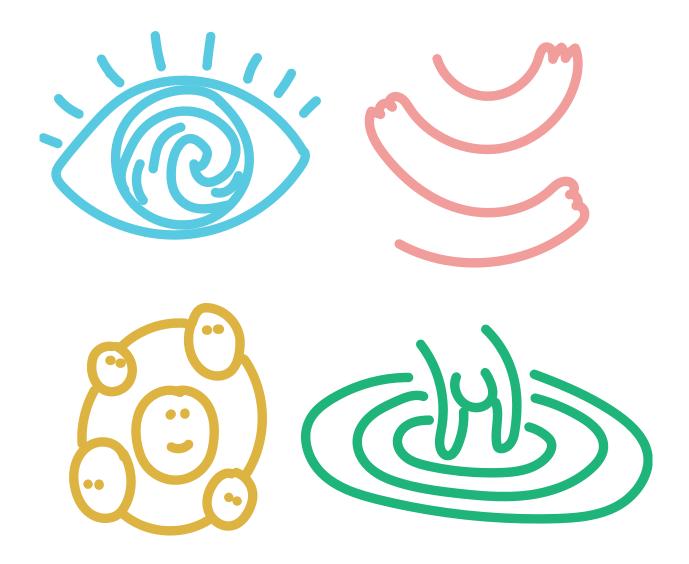
Speculative Care Futures



Re-Imagining Being in Community With Sensory Beings

Written and Designed By Max Alexander

Thank you to all at Cherry Road for supporting me and welcoming me into your centre and thank you especially to the service users and staff who've played with and alongside me.

Thank you to all who have shared your wisdom and been a sounding board for my ideas in many generous conversations; Kirsty Biff Nicholson, Ellie Griffiths, Jill Goodwin, Alison Stirling, John Connell and Liz Davidson.

Thank you to Nina Doherty and Mhari Robinson, my colleagues at Independent Arts Projects for believing in and supporting this work.

"I feel the world too much so open Bothersome work is to feel Inside pandering To language

The work is to feel the world that is touching me"

-Adam Wolfrond

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Foreword



What lies in the following pages is a made up report about a made up place full of made up people doing made up things.

Kind of.

Whilst the report is fiction, it draws together my experiences over ten years of working with hundreds of individuals who are described as having Profound and Multiple Learning Disabilities (PMLD), or, to use a newer term from researcher Joanna Grace; individuals who are Sensory Beings. Alongside those hundreds of individuals come many more hundreds of friends, family, teachers, carers, support workers, nurses, therapists and artists. Many people with different names, backgrounds, experiences, professions and reasons for doing what they do. All, in some way, being in relationship to some of the most marginalised and invisibilised members of our society and, for the most part, trying to do that in the best way they can.

This report takes those experiences and adds in some long standing questions, some gut instincts, some personal reflection and quite a lot of sincere optimism and hope. The quotes and stories shared in the report are all based on real conversations I've had and people I have met and shared space with. There are however no direct quotes and all names and details have been fictionalised.



It follows a twelve week collaboration between myself and Cherry Road, a Local Authority-run day service near Edinburgh, which provides holistic care, support and opportunities for adults described as having PMLD. During this project I worked with staff and service users to provide a series of play sessions tailored to individuals- both for service users and staff. I wanted to explore the different ways we could find to share space together. My intention being that this might point us in the direction of making life for both staff and service users feel more connected, authentic and equitable. I'm interested in how we can make sure the dominant culture of these spaces is made up of ways of relating and being together that feel authentic for staff and service users, because I deeply believe that is where richer and more joyful relating is possible.



I'm also painfully aware of how much organisations like Cherry Road have to do with so little. Be that resources, money, time or staff. Or all of the above. The role of an artist in these spaces is a privileged one. I get to come in and ask questions and take my time and reflect and play in a way that people working in these spaces everyday don't get to do. I'm always asking myself how can I make the most out of this opportunity and how can I be respectful to this community of people whilst I do that. This was something I reflected on a lot whilst my experiences with them were feeding into this piece of writing.

Following the project at Cherry Road I planned to produce some kind of report or resource. I decided I'd figure out what that might be when I got to it but assumed it would be an account of the work at Cherry Road. When it came to thinking about what it might be, I got stuck. In a conversation with Alison Stirling, Artistic Director of Artlink, who has worked with Cherry Road and settings like them for many years, I asked what she thought might be most useful. She responded by telling me to "think about the future of the people" as "we don't do that enough" (I'm paraphrasing here). And she was right, when talking about the future of service users like those at Cherry Road we usually just talk logistics; Where are they going to go? Who's going to look after them and is there enough money for what they need? We don't really talk about what the future looks like and feels like. We don't even really think of it in terms of possibility, we think of it in terms of problem solving.

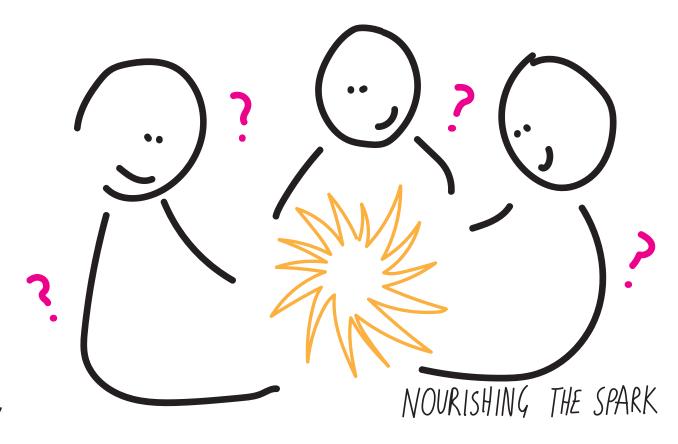
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Something I've noticed over the years of working with Sensory beings is they are often viewed as static. As if they are who they are right now and that's who they will always be. We don't really think of them as having a life that moves or changes. Externally or Internally. But they're not static; no one is. Whether we can see it or not, everyone has a past, present and future. And this group of peoples' futures deserves attention just as much as anyone else's.

So I came up with the idea of writing a speculative report. Inventing a place in a similar vein to Cherry Road and imagining what could happen if, with the right resources and support, a staff team decided to shake things up a bit and explore what their community could look like. Something I immediately came up against was a feeling that this just wasn't realistic. This was worth paying attention to in itself because the things that I'm writing about aren't impossible or even implausible. They are all quite simple human things that are made more complex and less human by the intersection of a non-disabled and neurotypical dominated culture and scarcity of resources.

I put the idea of 'it not being realistic to one side' and decided instead to imagine what we could do with time, willingness, the creativity and deep empathy of neurodivergent knowledge and the cultural non-negotiable that Sensory Beings are full human beings and should be treated as such.

I hope you get something out of this piece of writing, and that even if just a small spark of an idea comes from it, you feel emboldened to take a risk and explore.



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About the Author



My name is Max Alexander and I work under the name Play Radical. I'm an artist, play worker and inclusive play advocate and thinker. My work centres play and connection with a particular focus on autistic, neurodivergent and disabled experience.

I create spaces for play using a mix of approaches; as a maker, visual artist, writer, facilitator, communicator and play worker. These spaces might be short quiet pockets of time shared between just two people in a living room, in a park under some trees or in a nondescript room in a day centre playing with strange sounds, exploring tactile sensations, or engaging in slapstick repetitive imaginative play. They might be bigger installations with



playable sculptures, dens, big bodily movement and raucous ever evolving games. They will often exist somewhere in between, but regardless of scale, time and who is in the room, they tend to hold space for silliness and sincerity in equal regard.

As an autistic artist, my lived experience cannot be disconnected from my work. My experience informs an approach to creating and facilitating participatory work which views care, access and de-pathologisation (moving away from the idea that certain kinds of human existence are 'wrong' and need to be fixed) as essential, urgent and joyful elements. I see finding ways to communicate, advocate and educate around autistic, disabled and neurodivergent inclusion as a key part of my creative work.

I have over ten years experience working with and alongside disabled and/or neurodivergent individuals across school, playground, social care and community settings. As a specialist practitioner I am keen to share the work I do in an open and reflective way, and learn from others as much as I can. www.playradical.com





Max Alexander has been supported in this work by Independent Arts Projects (IAP) as Associate Artist. Max's initial residency with Cherry Road took place as part of a six month bursary, supported by the National Lottery Extended Programme Fund from Creative Scotland. Max's work on this report was completed during a year-long post supported by Culture Collective, an innovative and award-winning fund created by Creative Scotland to support artists to work with communities across Scotland, supported by the Scottish Government.

