‘Being With’ in Sensory Theatre

Written by Dr Jill Goodwin and Ellie Griffiths

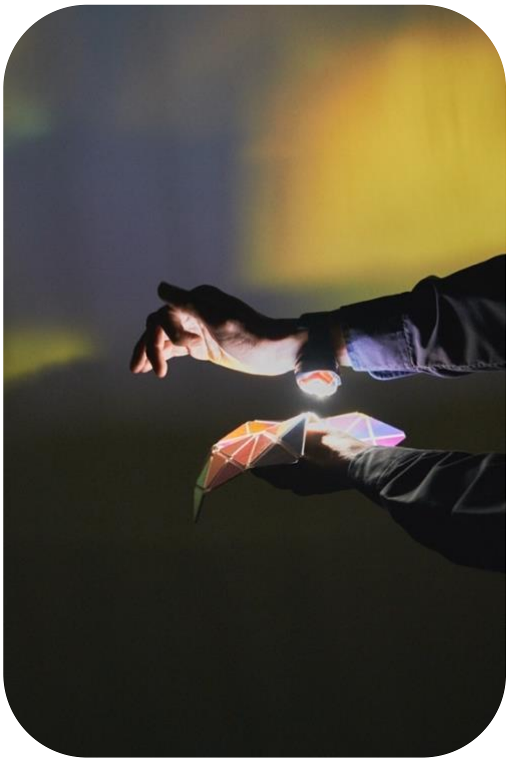
Easy Read Version

Oily Cart
(name of theatre company)

What you will find inside

Introduction

This report is about the main things Jill and Ellie were questioning and talking about when Jill was Researcher-in-Residence with *Oily Cart* (from 2020 – 2022).



We hope it will be of use to anyone working creatively with disabled children.

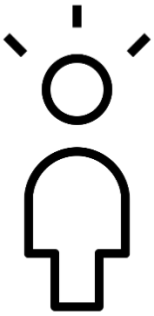
It does not feel good to write about disabled children who can’t tell us their thoughts in a way we understand. But we have written this report because we want to make sensory theatre better and more inclusive.

About the Writers:

Dr Jill Goodwin is a researcher and an artist who used to be a teacher in a specialist school.

Ellie Griffiths is a Director of *Oily Cart*, a sensory theatre company that make shows for disabled children.

This is Jill's *Golden Tent*, an art piece that she made for disabled children and their teachers to go inside and just 'be' together. Although Jill made the tent before working with *Oily Cart* we carried on thinking about some of her ideas while she was Researcher-in- Residence.



Oily Cart made Jill their Researcher-in-Residence so they could discuss some difficult questions. We mainly talked about making shows for disabled children who connect with others without using or understanding words.

The residency had two parts:

- A creative part (which led to a new show, *Space to Be).*

- A talking part where Ellie and Jill spoke to different people to get their thoughts on the difficult questions.

Space to Be

Space to Be was a show without any actors that was posted to the homes of families who were shielding their disabled child during the covid lockdowns.

The families were sent 5 boxes with music and sensory things inside. They opened one each day.

The show was designed so that people with different ways of being in the world could share an enjoyable creative experience. We wanted the family to join their disabled child in 'being' rather than 'doing'.

“…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”

Samantha Bowen, parent to Lucy

“…like we were both experiencing this in exactly the same way and getting the same level of enjoyment out of it…”

Emma Murphy, parent to Hugh

Here you can watch a video to see the reactions of some of families who took part.

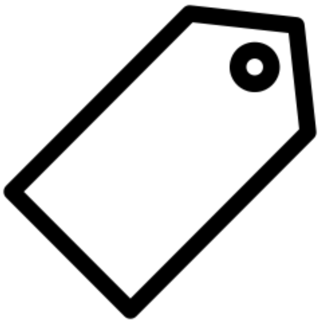
Conversations

Oily Cart want to improve their work by learning from people who have different points of view.

During Jill’s residency, there were three things we talked about a lot. They were:

- **Language and labelling**
- **What makes a person?**
- **The supporting adult**

Language and labelling



Oily Cart think hard about what words they should use when they write and talk about the young people they work with. They don’t want to use language that upsets disabled people or limits their potential.

