PERCEPTIONS OF DISABILITY AND INCLUSIVE PRACTICE
A REPORT FROM MAKING ROUTES

SLG
BATTERSEA ARTS CENTRE
MAKING ROUTES
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Perceptions of disability and inclusive practice in Making Routes

The following pages represent what happened and what was discussed during three creative evaluation sessions held at Oasis Play, South London Gallery and Battersea Arts Centre during Making Routes, funded by Spirit 2012. The aim of these sessions was to create a relaxed, informal environment to have frank conversations about disability with staff, artists and participants.

These sessions took the form of ‘Puffing and Wooling’ performances – led by artist Tilley Millburn and her friend Del the pig, alongside collaborator Catherine Dunne. Puffing and Wooling is a practice developed by Tilley that can be carried out at home or in public venues. Participants are encouraged to wear socks or slippers and snuggle up with blankets, pillows and soft toys. For Making Routes Tilley and Catherine would arrange candles and comfy materials and play a calming soundscape featuring guinea pig noises. They read lullabies, told funny stories and guided participants in the art of Puffing and Wooling by leading mindfulness-type exercises.

Throughout the programme these special environments also became spaces in which to introduce questions about people’s personal experiences of disability, societal attitudes and organisational barriers for instance. Tilley and Catherine also devised activities for pairs or small groups to promote conversation between people from different organisations.

This document captures some of this conversation and provides some analysis around what was learned through the process.

CREATIVE EVALUATION

MAKING ROUTES

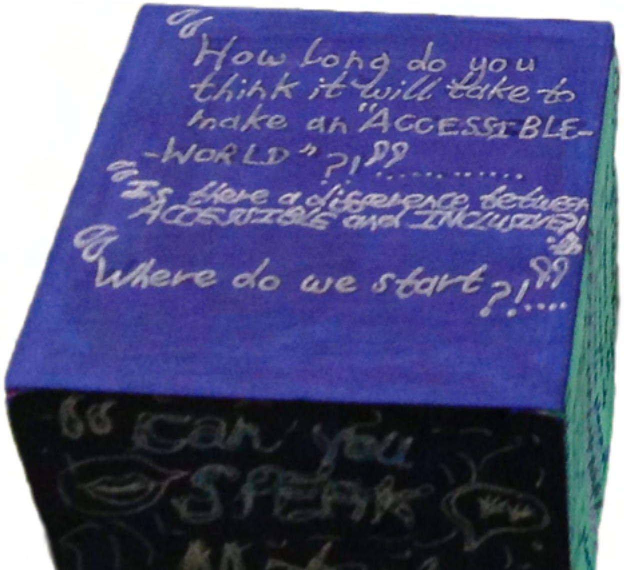
WHAT? A day of relaxed chat, games and "Puffing and Wooling" with Tilley, Del and Catherine – exploring ideas around disability, inclusivity and accessibility…

WHO? Staff from Oasis Play, Battersea Arts Centre, South London Gallery and Heart n Soul

WHERE & WHEN? Oasis Play, 7 February 2017

WHY? To capture attitudes and reflections and share organisational approaches to inform Making Routes

Speed dating!



Puffing and Wooling

"Make yourself comfortable"

"We're going to start with a bit of relaxation and meditation"

"Will everyone close their eyes + take 3 deep breaths…"

"Listen to the hush in this space. Feel it consume all your worries…"

"In the art of
Puffing and
Wooling we can
create our own
sanctuaries…"

"Swap your
rushing for
healing "

"Let yourselves
unwind and
appreciate a
clearer and
healthier state
of mind "

Earliest memories of disability

"Did you ever get a moment when it hit you that someone was quite different, and maybe in a way that you hadn't really noticed before?"

My uncle Roland had Down's Syndrome. He lived to a good age… but most of his life he was in an institution of some kind… I remember he loved music - he went around the world and went on cruises… He had quite a good life in many ways and had such a sense of humour, he was very gentle.

I had an uncle as well - my dad's brother, he was the youngest of 8 and he had Down's Syndrome. He was born in the early 60s in Ireland. There was a lot of stigma around disability in Ireland at the time… the thing I remember my dad saying was he was never told that he had a disability. At the time disability wasn't a word that was used. And yeah I think when I was at school there was nobody at school who was disabled, which was a shame.

I wasn't diagnosed with Asperger's until I was nearly 20. The ridiculous thing was I used to be in a separate group and be put on a separate table - it was if you were a bit thick I suppose - it was if you were behind with English and reading, but I was actually advanced… So I disagree with some of the things that were done.

At primary school my best friend was Deaf. And I thought it was the coolest thing in the world. And he taught me sign language. So I would talk to him throughout the whole class and nobody knew what we were saying… I thought he had a superpower. It was something that was so fun between me and him that he was Deaf, then it gave me a life skill.

I've got two siblings who've both got disabilities - my brother has cerebral palsy and my sister's autistic. I've always been around people with disabilities, never really noticed that there's any difference…Because of them, being with them at their schools and places like Oasis and other centres for disabled people, it's just always been a huge part of my life. I feel very comfortable around disabled people because it's literally just been part of me for 30 years.

I also have an uncle who has some sort of neurological disorder - he's non-verbal and he is a wheelchair user... My first memory of understanding that there was something different about him was going to visit him and asking him "do you remember last time we came and watched this film?" And obviously he didn't say anything back to me. And I remember thinking - why is he not remembering this thing that we shared together? And my mum having to explain to me - he probably does remember but he can't speak to you about it. And I remember being really troubled by that - if he can't speak to anybody about anything how does anyone know what he's thinking?

Perceptions, languages and attitudes

"Do you think anything can be improved?"

To some extent the language and the way people are perceived has changed a hell of a lot in many ways for the good. But then if you think about it, in some other ways we've also gone backwards maybe.

I remember when I first joined Heart and Soul the approach was 'no jargon and no judgement' - and I think that's really stuck with me in my life.

I grew up in a time when there was a lot of discrimination around disability. I remember going to school and the phrases that were used were always very derogatory about people who had additional needs. So I actually think we've moved so far from when I was at school that I'm actually quite impressed… I think now there's more recognition around mental health and the traumas that people suffer without it being visible.

Working at Oasis I think that so many cultures have changed now, especially with young people, like here they are cultured into understanding and supporting disability, which is totally different from when I was their age. And I see it every day how supportive, how caring, how compassionate young people can be, and how understanding they can be around children with disability. So I'm just so impressed with where we are now as a society. Obviously we regress sometimes but I think that it's fantastic where we are in terms of understanding and support and awareness.

Labelling – help or hindrance?

My grandmother, I didn't really know this at the time but she was diagnosed - it would have been called manic depression in the 60s, it would be called bi-polar now. And I basically grew up with her always in her bed... And as far as I was concerned she always had time for me - she would always read to me, she was always there. And I never really thought there was anything wrong with her apart from she had this draw that was full of pills…And in a way her not being labelled was very helpful because she was just my gran and she was always there. And in a strange way I think it subtly has affected Heart n Soul starting because there was no judgement and there were no labels.

My sister who's 27 now only a few years ago self diagnosed and then got a proper diagnosis of dyspraxia… And thinking back what's really interesting in terms of one my earliest memories - I'm retrospectively re-subscribing experiences from when she was a baby… The differences in us in childhood, the struggles that my mum had with her…a lot of the things looking back are to do with her not having any support or not having that disability diagnosed.

I think there's a danger that we put people into boxes but sometimes it can be helpful… It's more about things that we can provide for people. So maybe it's more important to say - this is me and this is what I need to be able to do something.

The terminology changes so rapidly and I think a lot of the terminology that was used many years ago was very negative, but I think still today people are very scared of saying the wrong thing. I've worked with artists who are very much about - I'm an artist and I would define myself as having a disability - and I've worked with other artists for example who might have a disability but don't want to be associated at all with a disability.

it's not as though I don't associate myself as disabled. I do quite often use that term or I talk about the autism or Asperger’s. So I wouldn't say that I'm exactly shying away from that. But at the same time I recognise that it's maybe not necessarily the most positive word to use. If you just look at the English language and if you put “dis” in front of anything… it's a negative. So if you say disabled it's like you're saying that that person is not able. But to say that that person is not able is a very narrow way of viewing someone, and describing someone. But at the same time I recognise if I don't have my diagnosis I don't get the benefits. I don't want to be on the benefits but I can't earn any money from what I do at the moment so I need my benefits.