Independent Arts Projects (IAP) is a Leith-based arts charity who works with artists and performance makers to develop, produce and tour productions & arts projects for people across Scotland. We connect artists and communities and make space for people to be themselves and see themselves. IAP supports artists to be artists. We often work with artists and arts workers who have been marginalised, as creators, and leaders - providing the conditions for the critical next steps in their creative and professional development. Our aim is to make space for people who are sometimes isolated or excluded from mainstream arts experiences to be themselves and to share in the joy and benefit of being part of high-quality creative opportunities. We believe that everyone has a right to creativity no matter their age, background, experience or identity.

https://www.independentartsprojects.com



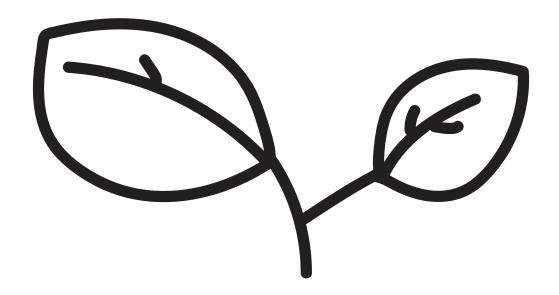






Re-Imagining Being In Community With Sensory Beings:

Two Years of Learning and Exploring at Springleaf Adult Learning Centre



Introduction



Who Are We?

Springleaf Adult Learning Centre is a local authority funded service providing non-residential holistic care and support for adults described as having Profound and Multiple Learning Disabilities (PMLD). We describe the adults who use our service as "Service Users", a term that never feels 'quite right', but we feel is the best term we have currently (and therefore will use throughout this report).

The majority of our service users attend the centre 2-5 days a week and tend to spend the rest of their lives either at home with family or in residential care/supported living. All of our service users require high levels of around the clock care including assistance with eating, communication, personal hygiene and toileting, mobility, travel, medical interventions, physio and occupational therapy. We have 25 service users currently who access the centre and a staff team of support workers, managers, gardeners, chefs, cleaners, office workers, occupational therapists, nurses and physiotherapists. We also have creative practitioners who work for local third sector organisations who add to our programme. They bring a wide range of offerings including live music and music making, sensory workshops, puppetry and dance sessions.



The centre was founded in 2001 and was part of a response to the nationwide closure of long term residential institutions for learning disabled individuals. In the nearly 23 years since, Springleaf has learnt and grown along with wider society in understanding the needs, potential and perhaps most importantly, value, of the lives of our service users. We have done this through multiple rounds of austerity, budget cuts, the loss of many service users and staff members and a global pandemic. We've been flexible to change and

have often found ourselves with far less resources, such as staff, money and time, than we need.

Although things have come a long way for inclusion and understanding for learning disabled and otherwise neurodivergent individuals in that time; our service users remain a highly marginalised population. We believe we must keep learning and growing and striving for the best possible life for everyone in our community. We believe that meaningful inclusion benefits everyone and makes for a kinder, more beautiful and more connected life.

What is this report about?

Two years ago we decided to take a look inwards, acknowledge how far we'd come and think about where we might want to go next. We found that we had so many questions, ideas, and quiet nagging feelings about how things could be better. How we could do better. All of these were things that day to day, we just didn't feel we had the time, or sometimes confidence and permission to really explore. We set off on a journey to investigate these. To see what would happen if we gave ourselves permission to be a bit unsure, to not be perfect, to not see any idea as small, or silly or insignificant.

This report is an outcome of these last two years. Steered by a small working group meeting once a month (mostly!), we have worked to deeply listen and pay attention to the members of our Springleaf community and then introduce explorations to the day to day life of the service. Some things have worked, some things haven't and some things we still don't have a verdict on yet!



We have done all this whilst working with dwindling budgets and increasing demand on our service to provide more despite having less and this has frustratingly limited us; Imagine what we could do without those pressures.

In these pages we will share the questions we had at the beginning of this process, some of the explorations we've tried out in the process of trying to answer our questions and four case studies of members of our community and their experiences during this time.

We hope by creating this resource we can inspire others to take risks, try new things and support each other to look inwards to see what we have the power and creativity to change.

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Our Questions

At the start of this project we came up with questions that we wanted to explore and invited the wider staff team to share questions that they thought were important to consider when thinking about how we might improve our service. There was the opportunity to do this anonymously through a submissions box and to share them out loud during team meetings over a couple of weeks. We then pulled them together into the list below. We knew from the start that we wouldn't be able to answer all these questions But they became useful starting points to think about the ideas we might explore, and were a helpful place to come back to when we felt lost or stuck.

How can we make sure our 'care' includes meaningful interaction and quality attention?

What different kinds of attention can we pay to people? How do we learn new ways of paying attention?

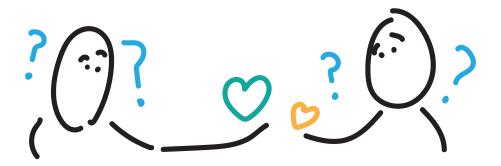
How can we move away from the disabled individual's experience being seen as 'special' or 'different' whilst the non disabled caregivers' experience is seen as 'normal'? Can we do this whilst still respecting each others needs?

How do we care for care staff?

How do we care for care staff whilst ensuring service users' needs are met and respected?

How do we recognise care staff's vulnerabilities and support them?

How do we make sure we listen to (especially when there are no words spoken) and learn from our service users every day?



How do we challenge ourselves to keep 'unlearning'?

Do people on some level not believe meaningful connection between people of profoundly different ways of being is possible? How do we challenge this in helpful ways?

How can we share experiences that feel genuine/meaningful when we are so different?

What does 'sensory' even mean? Does it mean different things to different people?

How can we make sure we recognise and prioritise the connections between service users?

How do we make sure we value 'being' as much as 'doing'?



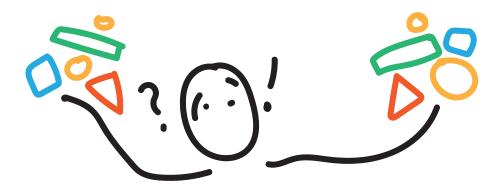
How do we slow down?

How do we quieten down?

How do we stay open and curious to our service users when we are under stress and pressure?

How can we make it feel okay and even enjoyable to take risks?

How do we do all this with the pressures, unpredictabilities and resource limitations of a social care environment?



Exploration: Understanding 'Sensory' and Experiencing Together



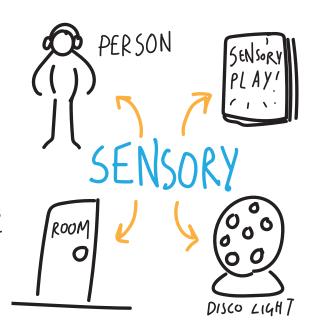
The Problem with 'Sensory'

'Sensory' is a word we use a lot in our service. We describe things as 'Sensory', we describe rooms as 'Sensory', we describe ideas as 'Sensory' and we describe people as 'Sensory'. Sometimes we even describe people in levels of 'Sensory-ness'. We might say; "She's very 'Sensory'' or "He's not 'Sensory' most of the time but sometimes if he's having a bad day he needs things to be more 'Sensory'."

But when we thought about what we actually meant by "Sensory" we were a bit stuck. We found that this word that we use all the time, a word that we thought of as being very helpful and accurate suddenly didn't really seem to mean anything. It still felt important, it felt like it did tell us something about a thing or a place or a person... but something was still being lost and it also sometimes seemed to create barriers.

We found that staff often have a feeling or an idea about how good at 'Sensory' they are. If they saw themselves as being "Good at Sensory" then they would feel able to take risks, try new things with Service Users and often have fun doing it. If they felt they were "Bad at 'Sensory" then they wouldn't feel confident in trying things out and would be more likely to not value their own skills and perspective in working with service users.

We also felt that the way we use the word sometimes stops us from acknowledging our own 'Sensory-ness' and this limits how we relate to and engage with our service users. We know that every human being has senses and experiences the world through their own unique make up of sensory sensitivities, curiosities, likes and dislikes.... so in one very key sense everyone is sensory. However we know this is not what we mean when we describe our service users as 'Sensory.' It was clear that a distinction was important, but currently we were making it in a way that divided us further more



Page 15 each other more.

Linguistic Beings and Sensory Beings

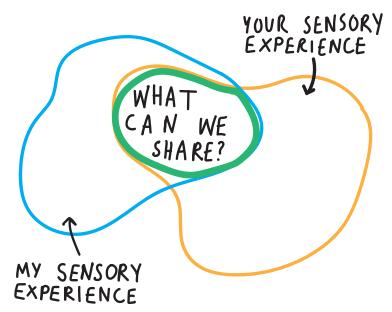
We found Joanna Grace's idea of "Sensory Beings" and "Linguistic Beings" (Grace, 2018) helpful to understand this difference. Grace describes Linguistic Beings, like our staff and anyone reading this, as those who have acquired language which informs the way they think about the world and changes the structure of the brain to store information in language form. She describes "Sensory Beings" as those who experience the world in a primarily sensory way which means their experiences "can exist in isolation without association to objects or meaning" which enables them to have "an exceptional ability to occupy the present moment." Grace emphasises that both Sensory Beings and Linguistic Beings have a lot to offer each other, but, to let this happen Linguistic Beings need to not impose our way of being onto Sensory Beings and spend time "sensing as well as showing."

