simmons & Watson (2014:26) state, 'it is not unreasonable to suggest that the prejudice children and adults with PMLD face stems from the view that some are not identified as being people at all'. It is clear that if we want to overturn this disturbing status quo, then the link between personhood and human faculty needs to be severed, for as Reinders wisely states:

> ‘If human beings with profound intellectual disabilities are to be dignified, then the grounds of their dignity cannot be found in human agency’
>
> (Reinders, 2008:11)

Fortunately, there are people working hard within the field of philosophy to disrupt moral status debates and change this standard definition of personhood. The theoretical arguments they use are complex and beyond the scope of this piece of writing.[4] However, there are examples of research that seek to articulate the agency, and recognise the personhood, of individuals who communicate non-linguistically in a more practical way. To give just one example, educational researchers Simmons and Watson have developed an interpretive research methodology to demonstrate that ‘voice’ is not the same as ‘linguistic competence’ and Simmons carried out further empirical studies to highlight the contextual and reciprocal nature of embodied experience (Simmons and Watson, 2014:pp.26-27). By redefining the notion of voice and by calling attention to non-linguistic ways of being in the world, the life experiences of cognitively disabled individuals are afforded greater respect and deficit notions of personhood can be challenged.

Agency and meaning

Connected to the idea of personhood is that of agency. Khaled and children like him present a significant challenge to the commonly-held belief that personal agency (as traditionally understood), independence and progress are essential features of a worthwhile human life. These beliefs are often behind the continued use of charity/tragedy models of disability, and they can subtly trickle into funding applications and marketing for sensory shows. The best artists and organisations working in the theatre for young audiences’ sector have long focused on making shows that give greater agency to young people. But in the context of arts provision for children with the most barriers to access, this can lead to a focus on their actions and reactions and the demonstration of choice, which may not always be appropriate. In her Sensory Lexiconary training, Joanna Grace questions the practice of pursuing choice-making when individuals may not understand the options they are being offered. This can place unachievable demands on individuals whose modes of expression may be unique and hard to interpret, with the consequent risk that so-called choice-making becomes a process that (although well-meant) lacks any meaning for the disabled individual themselves.[5]

The idea of what is meaningful in relation to the lives of children like Khaled, also featured in our conversation with Professor Melanie Nind, who pointed out:

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[4] If you want to know more though, there is a good discussion in Curtis & Vehmas, 2021 pages 185 - 212

[5] We discuss ways in which we might rethink the concept of agency later when we consider the role of the supporting adult.

> *“I think there’s a lot of interrogation of that concept of ‘meaningful’ to be done if you really want to engage critically with that, because when it’s used in the literature it’s – we want to develop a meaningful life for people with disabilities, and what they mean by that is not a wasted life – but, well, how do you know it’s not wasted? And that really takes you off into productivity again instead of ‘being’, doesn’t it? And coming back to, you know, an evening in a pub with a friend (which we’ve all really missed), that’s meaningful, phatic communion – being with someone – but you don’t talk any sense, you don’t produce anything, its just socially being together and sharing and enjoying each other! So, that isn’t about a wasted time.”*
>
> Melanie Nind

That there can be meaning without any sense of productivity or action is important. One of the assumptions within my (Jill’s) PhD research was that if the supporting adult can shift their mindset from 'doing' to 'being' and become more in touch with an embodied sensory awareness in themselves, then they may be more likely to find an authentic (meaningful) connection with the cognitively disabled young person.

MIRROR MIRROR | CREDIT: NEAL HOUGHTON

Can we talk of shared experience in this context?

During our critical conversation with Professor John Vorhaus, we were interested to hear his analytical take on the idea of 'being together' and how we might judge its value:

> *"...So, you might think that being together is really precious, but only because it allows something else, like a bit of joy, or less disconnect, or something of that sort. Or you may think it's just valuable in itself. So that's one way to begin to think about – so why does it matter? Does it matter in itself or just because of other things that it brings about?*
>
> *And then there's also a moral question – I think Ellie you introduced the word equality a minute or two ago, and for some people there is a moral value to what you, your company, what Jill with Golden Tent etc. are trying to do, and the moral value has something to do with equality. That there is something about just being together that is equalising. I think it's quite difficult to work that idea out, but it's an interesting idea. That's not now to just look at the value but also the moral value of bringing people together. If one is to make sense of that, which I think is difficult actually, but if one is, I would come at it in the way I was suggesting earlier, by suggesting that what it can do, when you bring people together in the way that you might, is to suspend a lot that might otherwise be un-equalising, or discriminatory or disadvantaging – the hierarchy of power or status or seniority and all that. And there is a way of suspending it all, and once suspended you have a more equalising encounter."*
>
> John Vorhaus