I think most people are not necessarily ashamed of their condition but they just don't want to be defined by it.

Are there any alternative words being used at the moment that explain somebody's condition other than the term “disabled?”

A lot of people are using the term neurodiverse at the moment. So for people who have neurological conditions - but also trying to open up that whole conversation around different neurology in a similar space to the discussion around autism - understanding neurological conditions on a spectrum.

The other side of that is if you're not neurodiverse then you're neurotypical. It is interesting to be given a label - how does it feel? I'm neurotypical apparently! But labels are just words at the end of the day and they shouldn't get in the way of our humanity I think. We can get very hung up on words and they can prevent action.

I definitely think my diagnosis was useful from the point of view of my parents - particularly my mum. We did have quite an emotional time when I was going through the diagnosis, and then finding I got the diagnosis officially - we cried together. It was a grieving process - I realised that I hadn't changed as a person, I hadn't died and been born again, but it felt as though I had in a way because you're suddenly seeing me now - I've got this diagnosis, so now certain things are becoming clear, the way I do things and why. It's all becoming clear the struggles that we had. And my mum felt bad. She actually always suspected that there was something actually... So it was the sudden realisation that there was a reason and that my mum should have got the support.

My dad died 16 years ago but I think back to some of the behaviours that he exhibited and I think that he was bipolar. He never got diagnosed. But I could sort of understand because I'm aware of the different ways that people are, it helps me understand who he was to think of him through that filter. And I think if any of these things actually help us understand each other better, or get the support that we need to be fully here… and we're all different. So if it's mechanisms to help us understand that we're all different and how we can all be together better than that's got to be good.

You might be more compassionate if you're a little bit more aware that somebody has a condition - you might be more sensitive, whereas you might have been judgemental initially. As far as I see it everyone has disabilities… So the challenge is to move forward and think about how we create more empowering titles.

Accessibility factors

What makes a place accessible and inaccessible?

Supermarket

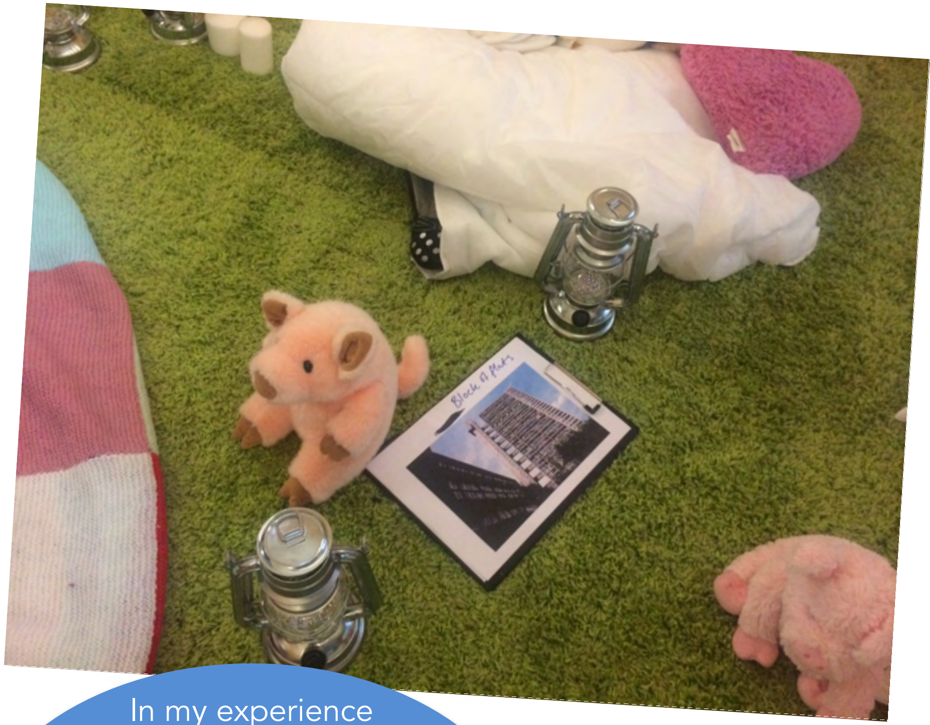
Can be isolating/impersonal

Overwhelming, busy

Generally well-categorised

Well-lit, clean, flat

Autism-friendly hours – useful or tokenism?



I think places should work on making their spaces accessible for the majority of the time rather than segregating people

They go on about us needing routine, but with me I don't have a set day and a set time that I usually go supermarket shopping. So for someone like myself it wouldn't help very much

In my experience whenever you make things more accessible for a particular group of people, actually everybody else who experiences it thinks, well actually that's better for me as well.

I think it's very important that the whole nature of adventure play should be adventurous for all, and I think that sometimes there is a lowering to the lowest common denominator of children's play spaces sometimes. I think it should be a place where you go and you find exhilaration, you find creativity, you find physical movement, you find mental stimulation. And I find quite a lot of places, in their bid to be conscious of children with disability, don't have enough challenging and exhilarating opportunities for all the children. So sometimes all the children, including the children with disabilities miss out on what should be a really fun, challenging self-esteem building environment that you push yourself beyond where you'd normally go. So I think it's important that if we design children's play spaces that we actually make it as fun as it can be for all users.

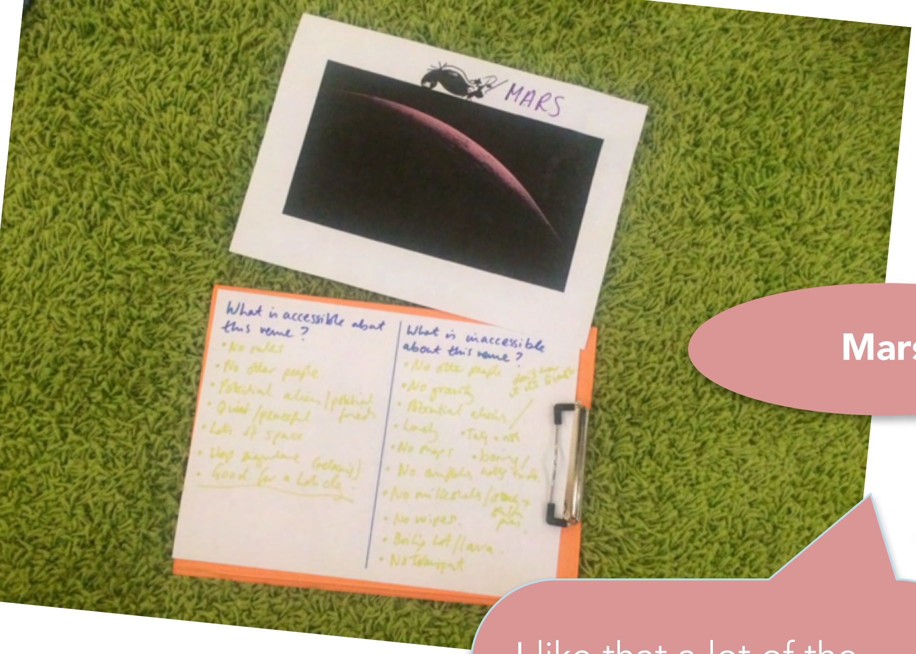
I am 33 but I like to go on the swings!

Do you think playgrounds have become less risky and too safe?

Absolutely, and less fun, because the history of playgrounds was that they were old bombed out wrecks after the war and children used to go there and do very risky play and adults were an add-on many years after the children had learnt how to take risks. And children I find tend to be better risk assessors than adults in terms of what they can and can't do.

Playground

It's rare that as a child now that you get to play in a space where there are very few adults, and it's so important because that's when you test your boundaries and you're able to take risks.