This distinction allowed us to understand that the experiences of Sensory Beings and Linguistic Beings are different in very fundamental ways. But this distinction doesn't need to be a divide. Both Sensory Beings and Linguistic beings can share space and experiences in a Sensory way.

Experiencing not Translating

We began to define the term 'Sensory' as meaning someone or something where the sensory experience is essential and central. This helped us recognise that often, as Linguistic Beings, we were trying to apply meaning or, sometimes justification, to why we were doing something purely sensory with our service users. We were trying to translate the experience of our service users into one which used our ways of understanding and making meaning. We were trying to translate language into senses or translate senses into language. When what we needed to be doing was simply experiencing the moment and being with each other.

This 'translating' rather than 'experiencing' might look like two staff members sitting next to a service user who is fully immersed in watching a light display and, instead of taking in the lights alongside them, sitting and talking about what they think the service user is experiencing. Or perhaps a service user might be deeply focused on rolling a ball across



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a table and a staff member might take a quick look and think they're "just rolling a ball" before getting back to something else, rather than sitting alongside them and trying to pay attention to the noise and the colours, or even picking up a similar ball and trying it for themselves.

Sensory Pairing

We wanted to experiment with finding ways to enable staff to share sensory experiences with service users where this 'translating' wasn't needed and staff could feel comfortable and curious to experience together. We came up with the idea to get staff to really think about and explore what sensory experiences they enjoyed. We then got them to think about sensory experiences service users they were working with enjoyed and find creative ways to combine them so both parties were coming to an experience with something familiar and enjoyable. We called this 'Sensory Pairing'. Below are some examples of the Sensory Pairs that were explored.

Books



Angie, a staff member, collects books and while she loves to read she also enjoys the collecting and organising and displaying of her secondhand book shop finds. She was unsure about how this could be explored with an element that Eilidh, a service user who Angie spends most of her work days with, would enjoy. Angie brought a bunch of books into work anyway.

Whilst sitting with them she realised that she enjoyed books just as much, if not more, as a sensory object then as something to read. Then when watching

Eilidh grinning and leaning her head towards a rotating fan Angie realised that might be an element they could explore together. Angie started experimenting with softly and repeatedly fanning the pages of books near Eilidh and noticed Eilidh falling quiet and tuning in. This led to the discovery that Eilidh loved the sensation of Angie fanning the book right next to her ear where she would relax and vocalise softly. They also discovered that looking into the book as the pages were fanned slowly led to excited vocalisations and deep looking. Angie started focussing on finding books with colourful pages and this seemed even more enjoyable

Page 17 enjoyable.

Coffee

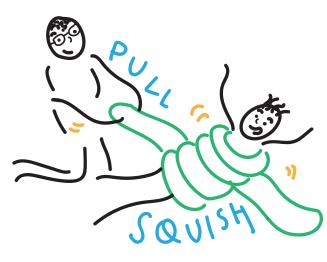
Bea, a staff member, loves coffee. She likes the taste and the caffeine but especially enjoys the smell. Jack, a service user, loves watching and listening to pouring things like sand and dirt. He sometimes likes to get his hands involved and feel the materials, but mostly seems to like the visual and sounds.

Bea started waiting until Jack arrived to make her coffee in the morning. Bea would bring the kettle, two mugs and two jars of coffee granules and sit with Jack. Bea would make her coffee and then, whilst she slowly drank it, would



take time transferring Jacks coffee granules from mug to jar and then jar to mug, experimenting with doing this at different speeds and angles. Jack would watch keenly, smiling and vocalising happily. After a few weeks of this other staff began to notice Jack would also perk up at the smell of coffee and seemed to enjoy being around it.

Squishy Worms



Jason, a staff member, loves to rock climb and realised that one of the things he finds so enjoyable and relaxing about it is the feeling of stretching out his body and using all his muscles at once. Rishi, a service user, loves being engulfed in blankets or buried in bean bags. Jason got the help of another staff member to create giant squishy stretchy worms.

They could be wrapped around the body giving a firm but squishy hug feeling but also pulled and stretched with the arms and legs. Jason and Rishi found lots of ways of experiencing these together and would often alternate between giggling

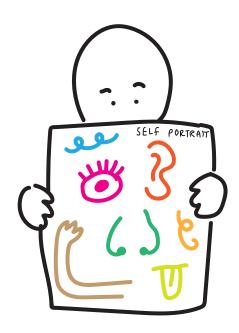
as Jason pulled and wrapped the worms around Rishi and quietly laying together. Page 18

Conclusions

This idea of 'Sensory Pairing' is something we've started integrating into our service more and more. Staff now all have their own 'Sensory Profiles' up on the centre walls alongside the service users 'Sensory Profiles'. For some staff this was a really easy thing to do, for others it was much trickier and has taken time to build up. But giving time and making space for staff to explore and understand their own relationship to the sensory world more has really helped them find new ways to connect with the service users. Staff have also noted that they feel more confident in not having to justify how they are spending time with service users to each other because they know that we are intentionally working to spend more time just being and experiencing together.

"Anything can be sensory! It's just how you approach it!" - Tamsin, Staff Member

Some staff who initially expressed feeling uncomfortable or self conscious about creating and exploring Sensory Pairs with their service users now delight in the challenge and opportunity. Some do still find it challenging and sometimes the reasons for this are hard to pin down but staff have expressed feeling like they're "not creative enough", struggling to figure out what sensory experiences they can share and not having the time to think about it. We are trying to find new ways to support staff in this process. An outcome that we didn't initially think about or expect is finding new and surprising things that our service user enjoyed. Through the Sensory Pairing approach we were more likely to introduce service users to things outside of their comfort zone, or outside of what we already knew or expected of them. As it was also paired with something familiar that we knew they liked, this seemed to remove some of the barriers that often stopped both staff and service users being able to try new things.



Case Study: The Deep Explorer

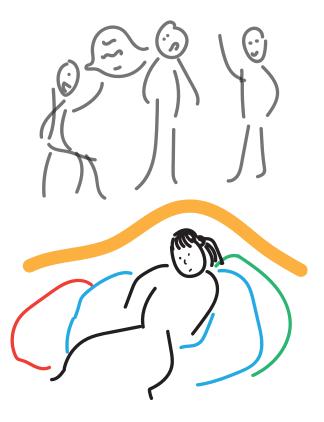


Jess is a service user in her early twenties. She started attending the centre when she left school at eighteen. Since then she has increased her days from one to four a week. After a couple of years at the centre she seems well settled. It has been a big change from school where she spent most of her time separate from her peers with two members of staff supporting her. She spends most of her days at the centre with a small group of staff and service users in a bright room with tables, chairs and a sofa. She has time by herself with an art therapist once a week and swimming with support staff once a week. Jess is the youngest by about ten years within her group at the centre. Jess will typically be quite quiet and seemingly withdrawn but will come out of her shell to laugh mischievously if something unintentional and disruptive happens such as a dropped plate or stubbed toe. She enjoys painting, drawing and listening to music.

Early On

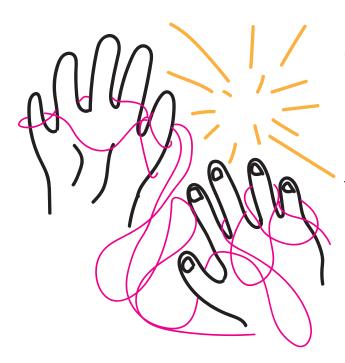
Earlier on in Jess's time at the centre staff generally described Jess as being "pretty content in her own world" but also "difficult to engage". They expressed concern about Jess being so much younger than most of the service users and worried about her not having peers.

There was also concern about Jess getting what she needed in terms of stimulation and experiences. When Jess was transitioning to the centre with the support of her school staff she was described as someone who was "very sensory" and loved to explore. This is not really a side of Jess that had come out much in her first couple of years at the centre which was also of concern to staff. Staff would regularly take Jess to the centre's sensory room and she would typically lay in the corner on beanbags and not seem particularly interested in the rest of the room.



Non-Verbal Invitations

A bit of a breakthrough came for staff and Jess when they decided to make their sensory room visits non-verbal time. Instead of asking Jess if she wanted to touch things or look at things in the room, the staff just started placing objects next to her instead. This seemed to be exactly what Jess needed and she would pick up the objects- a torch, an inflated balloon full of glitter, a ball of wool- and spend time deeply exploring them and playing.