Indeed, all of these motivations can be evidenced in the team's thinking and discussion around the creation of *Space to Be*. We wanted families to experience the intrinsic and instrumental value of simply 'being' together – particularly during the extreme circumstances of the Covid lockdown – but the idea of creating a 'more equalising encounter', which John articulates as a separate moral goal, was also a big part of this. Parent Emma Murphy appeared to be speaking about this sense of equity within a shared experience with her son Hugh when she reported on the Day 2 speaker pillow and blanket experience - *"It was just like this really intense sharing of an experience..."* (see full quote on page 11 above).

John Vorhaus also questioned us on what we meant by the idea of shared experience in relation to a pair (or group) of individuals who have very different ways of processing the world. His challenging questions really made us think about the value and purpose of our work. From a philosophical perspective John was asking – what needs to be true for us to declare that an experience has been mutual in this context? Does there need to be an awareness of each other? An awareness of the same stimuli? What about if you are responding to the same stimuli but are unaware of the other person? Or if you are aware of the presence of another person, but not as someone specific? When the idea of shared or mutual experience is an important tenet in your work, these questions are challenging to answer, especially given that we may not know for sure what awareness our audience members have. This brings us back to our earlier point about the risks of overstating the impact of our work given its complexities – we need to always be cautious and conscious of how we are interpreting what we witness.

What about beauty and aesthetic experience?

We also spoke with John about concepts such as beauty, awe, and 'aesthetic' or 'elevated experience', discussing whether these are appropriate ideas to bring to our work. What do we mean by these words in this context? Do the notions of beauty and aesthetic experience pre-suppose some level of conceptual understanding? It was valuable (and challenging!) to make space for doubts and questions around what type of experience we believed we were offering our audiences with the most barriers to access. One of the important premises of our own understanding is that aesthetic experience is something that primarily happens at an 'affective' level. The notion of 'affect' is drawn here from the field of psychology and refers to feelings or instinctual reactions occurring before more complex and identifiable emotions that can be linguistically articulated (Goodwin, 2020a).

There have been some exciting developments in the field of neuroscience recently that support and affirm our faith in the value of aesthetic experience in terms of affect. Neuropsychologist Mark Solms has been able to evidence that even a child born without a cerebral cortex, for example a child with hydranencephaly (where the cranium is filled with cerebrospinal fluid instead of brain tissue) is emotionally conscious and has a rich affective life (Solms, 2021). Although these children are unable to report on their experience (because language is a cortical function) they clearly display a range of situationally appropriate emotional responses. Many of us instinctively know this from our contact with cognitively disabled individuals, but it is exciting to have our instincts validated by these scientific developments. What Solms (2022) has been able to establish is that affective consciousness is fundamental to all human beings and as sentient beings we are constituted by feeling.

SPACE TO BE | CREDIT: IMAGE SUPPLIED BY FAMILIES

Good sensory theatre works directly with affect, and we (Ellie and Jill) have both witnessed examples of children with the most barriers to access appearing to respond deeply to an aesthetic experience. The affective lives of cognitively disabled individuals – potentially rich lives they cannot report on – deserve recognition. This is an important premise in the face of developmental deficit models that can abound in relation to people who are learning disabled ("he's like a two year old"). In a recent obituary, Peter Gordon wrote these words about his son Robbie:

> 'He could not communicate with us, but he could express in his face and his eyes quite complex emotions – expressions apparently beyond his cognitive abilities.'
>
> Peter Gordon (2022)

The idea that non-linguistic individuals can have a rich affective life underscores our commitment to sensory theatre and is behind our efforts to extend inclusive practice into new areas. The late Sir Ken Robinson defines aesthetic experience as one in which your senses are operating at their peak, you are present in the current moment and you are 'resonating with the excitement of this thing you are experiencing' (Robinson, 2010: online). Similarly O'Sullivan (2001) describes the transformational power of art as lying in this very ability to provoke embodied moments of intensity, moments that occur on a different plane from linguistic understanding. 'Art is less involved in making sense of the world and more involved in exploring the possibilities of being, of becoming, in the world' (O'Sullivan 2001:130). O'Sullivan warns that if we persist in filtering and summarising our experiences of art through words, we run the risk of only ever seeing what we already know. He advises us to switch to a different register by becoming physically still and adopting a more meditative state in the presence of art in order to experience its affect. By describing aesthetic experience as something primarily embodied rather than conceptual, Robinson (2010) and O'Sullivan (2001) uphold a fundamentally inclusive definition of the arts, one that is as available to Khaled as to anyone else. This is important, and has bearing on how we approach, view and understand the work we make with and for audiences who have different ways of processing, or multiple barriers to access.