What is accessible about this venue?

- No rules
- No other people
- Potential aliens / potential friends
- Quiet / peaceful
- Lots of space
- [illegible] (relaxing)
- Good for a [illegible]

What is inaccessible about this venue?

- No other people
- No gravity
- Potential aliens
- Lonely
- [illegible]
- No maps
- [illegible]
- No [illegible]
- No milkshakes / steak + stilton pie
- No wipes
- Boiling hot / lava
- No transport

Mars

No rules, no other people

Potential aliens

No gravity

Don't know if it's actually livable

No shops, no cornflakes, no steak and stilton pie

I like that a lot of the things on the accessible list are things that people like as well – [they are] related to things being nice and welcoming - it's interesting.

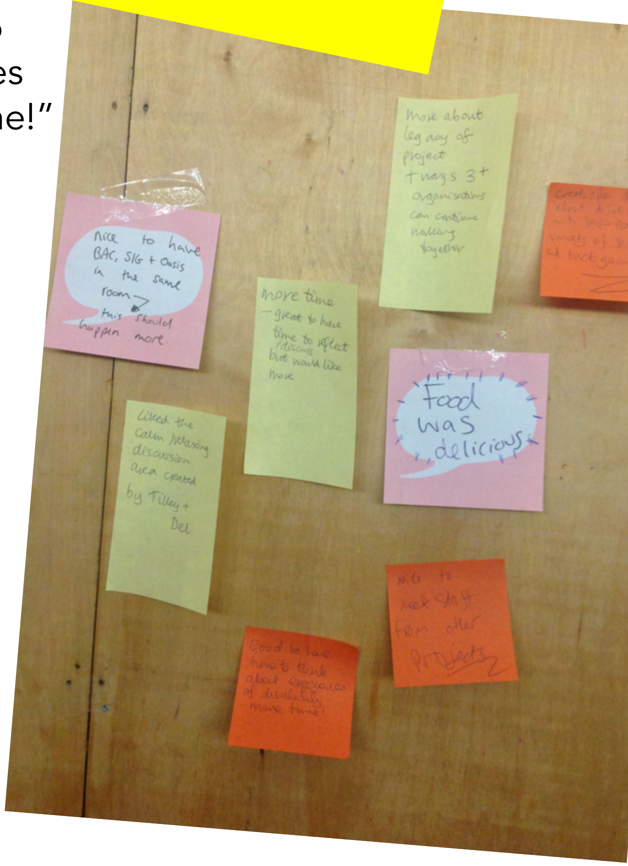
It comes with that tendancy to think about accessibility as a physical thing.

From that exercise one of the most important things is - ask people how they'd like things to be - we often don't do that, we assume that we know. We've had lots of insights - ask a whole variety of people.

I was thinking that my positive experiences of hospitals are often around children's wards that are often brighter and friendlier and if I had to be somewhere for a period of time I'd much rather be in a children's ward.

Team chats

Feedback



"Good to have time to think about experiences of disability – more time!"

"Nice to have BAC, SLG + Oasis in the same room – this should happen more"

"Liked the calm/relaxing discussion area created by Tilley + Del"

"Great open discussion about disability with people from a variety of settings and backgrounds"

"Nice to meet staff from other projects"

"more time – great to have time to reflect/discuss but would like more"

"More time would be great!"

"More about legacy of project + ways 3 organisations can continue working together"

"Enjoyed hearing from other organisations about their residencies"

"Food was delicious!"

What did we learn from session 1?

This session involved Project Team members and members of staff (of varying levels of seniority) from Oasis Play, South London Gallery, Battersea Arts Centre and Heart n Soul. Some participants were heavily involved in Making Routes, while others were part of the same learning or production departments but not directly connected to the programme.

Conversations about people's earliest memories of disability revealed that many participants had at least one relative who was disabled in some way or who had a diagnosed or undiagnosed condition that affected their lives. Participants highlighted their awareness of historical stigma and noted positive signs of attitudinal change. It was clear from the conversation that staff from Oasis Play and Heart n Soul have a highly developed sense of confidence in talking about disability, and their organisations have prioritised inclusive ways of working over many years.

Participants from the two arts organisations demonstrated awareness of structural and institutional barriers but appeared in some cases to be quite cautious with their language and conscious of "saying the wrong thing" (some members of staff did not speak up in the session). Their experience of working with artists seemed to reinforce this sense of caution around associating people with their disability.

Tilley talked very openly about the treatment she has encountered as someone with an autism diagnosis, as well as the limitations imposed upon her by institutions. It felt essential that there was at least one person in the room talking from direct personal experience (rather than it just being a group of non-disabled people talking about disability). Her openness seemed to create a permissive space for people to discuss quite intimate thoughts and feelings.

Discussion in the activities showed participants' sophisticated understanding of the steps that still need to be taken for organisations and companies to be fully accessible and inclusive. People talked critically about the tendency for tokenism as well as the importance of creativity and risk in thinking about inclusive practice.

CREATIVE EVALUATION

2

WHAT? An afternoon of relaxed chat, games and "Puffing and Wooling" with Tilley, Del the pig and Catherine – exploring perceptions around disability, inclusivity and accessibility…

WHO? Making Routes artists and staff from Oasis Play, Battersea Arts Centre and South London Gallery (SLG)

WHERE & WHEN? SLG, 17 August 2017

WHY? To capture attitudes and reflections to inform Making Routes

MAKING ROUTES

"I must say I like this space, it's perfect for this! But the thing with Puffing and Wooling is that anywhere is perfect for it."

"We delight in making you feel good!"

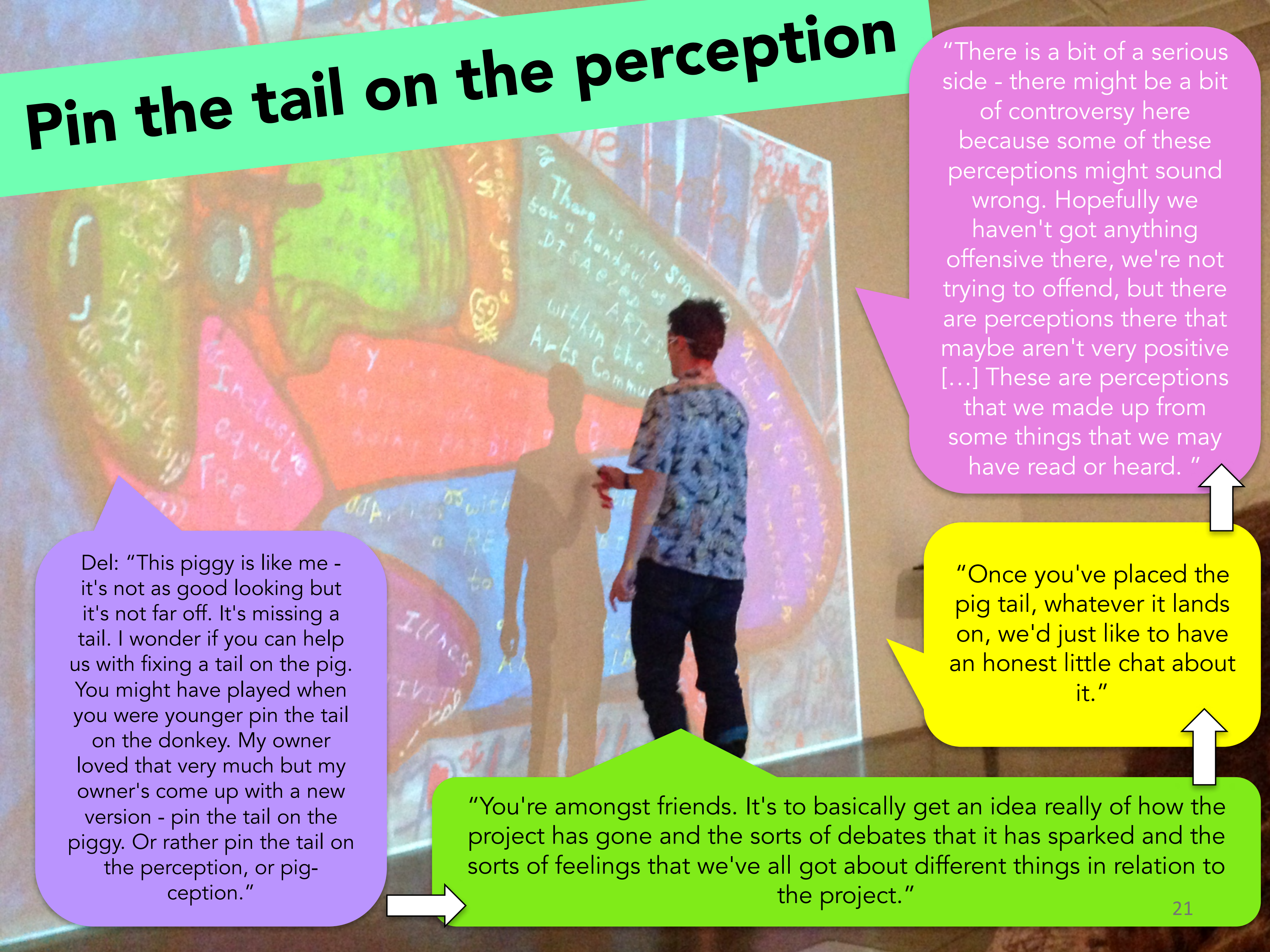
"Puffing and Wooling basically is about relaxing, dossing or chilling out, or whatever you want to call it. It really actually doesn't matter what you call it. We call it Puffing and Wooling. We just think it's a good thing to make time for yourself. That's what it's about - making time for yourself and doing as little as you would ideally like."