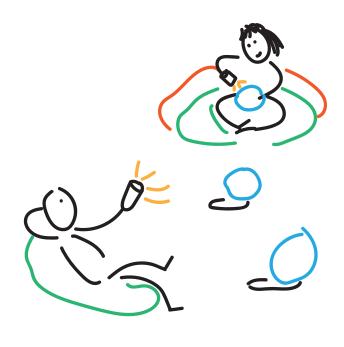


Connecting Through Wool

The wool had come from a member of staff, Carrie, a knitter and weaver. Jess loved looking up close at it with the torch and watching it throw shadows on the wall of a dark room as well as just running it through her fingers. Jess and Carrie started spending time in the morning's together where Carrie will sit next to Jess on the floor and knit whilst Jess will place wool in and out of a bowl, unravel it and reravel it and hold it to the light, wrapped between her fingers, wiggling it and looking through.

Expanding Experiences

Jess still goes to the sensory room regularly and staff do their best to keep this time non-verbal. Jess still heads straight for the beanbags in the corner but now tends to sit up, cross legged and looking outward to the room. Staff will place different objects near Jess or hold them out and Jess will take them and begin to explore. Tom, the artist, has started working with Jess in a similar way and through these sessions is introducing Jess to more and more objects and sensory experiences. Staff still have concerns



about Jess's lack of peers at the centre but less so now they see her interacting in Page 21 different ways with different people and finding things in common other than age.

Exploration: Slowing Down

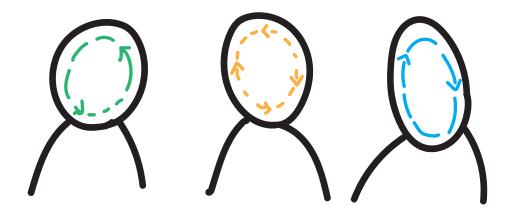


Why Slow Down?

Some of the most common questions that came up from staff were around the idea of 'slowing down'. Most of us seemed to have a strong sense that we needed to slow down more and in better ways whilst experiencing difficulties doing this. Although 'slowing down' seems pretty simple on the surface, when we started investigating it we found there were hidden complexities.

Our service users typically take longer to process and respond to information than our staff. Where we perhaps notice this most is when staff are interacting with service users and must consciously slow themselves down from their usual pace and instincts about how long an exchange lasts. When staff are alone with service users they generally reported feeling more able to do this but in situations when staff were jumping between interacting with other staff and other service users, or just moving through the centre together and meeting people and things along the way, they reported finding it much more difficult.

Often this difference in pace is described as service users having 'delays'. This is another one of those words that doesn't feel quite right. It does tell us something important; that the person with the 'delay' will take longer to process information and respond to it than the person without the 'delay', but it doesn't reflect the whole story... 'delay' only makes sense from the perspective of the person without a 'delay'. It takes that person's pace and way of experiencing the world as normal and says the disabled person's experience is not normal, which, perhaps statistically is true, and we do believe it is important to name these differences to help us support each other in the best way.



But the more we started to think about it the more we felt that this particular word impacts how we relate to each other in a negative way. It makes it feel like the person with the 'delay' is always having to 'catch up' to our 'correct' pace. When actually our service users are just experiencing time in a different way. In trying to helpfully 'see' and name our differences here we perhaps oversimplify and do a disservice to each other. Each of us has our own unique internal sense of time that impacts everything we experience and who we are.

But how do we actually apply this to how we interact with each other? Is it not true that the majority of the world runs at a pace closer to those without 'delays'? Yes absolutely. And perhaps we can't change that, but we can find our own pace in our day to day interactions and time spent together.

Reframing our discomfort around passivity

We found the writing of Jill Goodwin and Ellie Griffiths helpful in exploring these ideas. In their report "Being With' in Sensory Theatre" (Goodwin and Griffiths, 2023) they discuss the thinking behind and impact of a communal, sensory focussed art experience on families with a child who could be described as having PMLD. One of the themes is passivity, they discuss their experiences of being with individuals who, like our service users, may be seen as being more 'passive' than 'active'. They talk about how it can create discomfort and vulnerability to be engaged with



someone who is wordless, or doesn't have easily recognisable or perhaps socially valued responses. They discuss how often we are compelled to meet 'passivity' by "becoming louder, 'bigger' and more active" to try and get a more recognisable response and how this actually means we end up disrespecting the disabled individual. This felt very familiar to our own experiences and observations.

Goodwin and Griffiths draw attention to how our own discomfort and vulnerability in these interactions can stop us being present and meaningfully engaged with individuals. This gave us another insight into why we might find it so hard to 'slow down'. Part of it wasn't actually about slowing down itself but being seen to be passive or truly seeing and appreciating the apparent 'passivity' of another. So part of the challenge is about how we think about passivity. Goodwin and Griffiths write: "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."

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What stops us from Slowing Down?

So how do we support each other to reframe passivity, to slow down and to respect our service users' experiences and ways of being? We started by trying to find out more about why we struggle with it in the first place.

Here are some of the reasons ourselves and other staff shared that made slowing down challenging:

"I'm always busy... I do complain about it but I actually think I like being busy! I just don't know how not to be... I just have so much energy"

"I have ADHD and being told to slow down or sit still just stresses me out and triggers all that weird stuff from school"

"I guess it makes me feel a bit on-display or judged..."

"I think I worry about seeming lazy or that I'm not doing my job properly"

"I'm worried that if I let myself stop I won't be able to start up again, it takes a lot of energy to get myself juiced up for work."

"I get bored easily"

"I'm used to be in working environments where everything goes wrong a lot so I find it hard to relax"

"I've tried doing things like meditation but it just doesn't work for me"



Amongst these reasons we can see elements of discomfort around the feeling and expectation of slowing down, a sense that it's just too hard or we're not good enough at it and feelings of vulnerability or anxiety around being seen as passive.

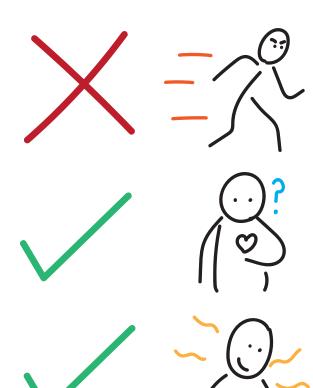
Explorations

With so many different findings we decided to explore and experiment with 'slowing down' in a few ways.

'Doing a Task' instead of 'Getting A Task Done'

We decided to start relatively small and each identify one task we did with a service user and we asked the wider staff to do this too. The task would ideally be something done everyday such as preparing and eating a morning snack, getting someone out of their wheelchair and into their walking frame and walking around the centre or providing a form of personal care. We then asked ourselves and each other to commit to reframing this task as not being something we needed to 'get done' but something we would simply 'do'. We set the following intentions:

1.When doing *the task* we will not rush.



2. When doing *the task* we will take time to notice how we are feeling and tune into how the service user is feeling.

3. When doing *the task* we will be playful and not take ourselves too seriously

We wanted to try and bring this idea of slowing down and being present and intentional with our service members into the everyday mundane things, rather than it being something reserved for specific sessions or spaces.

Lakshmi, a staff member, shared her experience of this with Sam, a service user:

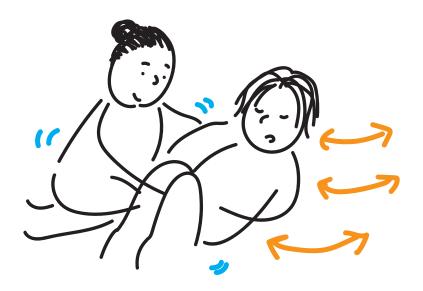
"Each morning I take Sam to the physio room to do his assisted stretches. Another staff member joins me to get him into the hoist out of his chair and onto the mats, they leave for a while whilst we do the stretches and then come back to get Sam back into his chair.

"I join Sam on the mat and go through his routine. There's so much to remember that I'm usually stopping to read Sam's programme between stretches. Sam usually seems quite checked out during this time, but then my head is also in different places thinking about what stretches we need to do, worrying I'm doing them wrong, hoping I'll be able to grab a staff member to help me get Sam back in his chair... When I stopped to actually think about what I was doing I realised I was really not paying attention to Sam and it was meant to be something that was about him and his body. So it felt like this was a really good task to try this experiment with.



"On the first day I felt a bit unsure, when we were getting Sam out of his chair I didn't really manage to slow down at all! But when the other staff member left I took a moment to think and realised that the easiest and most straightforward thing to do would be to just lie down next to Sam on the floor for a moment. This ended up being the best thing! We would just lie together for a few minutes. I found that the more we did this the more I could relax into it and would start to really notice how Sam was breathing differently on certain days, how his legs and arms would sometimes be really tense and scrunched up and sometimes they'd fall more relaxed... I'd then take a moment to read over his programme before starting the stretches. I'd already be more tuned into Sam so it felt like I could tell what would be harder or easier that day.