In children's theatre, there is a dominant notion that only pre-verbal children go to sensory shows and as soon as they understand and master language they should be given increasingly verbal content. This is in line with an intellectual, text-based UK theatre tradition where the works of Shakespeare are commonly accepted as top of the hierarchy. From this perspective, sensory theatre gets viewed as an adapted or diluted version of more 'sophisticated' (i.e. language-based) artwork that is made purely with the accessibility of disabled audiences in mind. However, for *Oily Cart* sensory theatre is about a stripping back to what is most deeply human, what is shared, and what connects us to our embodied sensory selves (which are so often shut down in modern life). Good sensory theatre tries to get directly to the essence of aesthetic experience, its affect, which is challenging work. The creation of emotionally-intense aesthetic spaces that disabled and non-disabled audiences can authentically share without compromise is an exciting goal and one which passionately drives *Oily Cart's* vision.

We began this section by discussing the definition of personhood as understood within philosophical debates about moral status, which is important because this deficit-based definition affects the rights and treatment of cognitively disabled individuals within society. We noted that some researchers are seeking alternative definitions of personhood and also that we need to be careful when we talk about meaning and choice in the context of cognitively disabled individuals. We offered a fundamentally inclusive definition of aesthetic experience (that can be backed up by neuroscience) and got excited about what this means for sensory theatre. We move on now to our final key theme, the role of the supporting adult.

MIRROR MIRROR | CREDIT: NEAL HOUGHTON

THE ROLE OF THE SUPPORTING ADULT

The role of the supporting adult, and their importance (and influence) as audience members, was a frequent topic of conversation in early discussions between us (Jill and Ellie) long before the creation of the *Space to Be* project. Jill's focus on the mindset of support staff in her PhD study had particularly interested Ellie who was keen to create experiences that offered artistic equity for the child and their supporting partner. We appreciate it can be hard for support partners to know what is expected of them as audience members and it is not uncommon to come across reluctant/disinterested/embarrassed partners, or those who try to control or interrupt the young person's responses. Nevertheless, we are reliant upon support partners to gauge and interpret the responses of the disabled audiences we work with and to ensure their wellbeing, so we want them to carry out their role in an open-minded, curious way and hopefully to have a positive experience. With *Space to Be* our goal was to invite parents to tap into an embodied sensory presence alongside their disabled child in order to share the experiences together.

Sensory wellbeing (for all)

The nature of our discussions about the supporting adult role changed significantly during the first Covid-19 lockdown in March 2020 when it became clear that *Space to Be* needed to be a show that could take place inside the family home during a time of extreme isolation, anxiety, and stress. In the absence of live performers we had to invite parents to become the show's facilitator and audience member alongside their child – at a time when many were emotionally stretched to their limits. The ideas we had been discussing about how to create equitable spaces where linguistic beings are more connected with their embodied senses felt even more pertinent at this time when people were instinctively turning to nature and the outdoors, and/or to music, baking, crafts and hobbies, etc. to help manage the stress and uncertainty of the pandemic. The restorative effects of simply 'being' in nature and the value of sensory occupations were being widely acknowledged and reported during lockdown. Indeed, without this endorsement it might have been hard to justify this 'at home' show if the offering could be perceived as simply another set of tasks being added to a parent's heavy workload.