But it is not always clear which words are the most respectful or appropriate when we want to identify people.

It is always better to ask disabled people themselves how they wish to be described.

Presuming competence

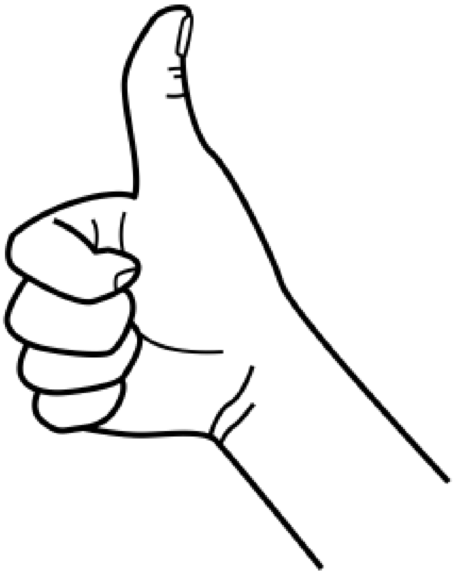
When a disabled child does not speak, presuming competence means talking to them as if they understand everything you are saying to them. You are presuming they can understand spoken language.

Some say this is respectful because you are respecting their understanding even though they do not answer. But if someone does not understand your words, is it still respectful to talk to them as if they do?

Some say that hidden within this approach is the idea that people who understand words are better than those who do not.

The social model of disability

The social model of disability says that people are disabled by all the barriers in the world that exclude them. These disabling barriers are a problem and not the disabled person themselves.



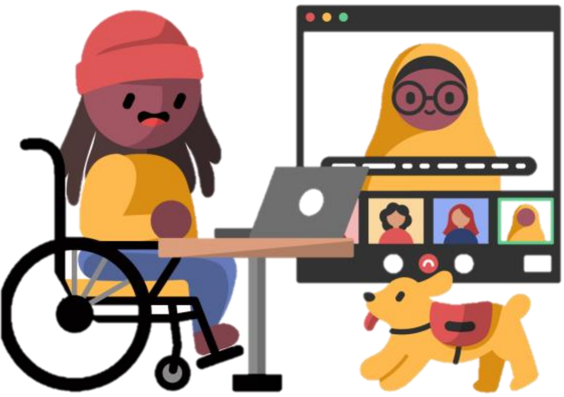
Disabled people came up with the social model of disability. It is an important way of thinking that *Oily Cart* follow.

In our conversations, some parents of disabled children said that the social model of disability did not match their family’s experience:

> *“ because it kind of almost downplays the literal day-to-day challenges of having a severe disability or profound disability, which are numerous.”*
>
> Samantha Bowen

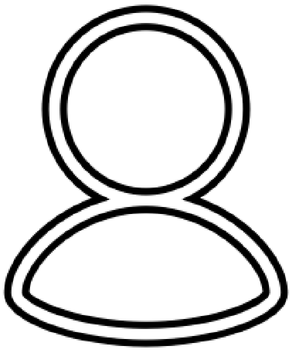
The views of the disabled individuals we spoke to were different to the views of parents.

These different points of view remind us of the need to listen to parents, families and disabled individuals so everyone is being listened to and understood.



What we really want to do is to create opportunities for disabled children who do not communicate with words, to be seen and heard in their own right. We think the arts (like sensory shows) can help to give them a different kind of voice.

What makes a person?

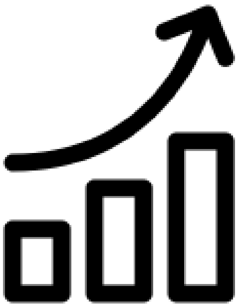


We looked at what philosophers (people who think deeply about people and the world) say about being a person. Some philosophers say that to be a person you have to be aware of yourself, be able to make choices and to understand things.

This view affects the rights and treatment of disabled people, especially those who do not talk. For example, during covid the UK government made a law that disabled people would not be saved if they were very close to dying from covid. Here is a link to an article about this: LINK

Warning, this could be upsetting to read

Luckily, there are other philosophers and researchers who don't agree with this view. They want to find different ways to understand what it means to be a person.