"I will let you listen to Catherine now. You will feel in the mood when you hear the dulcet tones of Catherine."

"If everyone is comfortable to, can you just close your eyes. We're going to take three deep breaths and we're going to breathe in for three, hold for three and breathe out for three…"

"Just keep your eyes closed and imagine that there's a bright white light sitting on the top of your head. And as it moves over part of your body, try to consciously relax that part of your body and release any tension."

Pin the tail on the perception



Del: "This piggy is like me - it's not as good looking but it's not far off. It's missing a tail. I wonder if you can help us with fixing a tail on the pig. You might have played when you were younger pin the tail on the donkey. My owner loved that very much but my owner's come up with a new version - pin the tail on the piggy. Or rather pin the tail on the perception, or pig-ception."

"You're amongst friends. It's to basically get an idea really of how the project has gone and the sorts of debates that it has sparked and the sorts of feelings that we've all got about different things in relation to the project."

"Once you've placed the pig tail, whatever it lands on, we'd just like to have an honest little chat about it."

"There is a bit of a serious side - there might be a bit of controversy here because some of these perceptions might sound wrong. Hopefully we haven't got anything offensive there, we're not trying to offend, but there are perceptions there that maybe aren't very positive […] These are perceptions that we made up from some things that we may have read or heard. "

Perception 1

Disability art is redundant - art is art

Gemma: “Aldean said: “We're all just together. Disability people and mainstream people working together. We need disability arts or they would see you as a mainstream person. We need it. I think keep it because then you let people know that's what it is, because you don't want to get too mainstream, because some people will feel that they are left behind.”

Gemma: “In the way that I understand it, it's not that the mainstream is negative, Aldean talks in some ways about having mainstream in him. But I think what he was communicating to me was that that might mean that the things he needs wouldn't be available to him. And wouldn't be available to other people. And it's really interesting because when he answered these questions it was never from that would be negative that he had a disability.”

Gemma: “So for him it's about - well people know I have a disability, well that's good because it helps me and it helps them.”

Will: “if a disabled person chooses to make some art, that doesn't mean that what they're making is disability art. So there's an agency thing where I feel like to a certain degree people should be able to choose how their work gets labelled. So in some respects art just being art is the right answer, but then also within our society there is massive prejudice against a load of people including disabled people. And one of the reasons that continues to happen is because people find it very difficult to think and talk about these issues.”

Will: “so of course the arts is an amazing space, an arena in which to challenge people's perceptions of things, to communicate ideas in lots of different ways. So the arts is in my opinion one of the best places to discuss excluded people and discriminated against people.“

Catherine: “It's about expectation isn't it? At Heart n Soul they're always saying to have high expectations for somebody and for good quality art - that's all everyone wants to make isn't it.”

Victoria: “For me it feels important how labelling some things links to people's perception of it. Because I think when it feels problematic is when people are viewing it as being something that sits ‘other than’... or that it might not have the same status as mainstream arts.”

Perception 1 ctn.

Disability art is redundant - art is art

Will: "I feel personally that disability arts is really important, not only because disabled people should be making art alongside non disabled people, but because the arts has this amazing power to challenge and shift perceptions. And so to throw that out the window would I think be a bad thing, but it's problematic in my mind, disability arts as a category, because it's only with excluded groups of people that work gets labelled as coming from a certain group of people."

Will: "There was an article that came out around the last Unlimited festival asking: is there still a place for disability arts festivals? Would it not be better if there just wasn't disability arts festivals and more of that work by disabled artists was just programmed across all the other festivals. Which I hear as an argument. But I also think challenging perceptions, giving people information that they might not otherwise have, having safe and creative and interesting spaces in which to talk about these things, that comes with putting a load of work in a space...so it is important."

Ciara: "We make very autobiographical work because we believe that people with learning disabilities have got a really interesting story to tell and very brilliant ideas and experiences, and actually yes art is art but we open up a dialogue to try and talk about different people's experiences."

Ciara: "From an Access All Areas point of view I think we mostly only get asked to cast people for disabled parts. And quite often hospital dramas! Something where there is something wrong. And what we are really trying to push for is to have more roles where we are putting people forward for normal casting, where it's not about having a disability at all. So I think at the moment we are in this space where we are using the disabled label to our advantage - to get more of our actors on stage and on screen. But with a view that actually can we work towards more integration please in the mainstream."

Katie: "There are some artists - I'm thinking about Ryan Gander. I read an interview with him and he quite categorically distances himself from the term disability arts even though he's a wheelchair user and he has a lifelong disability. But he's at a stage in his career where he potentially finds it easier to get the support that he needs in order to make his work - both financial and also that community around him. He's already got that in place. So maybe for an artist that's just started now, having that community around you can be a really positive thing."


Having a DISABILITY makes you a BETTER ARTIST!
Every body is DISABLE (in some way)
There is only SPACE for a handful of DISABLED ARTISTS within the Arts Community
Inclusive equal FREEDOM!
Mental Illness fuels CREATIVITY!
Artists with Disabi
a RESPON
to LABEL
as DISAB
ARTISTS!

Perception 2

There is only space for a handful of disabled artists within the arts community

Katie: "Obviously I don't agree. I think what's amazing about art and the arts community in general is that difference is celebrated and that's what makes art art. That everyone has something different to offer. So it can only be a good thing that there are more artists and that there's more diversity within that community."

Gemma: "Obviously there are organisations with incredible models where integration is happening all the time, though there are still issues because there are complexities to having that model exist because of the way the world is set up for particular people to do really well and for other people to be thought of as not having the same kind of abilities. But that's because we built the world that way, and the arts work that way and our offices work that way. "

Gemma: "We are non diverse in our organisations and the way we try to resolve it is at the end point where we say let's get a person with this label and shout to the world that we've got the person with this label. Not everybody, but it happens a lot. So if I look around where I work and go - it's not diverse here and in the arts, let's try and challenge that. It's weird I think sometimes we've created the prejudice and the lack of diversity."

Victoria: "I would play devil's advocate to that because I think I don't agree that there should only be space for a certain number of artists but I think that sometimes it can feel like people are competing for a certain number of roles or a certain amount of money or a certain number of commissions. [Ciara] I'd be interested to know your experience. You were saying you were trying to get directors to cast Access all Areas actors for a variety of parts but if you're fighting against that there's only a certain number of parts."