In her investigation into the carer's role in sensory theatre during the pandemic, theatre and performance researcher Alison Mahoney identified *Oily Cart*'s approach as a reframing of the facilitator's role in order to emphasise '...finding a sense of joy, play, or well-being in the act of facilitation' (Mahoney, 2021). Creating a show during the exceptional circumstances of the pandemic definitely expanded our interest in the role of the supporting adult in ways that *Oily Cart* hope to build upon in the future. Mahoney articulates the potential of this shift:

> 'The genre's renewed focus on the carer's role can and should extend forward into post pandemic sensory theatre, pushing the field to embrace the full range of experiences within a neurodiverse audience and giving carers a seat alongside those for whom they care.'
>
> Mahoney, (2021)

The drive for recognisable responses

We talked previously about the importance of challenging ableism and rethinking ideas of agency. In this section we want to dig a bit deeper into what this might mean – and at times here we are thinking of the performer as a supporting adult as well as the parent or carer. We have acknowledged that it can feel challenging to know *how* to be with someone like Khaled, whose body is still, whose language is wordless, and who may not visibly respond when we try to engage with them. In her (educational) research, Jean Ware (2003) noted that one-sided interactions are inevitably less enjoyable for the active partner, and as a result caregivers tend to initiate fewer of them. Ware also found that when school staff did initiate an interaction with a disabled child, it was often characterised by a more dominant and directive style than their interactions with non-disabled children. Meeting apparent passivity can sometimes compel us to increase our efforts to engage the disabled child by becoming louder, 'bigger' and more active. We (Ellie and Jill) have both been party to objects being vigorously shaken next to ears, or waved in front of faces, in an attempt to provoke a visible response. On these uncomfortable occasions, we fear the drive to elicit a reaction has overtaken respect for the person. We must always stay alert to such disproportionate intent and energy in situations where the power relations are so very unequal.

Even with a more sensitive approach, meeting passivity in another can feel really confronting – if we 'reach out' and receive no apparent response, it is easy to be left feeling uncertain about what to 'do' next. I (Jill) noticed how, particularly in group situations, this sometimes led me to deflect attention away from the encounter, rather than stay emotionally present and curious about what was happening for the person I was reaching out to.[6] I (Ellie) noticed how I would sometimes 'chase' the moments where I received a response to my offer – performers are often 'hungry' for this type of feedback and try to activate a response from an audience member to validate their work or their sense of self. When performing for or working with groups of disabled young people like Khaled it is easy to feel a sense of pressure to elicit visible or recognisable responses from them. And when observers, funders, evaluators are witnessing what we do – how else can they gauge its value? Audience response is the evaluative currency of the work.

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[6] See Jill's poem 'On Sitting Tight' (Goodwin, 2020b:61-62) on this topic

In the context of audiences that include children like Khaled, it is useful, therefore, to question and reconsider the notion of audience response. This may involve artists and performers 'de-investing' in the recognisable reactions they have come to expect from a neurotypical audience. Is it right, for example, to maintain the ritual of bowing to an audience if they are unable to actively applaud – or does this just put both parties in a potentially negative situation where performers may feel disappointed, and audiences that they have disappointed? Working in this context involves thinking through many of the specific cultural rituals we use to signal what theatre is from the perspective of the disabled audience member (Gill Brigg [2013] discusses this in her doctoral study).

Recalibrating our measures of success

To be clear, we are not suggesting that the active engagement of audiences is not a worthwhile aim. Neither are we suggesting that the idea of (respectfully) enlivening an audience member by sharing our more lively energy is not a good idea – on occasions this can be really important for children who have withdrawn into themselves. But we need to think carefully about how we approach this in relation to children like Khaled who may require particular conditions or extended periods of time to be able to demonstrate any visible response. For some children, prolonged periods of whole body listening on *our* part may be required before we are able to attune to someone's reactions – and even with the right conditions we still may not know how to interpret the responses we see. If we are to judge success only by visible responses then we are placing both performers and audience in a pressured situation. Jill's central provocation to the work of *Oily Cart* throughout her residency was that we should therefore learn to become more comfortable with passivity and stillness in order that new spaces of possibility might open up - spaces where the start (and possibly the end) point for mutually meaningful experiences is found in simply 'being' together.

LIGHT SHOW | CREDIT: SUZI CORKER

Spending time with the type of audience we have been discussing in this report brings a unique invitation to not just physically slow down, but also to try and enter the world of now. As linguistic beings, our lived sensorial experience has been subsumed into a symbolic language system. Children like Khaled offer us a unique invitation to (re-)explore being in the world pre-reflectively, without abstracting and classifying our experience through language. If we can learn to welcome passivity as an invitation for us to temporarily experience a different way of being, then perhaps we can recalibrate our measures of success. Could 'success' in this context be more about the impact we allow a child like Khaled to have upon *us* – i.e. *our* ability to accept the invitation to be still and present alongside them. This feels a potentially powerful way to recognise and redefine agency for children whose lives are spent accepting interventions of one sort or another from those around them.