"There's one stretch, where I rock Sam's body from side to side, and when I did this I noticed he would let out a little sigh... I started doing this one for a bit longer and he would sometimes close his eyes and seemed just very comfortable and happy.... It's definitely been a really valuable experience and I feel me and Sam are just actually spending enjoyable and relaxing time together rather than worrying about 'getting his exercises done' so we can get 'back to the routine."



The 'Slow Zone'

We decided to try and create a playful space to explore the idea so created the 'Slow Zone'. We moved some of the chairs and a table in the main hall and marked an area out on the floor with bright orange tape and made a sign to put next to it saying 'Slow-Zone'. We then put a few objects next to and in the space- some shiny bowls with bouncy balls in them, paper and pens, soft heavy blankets, a gym ball and some pots of play dough. We also put a couple of chairs in the space.

We introduced the space to staff at our Monday morning meeting and said it would be there for a week. We explained that it was a space to experiment with being slow in and invited them to spend time with service users in the space throughout the week. We then used the last five minutes of the meeting to invite staff to try it. Most staff headed off to do last minute prep before service users arrived but a few stayed behind. One simply took their coffee and sat on a chair in the space and sipped it slowly. Two others rummaged through the materials chatting away. Throughout the day and then the week however most staff used the space in some way.

At the end of the week we asked staff to anonymously share feedback on the experience by writing on notecards and putting them in a box, we also had chats with staff who we noticed using the space often throughout the week. Here are some of the things staff said:

"At first I just thought 'I can't do this' but then I realised I was trying to force myself to stay still and that wasn't actually the point, instead of trying to be still I just sat and let myself fidget and doodle and found it almost enjoyable!"

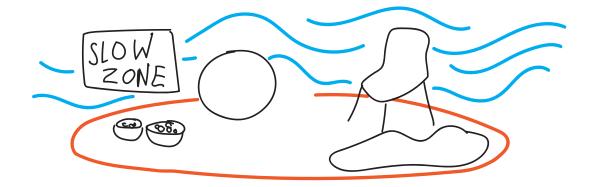
"I'm not sure how much she [service user] got out of it but I definitely found it relaxing and was a bit more at her speed when I was introducing the objects to her. She especially enjoyed watching the bouncy balls rolling around the shiny bowls. I don't know if I would've tried that usually"

"He [service user] really enjoys me being all dramatic and overacting so when we went into the space I started doing everything in like, cartoony slow motion, he found this very funny but also I noticed when I was holding out objects to show him he paid a bit more attention than usual. It might just have been coincidence but I think probably I was also just able to hold them out longer than I usually would because it was like part of the game and we were having fun"

"It was fun just having permission to like, really slow down and not just be jumping from stimulus to stimulus... it made me realise how much of the time when I think I'm slowing down I'm not really..."

"It's funny cause I usually associate slowness with boredom but this kind of turned it into a game and I got much more into it than I thought"

"I get the idea but I didn't really feel like it worked having it in the big open space, maybe it could have been more private in its own room or something"



Pacing as 'Access Need'

The third exploration we introduced wasn't an activity but something for us to reflect upon and think about on an organisational level. We wanted to make sure that, whilst being kind to ourselves and each other, we didn't just make this about our experience as Staff who are Linguistic Beings who typically aren't considered to be 'delayed'. We wanted to make sure to take it seriously as something that was potentially negatively impacting our service users. Our initial sense that 'slowing down' was something we needed to do but weren't doing properly came from a real problem that our service users face where their ways of being and the things they need to exist as themselves weren't being fully respected and met.

We've started thinking of pacing as an 'access need' that is just as important as the access needs we recognise already like ramps into buildings, wide doors that accommodate wheelchairs, straws for drinks and hoists for mobility. For our staff these access needs are generally very obvious and non-negotiable. What if we could get to a stage where pacing (which often means slowing down) is an obvious and non-negotiable access need too? We are working on how we can make this more tangible, what questions we can ask and how we can make sure it is a part of our policies and procedures. This is a journey we are only just starting but already just framing it in this way has made it easier to sit with our own discomfort and push through to do better.

Conclusions

All three of these explorations have already brought about successes and positive change whilst also highlighting that we have a way to go. When we worked to engage with other staff around these ideas it was often tricky to figure out how to explain or pitch the ideas in a way that wouldn't make people feel too self-conscious or vulnerable. It feels important to acknowledge and make space for the discomfort and trickiness that comes up for staff whilst also advocating for the importance of slowing down and addressing this issue in how we interact with our service users. We were also aware that it felt difficult at times because what we were trying to do



is so different to what most of the world is like, most of us live faster and busier lives than what we probably want or need. We intend to keep exploring and challenging ourselves and each other to discover what lies beyond the discomfort of slowness and the positive potential that could have on our service users' Page 29 experience here at the centre.

Case Study: The Playful Artist



Tom Jeffrey is an artist that has worked with service users at the centre over several years. He describes his practice as being about using play and playfulness to create connecting and joyful moments between people. He works a lot with individuals like our service users and feels he gets as much out of sessions as anyone else involved. We asked Tom if he could share some reflections and experiences from the past couple of years as he has been working regularly with our service users and staff as we have been on the exploratory journey. Tom shared the following words and images

A Space to Try Things

"I've noticed a lot of shifts here in the last couple of years, it feels like the culture of the centre has maybe loosened up a little. It feels more like a space where you can be playful and feel emboldened to try different things. Which is so important. I work in a lot of different social and health care settings and something I often see is a fear of taking any sort of risk.

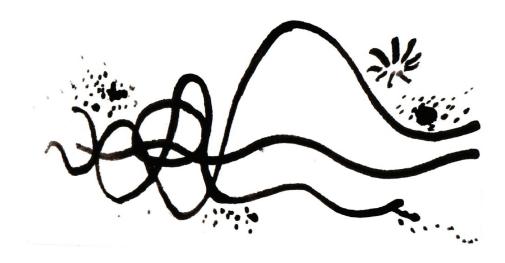
"So when I come into those spaces trying all these new things and not seeming like I mind too much if it doesn't go to plan... I often feel like I'm being a bit disruptive. It can feel like people are looking at me and expecting me to fail somehow. Then, if something isn't received well or doesn't 'work' as such it's seen as proof that we shouldn't have tried something in the first place rather than a provocation to try something else. I don't feel that so much here. It feels like a space where you can try things and that intention and energy is welcome."



Cultural Shifts

"I've also noticed that I'm not seen as quite as magical or radical as I used to be! Which is a bit of a blow for my ego but it's also really nice. A lot of the things I do in my practice are actually very simple..

"I try to create a shared vocabulary with whoever I'm working with- that might be a vocabulary of sounds or movement or objects to play with- it's rarely regular words. I try to pay attention to whoever I'm working with in a really open and deep way, try to notice whatever it is that sparks excitement or interest in them, however small. I try to show up as myself and just be another human being in the room who has likes and dislikes and excitements and fears.



"I really think the sort of 'successes' I've had over the years working here are as much about those three things as they are about any mad creative skills I might have. And now these are all things I think you are doing here more as just a natural part of your interaction and the spaces you create together. So I definitely need to up my game to stay useful and relevant here. Which is a very welcome challenge!"



Being Challenged to Think Differently

"I've also learnt a lot from being here over these past couple of years. I've always felt like when I come here I learn from all different members of your community but I've definitely been more challenged to reflect on what I do and why and how I do it.

"One incident in particular really stands out that has shifted something in me. A year or so ago I was in a session with a service user, we were having some quite intensive engagement staring into a spinning disco ball together, side by side, lots of soft vocalisations, humming from me, giggling from them. When, seemingly out of nowhere, she started to cry. It was just one tear at first but then more came. It felt like some big emotions were happening. But my first instinct was panic. Feelings of "what have I done... are they okay... what can I do.... what is happening...?" were rushing through me as I snapped out of this really embodied-in-the-moment mode I was sharing with this person and into problem solving mode...

"I had a word with myself and grounded back into just being with them, and sat quietly together for a while. The tears slowed but it felt like she'd kind of left the moment. After a few moments I brought the session to a close and took her back to her room. Once she was settled I stepped out with one of her staff members and explained what had happened. The staff member looked thoughtful for a moment before saying, "That might be a good sign, she does get weepy sometimes but this sounds a bit different, maybe she was just really in the moment and some emotions came up."

"I was completely struck by this response. Of course, I don't have a way of knowing what was going on for this person at that moment, but I had completely assumed something was wrong... that it was a bad thing. When I think about experiencing art myself, feeling any big emotion, even a teary one, is actually something I think of as this really human experience and often a sign that it has been an important or moving one. But in that moment with this person I hadn't even considered that.