Ciara: "It's exclusive by its nature in the mainstream TV and theatre world. I guess that's why we make our own work and give our artists the space and the resources to make what they want to make. So we have our casting and performance company and they are different things. It has been interesting recently with the whole diversity agenda of the Arts Council it is becoming a bit more of a thumbs up if you do tick that box to say that you are diverse in some way, and there's been a big push for disabled work and artists recently and we've definitely become a lot more popular somehow recently. Channel 4 are our best friends now! So there has been a bit of a shift change there. Probably yes, disabled organisations helping tick the boxes of other non-disabled organisations I would say."

Perception 2 ctn.

There is only space for a handful of disabled artists within the arts community

Dayo: “I think that we should be asking have we opened more doors for disabled artists? I think disabled artists we've still got a long way to go. Things are improving bit by bit, I just think that as a disabled artist we should ask ourselves do we get opportunities - because there are some disabled artists that don't get those things and it's really difficult. That's why we came up with the Launch Pad - a training and performance company and agency. That's the question I would ask - have more people been open to disabled artists?”

Tilley: “I obviously definitely don't agree that there's too many artists and I think there's competition whatever sort of artist you are. Even though you can be very unique there still tends to be at least one other person who tends to be similar in some way and trying to get funding for things. […] You don't want to be pigeon-holed but at the same time you've sort of got to try and fit somewhere in order to gain some kind of funding or to get that springboard as it were.”

Sarah: “Well I guess probably part of the reason I was interested in Making Routes from the start was from collaborating with children specifically. Because in a similar way I felt like any of the work I saw with children was usually about including children in this adult-created art form, whether it's a play or devised theatre or dance. So we're showing that children can also do it. […] And of course I'm not denying that I have an arts practice and I'm bringing that to the children I work with. But then how can the art really be developed by young people, or by whoever your collaborators are?”

Ciara: “I suppose it goes back to how you want to identify as a disabled artist. If you very much want to be identifying as having a disability and putting yourself in that bracket, that's one thing…”

Catherine: “And have you uncovered any new art forms?”

Sarah: “I guess it's also made me think about art forms when you were talking about what having open doors for disabled artists means. Non disabled people have mainly created art forms in history - then when we're talking about accessibility, could there be the risk of making the mistake of - oh we just want disabled people to fulfill these art forms that have been developed by non disabled people. So what does it mean for different people including disabled people to differently progress or create forms of art, rather than it being just fulfilling what people have said is art.”

Perception 3

Inclusive = freedom

Gemma: “Aldean said: "Being inclusive means everybody is together. It gives you freedom and pride and joy to express who you are. Not the fake you, but the real you. It makes you not afraid, so you're real. Heart n Soul is inclusive.”

Will: “I don't think inclusive does necessarily does mean freedom because certain people understand inclusive or accessible as this kind of weird regulatory thing. Certainly in the context of thinking of disability not just as a physical idea but of neurodiversity and all these different reasons that all of us can be disabled on an ongoing basis - there are too many layers for us to say inclusiveness equals freedom .”

Will: “There's so much emphasis on the idea of setting up a situation in which everyone can do the same thing or everyone can achieve the same goal, whereas actually we are saying if something's inclusive then it sets up the opportunity for people to do whatever they like, but there's not this normative, standard thing that in life we're trying to achieve - whether that's an arts workshop, a trip to the shops, whatever. […] But at the same time there is a part of inclusivity that is to do with making sure everyone's got the things they need to be on the same level, right? […] But I think often then accessibility gets sucked into that - trying to normalise experience rather than offering up the opportunity for everyone to have their own experience.”

Ciara: “I think sometimes inclusion can mean restrictive. I think being inclusive is very difficult to do, to do it properly. And I think it depends on how you define inclusion if you're working with an inclusive group say, as we have been here - with young people with and without disabilities. I think for everybody to have a good and equal experience in the group is so difficult to do. I think it's often about young people without disabilities - how you manage their expectations of what it is to be working with people with disabilities. Sometimes young people don't see a disability, and that's a glorious thing about young people.”

Gemma: “It's also about a uniqueness which means that we're not the same and we're not going to do things the same way, or ask for things in the same way. And that means there's not one way of doing everything.”

Ciara: “And it transcends disability and what that label is - it's about what each individual brings to the room. It says everybody's disabled in the same way, however we like to medicalise or give a condition to each other.”

Responding to perceptions creatively…

Perception: Disability art is redundant, art is art

Jo Paul: "We chose to think about being wrapped up in cotton wool, being over protective of disability, being too cautious to talk about it, about there needing to be a disability arts movement in the same way that there needs to be a feminist arts movement, although you might not want to opt in at times, or never. It's like how I don't opt into feminist art if I don't want to but I still support it."

Jo Brinton: "And kind of visible and invisible support structures, and the visibility of the necessity for a support structure and whether you feel like identifying with that need."

Sarah: "I quite liked when we were doing it there were access needs, but I also really liked how it felt - that wrapping the stick up in cotton wool was making it feel quite supportive and nice to touch but then there was a point where I started to think - this is too much! You can't really hold it anymore."

Jo Brinton: "And the fact that it might make you redundant, or the thing redundant if it has too much of that."

Manifesto tea party!

Tilley: "We have our own manifesto which we started to write and we need you to fill in the blanks. It's the Making Routes manifesto!

Catherine: "In your hat there will be a number written. Whatever number you have in your hat corresponds to a blank space on the manifesto."

The Making Routes Manifesto

Disability art is **necessary**

Making Routes is **exciting** and **thought-provoking**

Inclusive practice is **changing**

Creativity is **individual** and **everyday**

The young people have taught us to **play**, **be united**, and **not to assume**

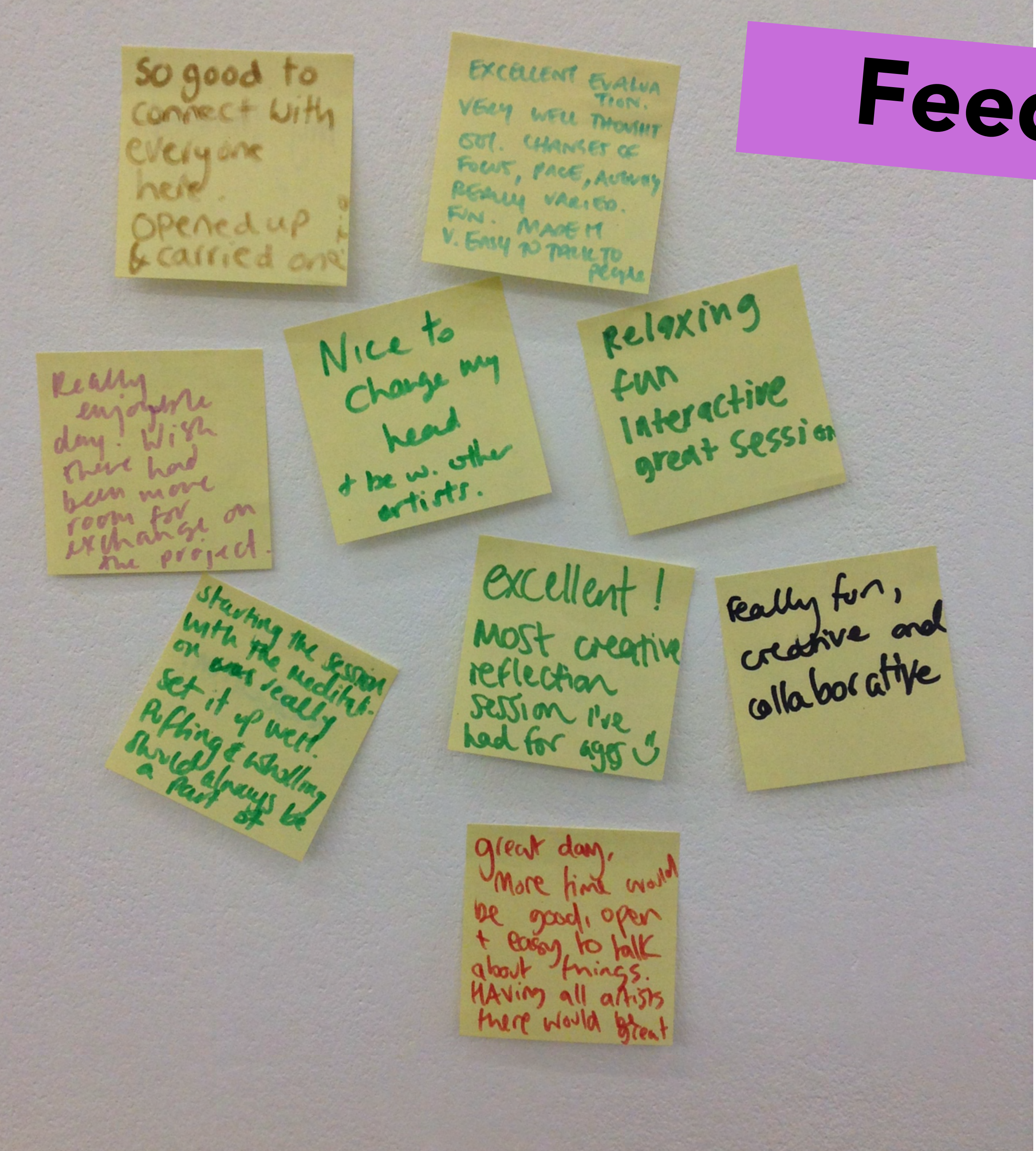
Being an artist on the Making Routes project has been **enriching**, **opening** and **surprising**