Educationalist Mercieca (2008) describes the moments when, as linguistic beings, we allow ourselves to enter the space created by sensory beings as times when we lose our certainty, our reliance on language, and recognise our own inadequacy. He says that to appreciate this is to recognise and embrace the intense spaces offered by the disabled child as opportunities for ‘becoming’:

> ‘...students with PMLD provide us with opportunities that show us, or better still make us experience, a lack in our own thinking; a deficiency in our thinking and living. But at the same time they offer us a possibility to fill this lack, to live beyond what we are living now.'
>
> Mercieca (2008:6)

In this sense, the agency of these children is not neutral, ‘It hits us practitioners and professionals at the heart of our identity’ (Mercieca, 2008:7) which he suggests forces us to ‘be’ creatively. If we can learn to reframe our discomfort around passivity, then we can begin to see it as a threshold inviting us towards these spaces of possibility. Relinquishing our reliance on language may also make space for us to witness the disabled child’s whole being without filtering what we see through a raft of pre-conceptions and projections.

In his book, *The Power of the Powerless*, Christoper De Vinck writes movingly about the influence his disabled brother had on the family. He asserts, ‘Oliver could do nothing except breathe, sleep and eat. Yet he was responsible for action, love, courage, insight.’ (De Vinck, 1990:31). From our experience of listening to various parents talk about their lives with their disabled children, it is clear that many have made this shift and are able to speak very positively about how their own perspectives and outlook on life have expanded as a result. We do not wish to adopt a romanticised or sentimental view here, we simply want to put forward the idea that a shift in how we think about agency can offer us a very different understanding of children like Khaled. Judging by the feedback we received for *Space to Be*, which was so emotional and moving, it seems that the show tapped into something at the heart of many families – the profound effect their disabled child has on their family constellation and on each other.

In this section we focused on the role of the supporting adult, an important but complex one in the context of sensory theatre. We explained how the Covid-19 pandemic brought a new relevance to our interest in embodied, sensory experience of the supporting adult. We then thought about some of the difficulties performers face when audiences do not respond in particular ways and about some of the expectations and rituals of theatre. We further discussed the idea of agency in relation to an apparently passive child, but this time we flipped the notion to consider the impact that we allow them to have upon us. Making this shift enables us to recalibrate our measures of success and our understandings of agency. We ended this section by acknowledging that many families have already made these kind of paradigm shifts.

FINAL NOTES

Final Note from Jill Goodwin

It has been an honour to undertake the role of Researcher-in-Residence with *Oily Cart* and I have been impressed by how keen Ellie has been to explore different theoretical perspectives, dig deep into ideas and be challenged by opposing viewpoints. I feel privileged to have been connected with *Oily Cart* during a time of intense change (although sad that Covid-19 has stopped this connection being face-to-face). The company have led me into new areas through their rigorous commitment to inclusion and diversity and I have felt both challenged and supported along the way. It is really exciting to witness the impact of this commitment on their own practices and the way the company continue to be pioneers in the sensory theatre sector.

Final Note from Ellie Griffiths

Having space to pause, reflect and dig deeper has been really precious. This piece of writing represents where *Oily Cart* is at now and how we view our creative challenges moving forwards. Our mission has always been to celebrate different ways of being in the world through the theatre we make. But what does it mean to commit to this in a radical way? Where there really is no hierarchy of response? Maybe only then can we create experiences that are truly shared. Working on this project with Jill has been a real pleasure. I am in awe of her integrity and rigour. In an arts landscape where we are under pressure to 'get it right' all the time (and shout about it!), these chances to acknowledge and unpick the aspects you find challenging or continue to get wrong are necessary and invaluable.

On behalf of *Oily Cart*, I would like to whole heartedly thank Jill and the contributors (including the young people we work for and with), for being part of our our first Researcher Residency and *Oily Cart's* continuing journey towards making theatre that ALL children can enjoy. The impact of these conversations and learnings will be present in in the work we make for many years to come.

**Oily Cart* has committed to having a Researcher-in-Residence every three years as an integrated part of their Artistic programme. We would like to thank Dr Jill Goodwin for her incredible work with us over the last two years. We would also like to extend the invitation to those working in a related research field who would be interested in this opportunity in future.

For more details please get in touch with us hello@oilycart.org.uk.

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