"This experience has really stuck with me and I think about it a lot and how expecting someone to have 'simple' or only 'good' emotions or reactions to things is really quite dehumanising. I'm extremely grateful to that person who let her emotions free in that session and the staff member who woke me up to what that might mean!"

Exploration: Grounding in our Energy



Valuing Different Energies

During our early meetings as a working group we spent time reflecting on and sharing how we felt about our own skills and practice. Something kept coming up that we couldn't really pin down, it was a bit slippery and elusive but felt important. We would talk about having to hype ourselves up or calm ourselves down, we would talk about uncomfortably pushing ourselves to try and be either more extroverted or more introverted and we would talk about finding it all pretty tiring. After many conversations we realised that what we were talking about could simply be called our 'energy'.



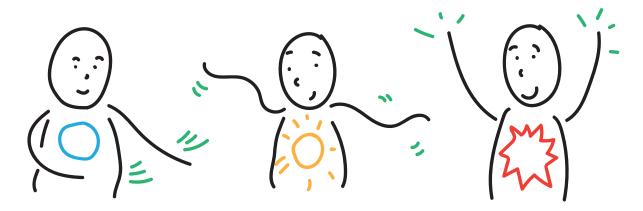
We found that we all had different ideas about what kind of energy it was best to have in our work, but we all thought that was a different kind of energy to the one we had. The more extroverted and dramatic among us felt like they were too much and the more introverted and quiet among us felt like they were not enough. We identified two big problems with this:

- 1. If we are forcing ourselves to be something we're not all the time can we genuinely connect to our service users as human beings?
- 2. If we all have an idea of what the best kind of energy is to have at work, then are we recognising that our service users are all different people with different needs and energies themselves?

When we consider these two problems we can see that actually, our team should really benefit from having a diversity of energies and ways of being amongst us. We need the bigger, louder energies and the guieter, gentler energies and everything in between and these should all be valued; especially as our service Page 33 users also have a huge diversity of energies and ways of being.

Grounding Ourselves

Still, it is undeniable that when we interact with each other, when we come into work, we sometimes need to shift and change our energy so that we can meet each other and provide for each other. However, it feels important that we do that from a grounded place where we get to move intentionally from where we are in the moment. This then allows us to meet our service users as equally changeable and unique human beings rather than pushing ourselves into whatever shape we think we need to take.



One of our team members, Gabe, reflected this in their sharing of their last couple of days working with Dylan, a service user:

"On Tuesday afternoon I was paired with Dylan who I'd never really worked with before. I was a bit nervous so I chatted to one of his usual support workers to find out a bit more about him. They told me all about how Dylan is just super into banter and slapstick and big noises but also is into sensory lights and stuff. Which kind of made me more nervous because that's just not me... I mean it can be, but it's not my sort of natural state you know. So I went to pick Dylan up after lunch and headed down to the sensory room with him. I chatted a bit as I was setting up the projector but wasn't getting much in return. I started like... this is kind of embarrassing... but I started trying to imitate the other staff member and joking around kind of loud... and Dylan just seemed stressed out by me and just didn't want to engage. I turned the projector on and just gave him some space sitting to the side.

"The next day I had Dylan in the afternoon again but this time had a bit of a chat with myself and just made sure I was more 'in myself'. I quietly set up the projector occasionally looking over to Dylan as I did so. At one point I caught his eye and he looked away smiling. I sat down next to him whilst the projector was on and took in the visuals. Every few minutes I would feel him turning towards me and I'd look and meet his eyes and again he'd quickly turn away smiling.

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"This became a slow game and after some time we would both be laughing as he turned away. It felt so much better than the day before, I was more comfortable and grounded and was able to slowly build up to meet Dylan's mischievous energy. Dylan seemed happier too and it felt like we found a really nice connection."



Gabe's story solidified the idea for us that it wasn't so much about what your energy is but whether you are able to act and interact from a grounded place.

Explorations

To explore this idea we wanted to create a point in the day where staff were able to take a moment to settle into themselves and get a feel for where they were at that day. We first tried doing very simple breathing exercises in our morning meetings. This felt a bit tricky, it was so different to what we usually do and after a few days it became apparent that it was perhaps causing more stress than helping. It seemed to make some staff feel uncomfortable and most just struggled to not be planning ahead for their day. The morning meetings initially seemed like the obvious place to explore this because it's at the beginning of the day and there is space to take a few moments for the exercise. However this was also the reason it was difficult. Because it was at the beginning of the day staff were mentally preparing for service users arriving and often had extra bits and pieces to get done so wanted to use any extra time for that.

This experience made us realise how things that are so culturally ingrained need to be approached with a bit more patience and care. We took a step back and decided to explore it on a smaller level and experiment with doing some kind of grounding exercise at the beginning of our working group meetings. We found quite quickly that it was much more enjoyable if we steered away from the more Page 35 traditional meditation and played with making our own versions.

A favourite amongst the group is a 'Zen Poem Body Scan'. One member slowly reads the same short zen poem out loud ten times. Each time the participants are invited to tune into an area of their body. The idea is to not overthink it and just follow wherever your attention moves in the body. When the poem has been read out for the last time we sit in the quiet for another minute or so and try to sit in however we are feeling.



Conclusions

Even in our small group we found we felt overly self-conscious and struggled to engage in these kinds of activities fully in the working environment. This reiterated that this is something to be approached with care when widening it out to our staff team as if it's too far out of people's comfort zones it may be more isolating and inaccessible than enjoyable and grounding. We intend to keep working with these ideas and hope to reintroduce them more widely at a later point.

Case Study: The Unflappable Nurturer



Ania has been working at the centre as a support worker for nearly ten years. She tends to get on well with most staff and service users and is generally known as a 'safe pair of hands'. Whilst she has service users she works with regularly when someone is needed to step in elsewhere she'll often be called upon. This means she will often find herself adapting quickly to different situations and supporting service users she might not know as well as others. Ania is known for her high energy and deeply caring, seemingly unflappable nature.

Ania wasn't able to be a part of the working group over these past couple of years but was very keen to get involved where she could. She has generally been a great sounding board for our different ideas and proposals and always up for trying things out and feeding back to us, so when writing this report Ania seemed like a good choice for a case study. We sat down with Ania to interview her about her experience.

Interviewer: Thank you for finding time to chat today! You've been an amazingly consistent and willing participant in our explorations this past couple of years. I was wondering if firstly, you could just tell us a bit about what made you want to be a part of this and how you've found the experience?

Ania: Of course, I just think it's important to try different things really and just any extra input or ideas we can get... it's really easy to just get lost in the day to day chaos of this place and we don't really get much chance to think about what we're doing. So I think it's been great to have you guys sort of, taking the lead on that and having the time to actually think about what we are doing here and why. I've definitely



found it interesting! I have sometimes felt a bit unsure or sceptical but done my best to put that aside and try the ideas out. But I have definitely been pleasantly surprised a lot!

Interviewer: I think the combination of scepticism and willingness to try is really a great thing you bring. It's good to ask questions, you know? Was there anything we tried that you thought worked particularly well?

Ania: The slowing down and non-verbal approaches definitely stood out for me. They're both things that I think I really needed to feel I had permission to do... but also that I find hard. My life is pretty hectic out of work and in work and I do just find it hard to slow down and yeah, quiet is good! I forget that a lot! I know I'm quite "ahhhh!"... (waves hands in the air either side of her face) you know, no one would probably describe me as quiet! But yeah, quiet or well, not talking, seeing the effect on service users when there is just more space and how some were able to express themselves more and also I felt like I just saw more of who they are and different ways of being together.

Interviewer: Was there anything that you felt didn't work so well?

Ania: Not really, well, there were some things that didn't sort of work right away or needed changing or that we still need to work on...But I think that does just feel good because we have to try things to learn that and sometimes in the past it has felt like if something doesn't work the first time we just call it a failure and don't try again. Like the 'mindful breathing' thing we tried in the morning meeting. It didn't really work for me in that sense... but also it did make me realise how I just don't really stop and just breathe between getting to work and going home! So I'm working on that because it definitely helps me be there and more present with my service users.

Interviewer: That's really great to hear thank you for sharing! Was there anything that surprised you?

Ania: Yes a lot... I think I've just seen so many new sides to service users and staff during this time. I think also for myself, I'm a lot more confident in my own skills now... a lot of what we've done over the last couple of years are things that I sort of, already did a bit of or sort of knew deep down were important but just maybe didn't feel like I was able to try them... or even be allowed maybe. Also the sensory pairing thing! It really got me to get more in touch with myself as a sensory person and it's just still something that I think about a lot and is becoming more of my everyday. And, I've always loved working with service users, but I think I just enjoy it more now.

Interviewer: What do you want to see happen now?