Lots of people think that making choices, doing things without help and making progress is what makes life worth living. We think you can have a good life without these things.

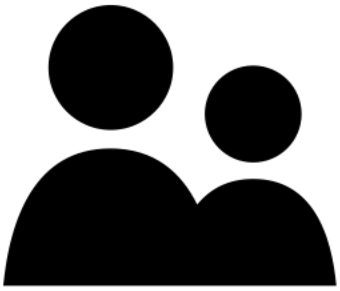
Lots of good artists and companies who make shows think that giving children choices is a good way to show their respect for children.

But in Sensory Theatre, this can lead to focusing on the disabled child’s actions and reactions. If we do this we might pay more attention to the children who can move and react a lot, which is not very fair.

For *Oily Cart* sensory theatre is about finding what is most deeply human, what we all have in common and can share. Connecting with our senses helps us all do this.

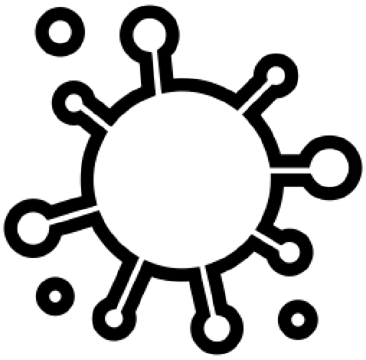
Oily Cart wants to create emotional, beautiful spaces that disabled and non-disabled audiences can really enjoy together in different ways.

The Supporting Adult



The adults that support the disabled children when they come to Oily Cart shows or workshops have an important but complicated job.

It can be hard for supporting adults to know what is expected of them.



The Covid-19 pandemic meant that our audiences were at home a lot more. It was a distressing and lonely time for many parents and families.

With the show *Space to Be* we tried to find ways to help the parents come into a sensory headspace so that they could share and enjoy the experiences with their children. We wanted to help them relax and be more aware of their bodies so they could enjoy sensory experiences.

The first package in the show was just for the parent/s. It had an eye mask, headphones to listen to a soundtrack and a sculpture to hold and feel. Lots of parents told us they liked this:

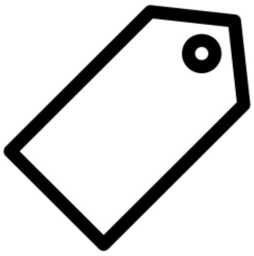
"...I want to thank you for thinking about the carer first..."

Samantha Bowen, parent to Lucy

Seeking reactions

When a person we are trying to connect with does not react in the way we expect, it can feel uncomfortable. Sometimes it is tempting to get louder and move around more to try and get a reaction from them.

But maybe it is better to be still and present alongside them? Perhaps this will open up new possibilities? This way we can feel the impact they have on us.



Also, if we stop relying on words then maybe we can be with the disabled child exactly as they are without any ideas and judgements about them.

Many families have already made these kind of shifts in how they see their disabled child. They love and value them exactly the way they are.

In his book, *The Power of the Powerless,* Christoper De Vinck writes about the impact his disabled brother had on the family:

‘Oliver could do nothing except breathe, sleep and eat. Yet he was responsible for action, love, courage, insight.’

What Have We Learnt?

We have learnt a lot during Jill's time with Oily Cart but we did not find easy answers to our questions!

With the creative part that led to ‘Space to Be’ we learnt that:

- Many families liked having a show in their home because it is so hard for them to get to the theatre.
- Many families liked being able to use the Space to Be packages when the time was right for them.
- Parents liked being given a sensory experience just for them.
- The family’s favourite sensory experiences brought them together in a special way.

With the talking part and our conversations we learnt that:

- People have very different opinions about the best words to use about disability and the best ways to do things.
- We need to keep listening to lots of different people, especially disabled people themselves.
- We need to keep trying to find other ways for children who do not use words to express themselves. We think the arts can give them a different kind of voice that we can hear.
- It can be good to be still alongside people who do not react or move very much and that we can think about their stillness in positive ways.