The legacy of Making Routes will be **change**

Making Routes has taught me **to be calm about my art**

My perceptions about **myself** and **collaboration** have changed since working on the project

Feedback…



So good to connect with everyone here.
Opened up & carried on

EXCELLENT EVALUATION.
VERY WELL THOUGHT OUT. CHANGES OF FOCUS, PACE, ACTIVITY REALLY VARIED.
FUN. MADE IT V. EASY TO TALK TO PEOPLE

Really enjoyed the day! Wish there had been more room for exchange on the project.

Nice to change my head & be w. other artists.

Relaxing
fun
interactive
great session

Starting the session with the meditation was really set it up well. Puffing & whalling should always be a part of

excellent!
Most creative reflection session I've had for ages ☺

Really fun, creative and collaborative

great day, more time would be good, open + easy to talk about things. HAVING all artists there would be great

What did we learn from session 2?

Just over half of the Making Routes artists were able to attend this session, and there was a mixture of disabled and non-disabled practitioners present, alongside the core Project Team staff. Aldean Blair was not able to attend but his creative collaborator Gemma brought with her a series of comments Aldean had made in response to the perceptions that Tilley and Catherine had prepared.

Aldean's points were very insightful and his characterisation of "mainstream people" sparked discussion about perceptions of non-disabled people and inverting the assumption that disabled people might aspire to fit into seemingly normative standards of behaviour. Even Gemma (who works regularly with learning disabled people) admitted that she had had to stop herself from layering her own interpretations over Aldean's provocations.

Project Team members articulated complex and balanced thoughts about artistic agency and the advantages and disadvantages of categorising the creative productions of disabled people as 'disability arts'. The presence of creative collaborators/enablers also provided insight into the dilemmas facing specialist organisations, which have to play the diversity game of other organisations to a certain extent to increase opportunities for disabled artists. Dayo reminded the group that there is still "a long way to go" to achieve equality of opportunity for disabled artists and Sarah demonstrated awareness of the power imbalances that exist in relationships between artists and participants.

CREATIVE EVALUATION

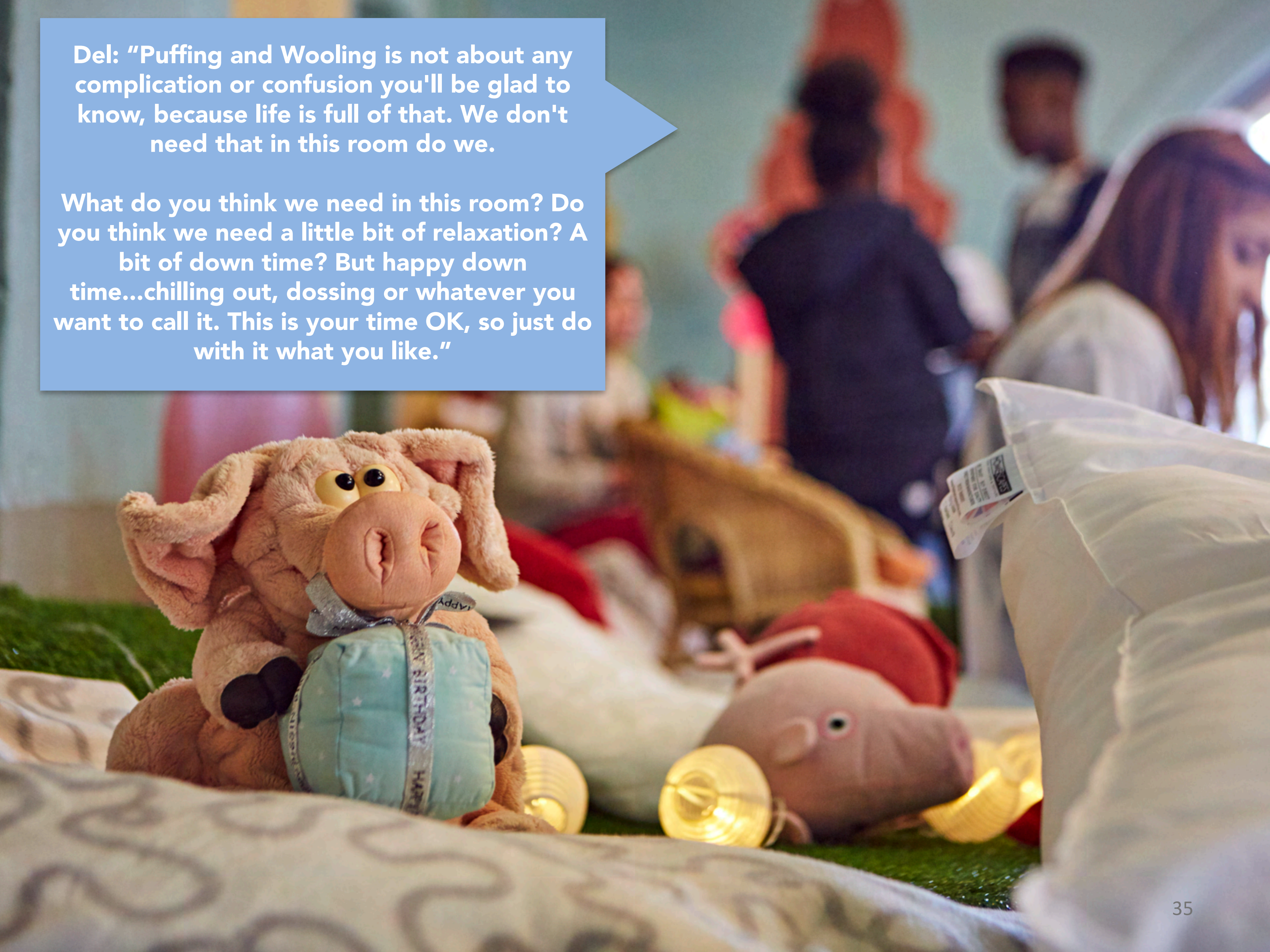
3

WHAT? An hour of "Puffing and Wooling" with Tilley and Del the pig, reflecting on the Making Routes Festival and inclusivity…

WHO? Artists, staff, children, parents, volunteers

WHERE & WHEN?
Battersea Arts Centre,
29 October 2017

WHY? To capture feedback which can inform the Making Routes evaluation



Del: “Puffing and Wooling is not about any complication or confusion you'll be glad to know, because life is full of that. We don't need that in this room do we.

What do you think we need in this room? Do you think we need a little bit of relaxation? A bit of down time? But happy down time…chilling out, dossing or whatever you want to call it. This is your time OK, so just do with it what you like.”