Ania: Just for things to continue! Not for this to get forgotten about. I definitely feel like a lot of the things we've been trying have just been trickling into the day to day in different ways. I think we need to sort of keep the momentum going so one day we just do all this stuff and don't even need to think about it.

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Exploration: Putting Down Our Words



The Role of Speech

As Linguistic Beings, speaking is often our first instinct when spending time with another person. This generally works out fine when we are coming together as Linguistic Beings who enjoy speaking and get meaning out of communicating and expressing ourselves through words. But when we are Linguistic Beings spending time and sharing space with Sensory Beings it is not always appropriate. Or at least, speaking can't function or be used in the same way.

Sometimes speaking might still be important in these interactions. There are plenty of Sensory Beings who show enjoyment at being spoken to, hearing a voice of someone they know and like, maybe enjoying the sensory qualities of that voice and intention behind it or feeling safety and comfort in the familiarity. For some the voices of others might be the primary way that they are aware another person is there and how they experience being with others. But even in these examples it's not necessarily words or language that is being shared but sound, voice and the emotions it carries.

Speaking as Comfort Blanket



Speaking is so much our default that it can be difficult to decentralise it. Speaking can also act as a comfort blanket for Linguistic Beings and sometimes when met with someone who doesn't speak, instead of moving to speak less or use speech differently, we will actually speak more and fill the space with our own words.

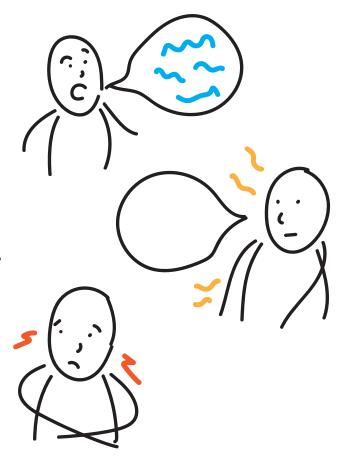
The other side of this is of course listening. We know that to listen we need to speak less and that is even more true when it comes to our service users who mostly don't use words

because we need to listen with all our senses. But we still don't do it enough! There's also something uncomfortable for us in all of this because to explore it further we need to acknowledge in defaulting to speaking, which we all do to some degree, we will likely be talking over our service users and possibly stopping them from being able to connect with ourselves and each other.

'Putting down Cognitive and Verbal Weaponry'

In trying to make sense of all this we came across an article by Gustaaf Bos and Tineke Abma (Bos and Abma, 2021) describing their research in a neighbourhood setting where people with and without "severe learning disabilities" lived alongside each other. Bos and Abma were interested in what was actually happening between these different residents and if the neighbourhood was as inclusive as it looked on paper. What they found was that a lot of what was described as 'Inclusion' was informed by non-disabled and neurotypical values. What was needed instead was for the non-disabled and neurotypical residents to find ways to let go of their familiar and comfortable ways of relating and engage in non-verbal and non-linear ways of relating with the disabled residents. This affirmed our instincts about the culture here at the centre. We also need to take steps to let go of our more comfortable ways of relating, often verbal ones, to meet our service users in shared ways of relating.

In the article Bos shares his own process of learning to let go of his 'cognitive and verbal weaponry' in order to connect with a resident he was spending time with. He describes reflecting on why he was finding it so difficult and realising that without his typical ways of communicating and interacting he would end up feeling unrecognised or unseen. This then made him feel "miserable and unsafe". We found this reflection helpful as it prompted us to question how what we needed from others to feel happy and safe might impact how we interact with others. One of the things that came up was that some of us felt that in speaking to our service users we were paying them attention and showing them respect because that is what we often wanted for ourselves. Another was that some of us found lack of speech uncomfortable



when with another person as it made us feel like we had done something wrong or caused upset. Both of these examples are reasons that might push us to speak more when with service users but they are based on our own needs and expectations and not necessarily on what the service user needs or expects.

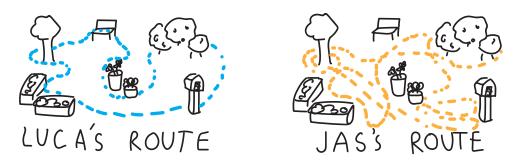
Explorations

We worked with staff to identify Service users who might especially benefit from more non-verbal time. We then, in collaboration with the staff who worked with those service users, set aside a half hour time slot three times a week where staff and service members would spend time together with the aim of not using verbal language unless absolutely necessary. Each week we gathered feedback from the staff about how the time had been and what had happened. There were two groups involved in this experiment.

Luca; Staff member, and Jas; Service user

Luca and Jas often spent time walking around the garden together, Jas was very comfortable outside and Luca also really enjoyed being outdoors, so this shared activity was big part of their relationship. Luca would lead Jas around arm in arm pointing out different flowers, commenting on the pigeons or other bird visitors and talking about the weather.

Luca was initially unsure about walking in the garden with Jas as part of their non-verbal time as it was one of the more verbal times they spent together. But Luca agreed to try it out. To avoid completely and suddenly changing the experience for Jas, Luca decided to talk to Jas as they walked through the centre to the garden and then as they stepped out together fall quiet. The first time Luca did this Jas seemed a little confused and stood still for a few moments, Luca took his arm and began to lead him round the garden on their usual route, still stopping and taking in the sights and smells and wind on their faces but not narrating. Luca was surprised to find that this didn't seem to make much difference to Jas and in fact the pauses they took to take in the garden got longer.



After a few times of spending their garden walks this way Jas started to lead Luca around the garden. Unlike when Luca was leading and they walked in a circular steady route around the garden, Jas would lead Luca in zig zags around the space, going to whatever drew his attention first. Sometimes he would leave Luca to go and be somewhere alone and then come back and lead Luca to somewhere else.

Simon and Raia; Service Users. Fiona and Taylor; Staff

Most afternoons Simon, Raia, Fiona and Taylor would spend time in a room together, the room had sofas and Simon and Raia would be supported to lay or sit on the sofas opposite each other. Depending on the feeling on the day they might spend time watching cartoons on ipads or listening to music with disco lights on. Often whilst this was happening Fiona and Taylor would sit and chat.

Initially Fiona felt that half an hour would be too long but agreed to give it a try. In order for the non-verballness to be felt they also turned off the music or cartoons during this time. At first this brought about protests from Simon whilst Raia would seem to drift off to sleep. Whilst the protests didn't last long or seem too upsetting for Simon and Raia sleeping wasn't necessarily a bad thing, it was felt that bringing in something to interact with would help get the most out of the experience and create a shared ground for everyone involved.

Two large yoga balls were introduced to the sessions. They were used in different ways, to squish against bodies, roll on the floor and, by removing the stopper, they would play with squeezing the air out and hearing and feeling it on faces and hands. Over the weeks this became more comfortable and enjoyable and there would also be moments of stillness amongst the activity. Taylor expressed that it began to feel like they were having a group conversation through the yoga balls. In a later session during a moment of stillness and quiet Simon and Raia both began to verbalise excitedly. It was hard to tell whether they were responding to each other but it stood out to Fiona and Taylor as they'd never heard these kinds of verbalisations from either Simon or Raia, let alone at the same time. After a couple of weeks of these sessions they started to spend up to forty five minutes without words.



We intended to carry out this experiment over four weeks and then evaluate how things had gone. Both staff parties were keen to continue the designated time slots but also expressed that outside of those slots they were now finding themselves speaking less and discovering new ways to share space with service users.

Conclusions

Spending more time de-prioritising speech and being together in non-verbal ways feels key to improving the experience of service users at the centre but also the relationships we all have with each other, staff and service users.



With just these two groups of participants we saw much richness coming out and staff members and service users experiencing new ways of being together. With Luca and Jas, Jas took the space created by Luca's non-speaking and used it to take control of his experience more and both Luca and Jas were able to spend more time in a state of sensing and experiencing the garden together. With Simon, Raia, Fiona and Taylor a sense of conversation without speaking was found through playing together with simple familiar objects. There was also the possibility that having this non-verbal space enabled service users to be more aware of each other. All of these things felt like valuable outcomes and experiences.



They also highlighted for us that we can pay attention to each other in so many different ways and removing speech allowed us to explore these more.

Implementing the idea of designated non-verbal sessions worked well as a way to help staff initially explore and experience the value of non-verbal space and we are planning to repeat this with other groups of staff and service users. Through this the hope is that over time comfortable and joyful non-verbal will become a natural part of the wider culture at the centre.

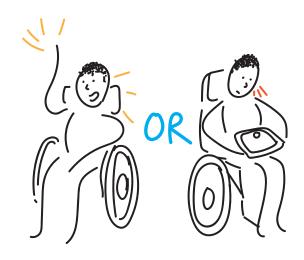
Case Study: The Surfer of Chaos and Calm



Dylan is a service user in his mid fifties. He has been a regular at the centre for the last ten years and currently spends five days a week here. He used to live with and be cared for exclusively by his parents and lived a relatively quiet life. He started attending the centre more and more when they became less able to support him with his physical needs. He now lives full time in residential care.