Del: "I would now like to try and focus on getting ourselves into a state that is less stimulated and more taking in maybe what is around you, or maybe trying to take in nothing at all. Maybe focusing on your breath, and I'm going to read a nice lullaby."

"If you feel more comfortable you can obviously close your eyes but that is not for everyone. By the way if you fall asleep that is entirely fine as well. We won't get much of an evaluation out of you but really the main emphasis is on you, so if you need to fall asleep, if that's the way you feel when you're doing Puffing and Wooling, then we want to go with that."

"Puffing, fluffing...how softly are you snuffling? Soundly sleeping, lucky you. Is your blanket woolly enough? Cushions, soft toys, rugs, candles, some are old, some maybe new…
Our aim is for your comfort…
We delight in making you feel good."

"We might like to know really very basically how you feel about today or how you feel it's all gone - what have you managed to actually look at, participate in, or maybe you've been working on it yourselves, so whatever angle you're coming from we just might like to know how you feel about this festival. And we might also like to know a little bit deeper about things like disability, because I think most of us are aware that one of the special things about this festival is the fact that it has all been about working with people with disabilities and without. It's about the collaboration between those artists and also the collaboration of the children and young people. And that is really a lot of what the project has been about."

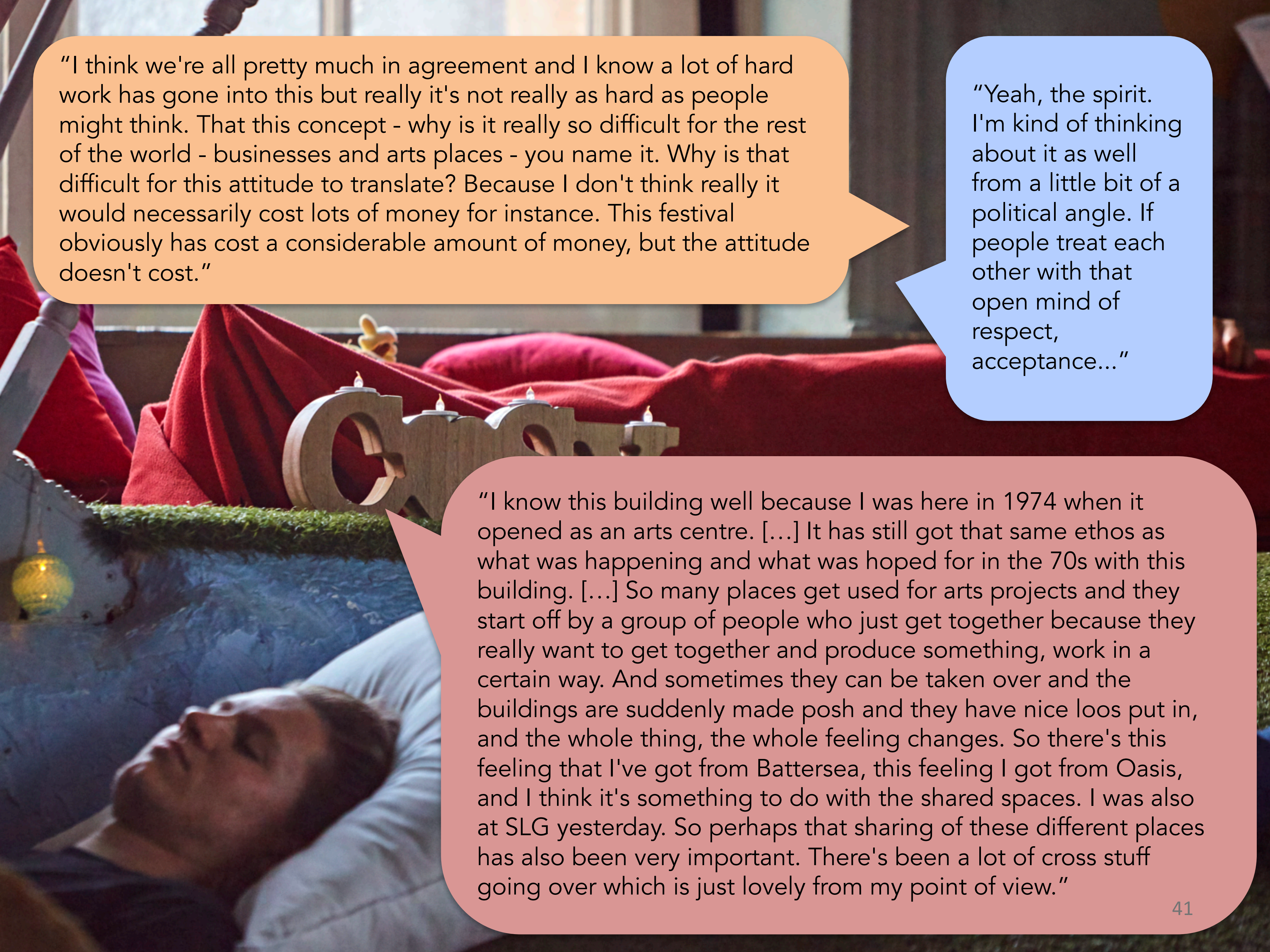
"We'd like to hear if we can a little bit, is there a particular moment that sticks in your head, either from what's been happening today or anytime throughout the project? Because obviously you've all been involved in different ways..."

"I had a beautiful time yesterday at South London Gallery playing in the foam. Sarah Hopfinger had put loads of foam into the installation in Art Block and we played in there in the morning. It was a lovely sensory, creative experience."

"I think my favourite moment so far was the performance upstairs just a little bit ago, which was a dance performance between a group of disabled and non disabled adults and children. About six or seven people doing this, but performing to a room full of people who were all really different who were sitting opposite each other. And it felt like you could move, and you could make noise, and we just watched these seven or eight people play and dance and connect with each other. And there wasn't a single moment where I felt bored or where I felt like I shouldn't be there, or where my mind went anywhere else other than just being in an amazing room with lots of different types of people. I felt, as someone who often doesn't feel very welcome in spaces, like I wasn't the only one in a space making noise, but it felt like that was totally ok, that made it better."

"Anybody else have a similar feeling about this festival and what it's been doing? Because obviously it's about fun and it's about creativity and socialising and mixing different kinds of people and taking people out of their comfort zone really. Maybe they live in a particular area of London and they do not tend to really venture five, ten, 20 miles outside of that area - I don't know what the radius is, but maybe there are people like that and so maybe this project has broadened people's horizons. Are there people in this room who feel as though most of the time they're maybe not 100% comfortable when they go to different places? Particularly when we're talking about arts-type places, culture places?"