All or Nothing

For the past few years Dylan has spent most of his days in a space with one other service user and two staff members. He would occasionally visit the sensory room where staff would put on projectors for him. In these times Dylan would often watch for a while before dozing off. Most of Dylan's interaction with others came from roaming the centre with a staff member pushing his chair a few times a day. On these excursions he would be enthusiastically greeted by staff members he passed who would joke around with him; dramatically hiding their faces, pretending to scold Dylan or injure

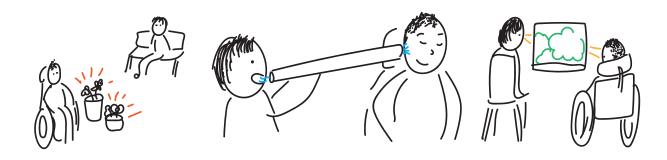


themselves in a slapstick fashion. Generally Dylan would enjoy these interactions; pointing, laughing and vocalising loudly along with the staff. Some days however Dylan would be much more withdrawn and become upset when interacted with, hiding his face and letting out low moans. On these days staff generally stayed with Dylan in his room, Dylan would then usually watch football on an ipad and sleep a lot.

In discussions towards the start of our project staff members who knew Dylan shared that his 'all or nothing-ness' with what he could cope with was becoming more pronounced. They felt that exploring different ways of being with Dylan could be really valuable but didn't really know where to start given they felt like he had two main 'modes'. They decided that they would set aside two forty-five minute slots a week where the aim would be purely to explore what time together Page 44 could look like.

New Ways of Being Together

Staff ended up using these sessions to try some of the different explorations we had introduced. Many of them were things they were already doing in some form, but having that focussed longer time gave them the permission and space to really push and explore them deeper. They did things like sitting alongside Dylan in quiet whilst looking out the window at trees blowing in the wind, they explored using their voices to make sounds rather than words which led to whole new kinds of conversations with Dylan, they rolled bouncy balls down pipes into his lap playing with the element of predictable surprise which he loves, they sat close and they sat further away. When Dylan wasn't wanting to interact with others in a loud acting out/humorous way they wouldn't default to him being in his room and instead wander around the centre and indicate that staff should greet him non-verbally and quietly instead. Some things worked really well, some didn't and some were unpredictable day to day.



Surfing the Wave

After a playful sensory session with Dylan one day staff were reflecting on how it felt different somehow, like something had shifted between them all. They came to the realisation that Dylan had occupied several different energies in that session. He had moved between moments of chaos and calm and back again, surfing the wave with apparent ease. It seemed that getting to know Dylan so much better over time just by experiencing different ways of being together had allowed them to break out of the 'all or nothing' pattern that Dylan had so often occupied or been hemmed into. Staff were more open to the different Dylan's and no longer had a default mode depending on which Dylan they thought they were seeing on a particular day.

One staff member shared a bittersweet reflection on the changes they'd gone through together; "I feel like we'd just kind of gotten a bit stuck with Dylan, we were seeing him in this sort of black and white way and that was probably affecting how he could actually be. It's been really important to realise and understand this. Sad too, I feel a lot of regret like I let him down, but things are so much better now and we won't

Page 45 go back to that stuck place."





A Need for Play

In our early discussions with staff two seemingly contradictory themes kept coming up. Firstly there was a sense of stress and concern about how to get everything that needs doing done whilst still providing a good level of care and opportunity for service users. Secondly there was a desire and need to be able to be more relaxed, open to taking risks and enjoying being together. A lot of us seem to feel these contradictions in our day to day work. We know we need to be more playful and engaged with the sensory world but we also have lists of tasks that need to be done. We know we need to try new things with our service users but also need to create a safe and comfortable environment



which often requires predictability. We feel we need to be more ourselves to build genuine relationships with our service users but we also feel we need to be an appropriate 'work version' of ourselves.

While we were going around in circles with all of this we started to think about play. Play is also full of contradictions. It's important and silly. It's chaotic and calm. It's easy and hard. It's simple and complicated. It's fun and emotionally challenging.

We started to feel like maybe instead of trying to solve all these contradictions maybe we could just create a space where they can all exist together and just try to play a little. This also felt like something we wanted to give to ourselves and each other.

Explorations

We approached Tom Jeremy, an artist specialising in play, who facilitates sessions with some of our service users. We proposed he join us on an upcoming in-service day to run a play session in the morning for staff which he happily agreed to.

On the day, after a morning meeting the staff joined Tom in the dining hall where he had set up a play space. He explained that all the objects and play-things in the space were the same things set up in the same ways he would set them up for sessions with service users. He spent a few minutes talking about the space and setting the parameters for the session. He emphasised that the aim was to simply explore the space and engage with whatever might capture our interest. He then put on some music and let us begin. At first many of us were quite hesitant and unsure, Tom moved about the space and stepped in here and there with invitations and permission to try different things. After about ten minutes a barrier seemed to break and people started to relax into things and engage more freely.

We asked Tom to describe his approach to the session:

"I wanted to make sure that I approached the session in pretty much the same way I do with the service users I work with here. Everyone has their own version of play and my job is to just help each individual tune into that and feel able to enjoy and get into the flow of it.

"The main difference today is just that people need different things in terms of accessing the space and permission to play. Access wise I'm doing a lot less then I'd maybe typically do in a session with a service user but I'm still occasionally showing or demonstrating things to people. Permission wise I'm doing a lot more than I'd maybe typically do in a session with a service user. Adults who are less used to having space to play tend to need permission more! Sometimes that's verbal permission but sometimes that's just the permission you can give by playing yourself, showing that it's okay and welcome."



Staff Responses

Staff overall responded very positively to the session despite many expressing being unsure at the start. These quotes were gathered from the written feedback form at the end of the day;

"I was surprised by how quickly it went once I started enjoying myself"

"Gave me so many great ideas and different ways of looking at things."

"Play can be so simple, we don't need to overthink it, we can just do it."

"So many things I did in session made me think of my service users, I can't wait to share them"

"It reminded me of playing with my boys when they were younger, it was good to be taken back there."

"It's great to take time to play when as an adult it is frowned upon. I found it a really calming and non-judgmental experience."



Conclusions

Play is perhaps one of the easier things to de-prioritise to make time and space for others but it is a valuable and important part of all our lives. We really valued getting the chance to remind ourselves of that. The power of just having a break from all the thinking and letting go and having fun can't be underestimated! A lot of the feedback from staff showed that getting to engage in play themselves also gave them a lot of ideas for how to play with and alongside the service users.

It still feels like there is more work and thinking to be done around addressing that tension between the pressure and need to 'get things done' and the need to be more playful with our service users. But just getting to experience being playful for ourselves feels like a good start. Whilst we don't have the time or budget to do something like hold a play session for staff more often, we intend to look for smaller creative ways to bring more play into all of our lives.

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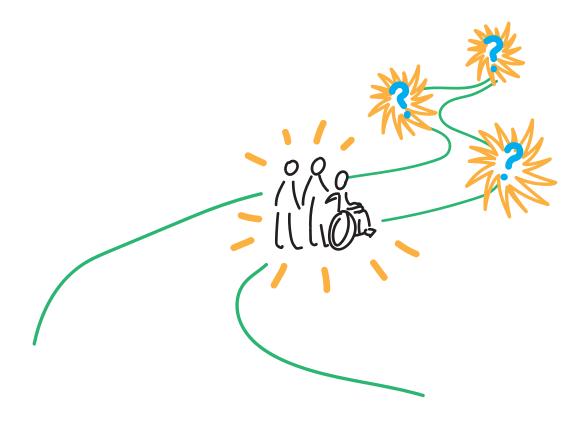
Conclusion



This report attempts to capture the thinking of and trying out of new ideas in our service with the aim of making our community here at the Springleaf Centre a place where Sensory Beings and Linguistic Beings can share joyful, authentic, playful and connective space.

We feel like we've come a long way in these last couple of years. We have felt more and more emboldened to look inwards and ride the waves of discomfort that can come with deep reflection. We've tried new things and practised being vulnerable and taking risks in our day to day lives. There have been times where it's felt frustrating for us as staff and like we just want to go back to our old 'normal'. But the more we've experienced and explored, along with the new things we've learned with and about our service users, the clearer it has become that that 'normal' was a normal that often didn't truly see and respect our service users for who they are. So there is no going back! There is more work to do and more ideas to try but there are also many new relationships and possibilities to enjoy.

We look forward to looking back on this report in another two, or five or even ten years time and seeing how far we have come again.



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