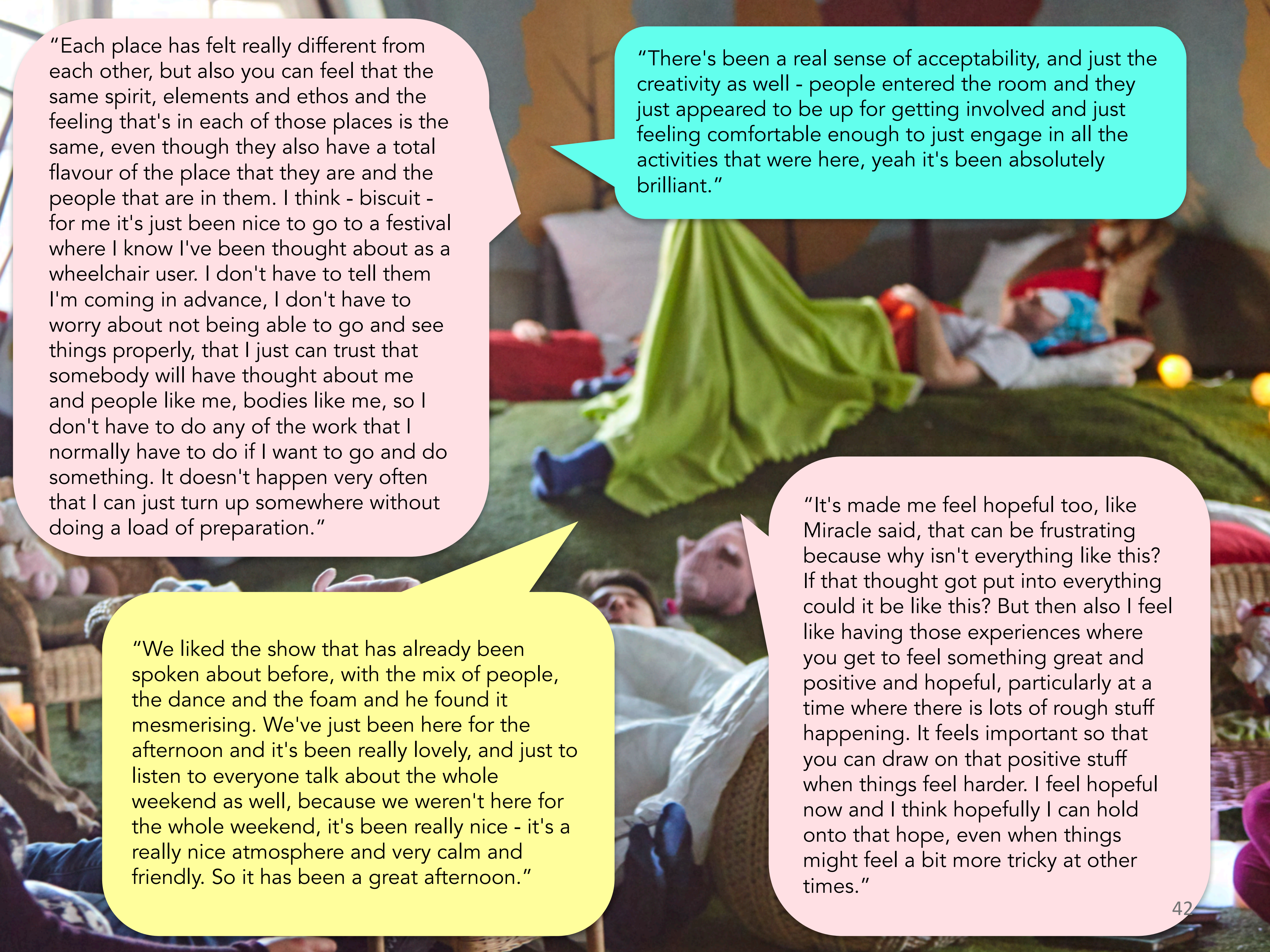
"I think I wanted to say, the festival - everything coming together - shows you what a happy world could be like, and it just demonstrates what a happy world could be like if only our experiences of the festival translated throughout the world. Nothing is ever perfect in a planet like ours, but it just shows that people doing things together, working together [...] it just gives you that texture of a happy atmosphere that can speak volumes for the world, if it ever could go that far."



"I think we're all pretty much in agreement and I know a lot of hard work has gone into this but really it's not really as hard as people might think. That this concept - why is it really so difficult for the rest of the world - businesses and arts places - you name it. Why is that difficult for this attitude to translate? Because I don't think really it would necessarily cost lots of money for instance. This festival obviously has cost a considerable amount of money, but the attitude doesn't cost."

"Yeah, the spirit. I'm kind of thinking about it as well from a little bit of a political angle. If people treat each other with that open mind of respect, acceptance…"

"I know this building well because I was here in 1974 when it opened as an arts centre. […] It has still got that same ethos as what was happening and what was hoped for in the 70s with this building. […] So many places get used for arts projects and they start off by a group of people who just get together because they really want to get together and produce something, work in a certain way. And sometimes they can be taken over and the buildings are suddenly made posh and they have nice loos put in, and the whole thing, the whole feeling changes. So there's this feeling that I've got from Battersea, this feeling I got from Oasis, and I think it's something to do with the shared spaces. I was also at SLG yesterday. So perhaps that sharing of these different places has also been very important. There's been a lot of cross stuff going over which is just lovely from my point of view."



"Each place has felt really different from each other, but also you can feel that the same spirit, elements and ethos and the feeling that's in each of those places is the same, even though they also have a total flavour of the place that they are and the people that are in them. I think - biscuit - for me it's just been nice to go to a festival where I know I've been thought about as a wheelchair user. I don't have to tell them I'm coming in advance, I don't have to worry about not being able to go and see things properly, that I just can trust that somebody will have thought about me and people like me, bodies like me, so I don't have to do any of the work that I normally have to do if I want to go and do something. It doesn't happen very often that I can just turn up somewhere without doing a load of preparation."

"There's been a real sense of acceptability, and just the creativity as well - people entered the room and they just appeared to be up for getting involved and just feeling comfortable enough to just engage in all the activities that were here, yeah it's been absolutely brilliant."

"We liked the show that has already been spoken about before, with the mix of people, the dance and the foam and he found it mesmerising. We've just been here for the afternoon and it's been really lovely, and just to listen to everyone talk about the whole weekend as well, because we weren't here for the whole weekend, it's been really nice - it's a really nice atmosphere and very calm and friendly. So it has been a great afternoon."

"It's made me feel hopeful too, like Miracle said, that can be frustrating because why isn't everything like this? If that thought got put into everything could it be like this? But then also I feel like having those experiences where you get to feel something great and positive and hopeful, particularly at a time where there is lots of rough stuff happening. It feels important so that you can draw on that positive stuff when things feel harder. I feel hopeful now and I think hopefully I can hold onto that hope, even when things might feel a bit more tricky at other times."

"Before anyone goes, this is something that anyone can do at any time - deliberately. Although the things I have in this room are rather lovely, they are quite affordable things, a lot of them are quite personal to me, so the whole idea of this, the whole ethos is around it being something which anybody could do, and it doesn't require to be living in a penthouse in a swanky part of London or a cottage in the Cotswolds, or whatever you think is the ideal place. You can make your own space. It's what you do with it and making that time that you have. Hopefully you have that spare time, and it's making that time really precious you know, getting quality out of that time, and not feeling that you're being selfish. It's not selfish at all to say that you want to spend anything from five minutes to even having a duvet day or two. There's nothing selfish about that but we all need to do it in our own way. Like the advert - but with Puffing and Wooling it's true - you're worth it."

Illustrations: Amber Anderson
Photos: James Lyndsay

MAKING ROUTES

What did we learn from session 3?

The final edition of Puffing and Wooling presented an opportunity to reflect on how the festival and programme in general had made a difference to people’s perceptions of themselves and cultural/play organisations.

Interventions by disabled participants associated with Making Routes revealed the degree to which the festival had managed to create an inclusive, welcoming environment for people who often feel discriminated against or unsupported in public settings.

Festival Volunteers and support workers were particularly keen to point out that the festival demonstrated the diverse scope of disabled young people’s abilities and it had raised people’s expectations about what was achievable.

Some participants commented that Making Routes highlighted the necessity for broader social change, and the problem of imagined constraints holding back organisations from being consistently inclusive. They suggested however that the programme offered a sense of hope for the future. Non-disabled participants also recognised how the creation of an accepting, non-judgemental environment benefited everyone.

What did we take away from the Puffing and Wooling Creative Evaluation?

The Puffing and Wooling methodology provided a unique, safe setting in which to be curious about disability and to reflect on the wider context of Making Routes. It taught us how to have conversations about what are often considered tricky subjects with humour and a child-like sense of wonder in a space of sanctuary.

We realised that it would have been beneficial to have dedicated Puffing and Wooling sessions with children and the programme’s volunteers, and perhaps even with parents and external partners. In an ideal world we would have held these at the beginning and end of the programme with the same groups, so to identify any shifts in perceptions or vocabulary.

What emerged instead were rich discussions between disabled and non-disabled adults, many of whom were experienced in inclusive practice. The sessions therefore also provided spaces to share knowledge between organisations and to extend important critical debate about key topics associated with disability and the arts.

Perceptions of Disability & Inclusive Practice

A report from Making Routes

Written by Nicola Sim

January 2018

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