

FROZEN LIGHT

Frozen Light Podcast

Episode Eight-Interview with Sarah and Dan Walker

- Lucy:** Hello and welcome to the Frozen Light podcast.
- Amber:** A podcast aimed at staying in touch with the PMLD community in the age of coronavirus.
- Jingle:** *Jazzy piano music with scatting.*
- Lucy:** I'm Lucy Garland and I'm one of the Co-Artistic Directors of Frozen Light.
- Amber:** And I'm Amber Onat Gregory and I am the other Co-Artistic Director of Frozen Light.
- Lucy:** And Frozen Light make multi sensory theatre for audiences with profound and multiple learning disabilities which tours theatre venues across the UK.
- Amber:** At this time and the theatre scene being shut, and people aren't going out, and we're unsure when people may be going to the theatre again we have started this podcast to stay in touch with the PMLD community during this time and we would absolutely love to hear from you. You can get in touch with us on info@frozenlighttheatre.com.
- Now that we've heard very vague plans about how the theatre sector might start to open firstly with rehearsals we'd really, really love to hear from viewers about their thoughts about coming back to the theatre in the future and how they might feel.
- Lucy:** Yeah, so please do get in contact. We're trying to hear from a wide range of voices as to how you would feel about going back to the theatre. What would need to be in place for you to feel safe to return and what Frozen Light can do to support you on that journey. So do please get in touch and we'll put our contact details at the end of the episode.
- Amber:** We're really excited today to be joined by Sarah Walker and her brother Dan. Sarah has previously been to two Frozen Light shows, one with her brother Sam and we can't wait to welcome them on to the podcast today.
- Phone ringing:** *Phone sound effect*
- Lucy:** So we'll just give Sarah a ring now.
- Amber:** Hi Sarah, thanks so much for joining us on the Frozen Light podcast today.

Can you introduce yourself to the listeners?

Sarah: Yeah, thank you so much for having me. My name is Sarah Walker. I am the sibling to two brothers who have PMLD, we're in our 30s now, and very suddenly we lost our younger brother Sammy last year. So it's just Dan and I now, and we're here to talk to you about our experience of lockdown.

Lucy: Amazing, well thank you for coming, and I know that we've met you at Frozen Light shows so we're really excited to talk to you today. So Sarah can you tell us what does your lockdown look like and how has life changed for you and for your family etc.?

Sarah: So life has changed quite significantly. On 17 March we made the decision to shield my brother Dan before any Government decision was made and many weeks before we received a letter instructing us to do so. Dan had had an ambulance admission to hospital for breathing difficulties only a couple of weeks before COVID sort of landed here and we felt quite strongly, and we still feel quite strongly, that to be honest he'd be unlikely to survive if he did get COVID.

So we have obviously taken every measure that we can to protect him. So we usually have a small team of PAs that we employ through an individual budget and so Dan's support is a balance of family support, I'm actually a paid member of Dan's team and support, and so no-one has been over the threshold since 17 March.

So we've not had any PAs in, we've not had cleaners in and we haven't had visitors, and Dan hasn't been out of the house at all although there's some breaking news on that that this week we've taken some small steps to be brave and go outside, and that was directed by Dan but we'll probably come to that a bit later.

So normally Dan would be going out every day supported by like a blend of family and PA support and that would be going on bike rides and that is an accessible bike. Walks, go to the zoo, he normally goes swimming several times a week and obviously all of that has stopped, and so we've had to try and find a new routine for Dan to keep him stimulated and happy during this time.

Obviously all of us have had to sort of change ourselves in this time but one of the main things for me is that on the 17 March I actually moved back into my parents' house. So Dan lives with my parents and I live just up the road but at the time of lockdown some very close family friends, our chosen family, were in the process of relocating so they had moved from Cambridge.

And they were staying in my house so they're in my house and I've moved

back in with my parents so that we could shield Dan. At first obviously we didn't know how long that was going to be so I took a bit of an overnight bag with some clothes and the weather has changed quite a bit since lockdown started so I've had to stand outside my house in my garden and ask them "In the third drawer down I think there might be a t-shirt" and get them to get some of our bits and bobs back for me so I've got more stuff to use.

So that's obviously quite significant but it does mean that we've got them nearby to remotely support us. It's Jeanette and Stuart and their children, Indigo and Malachi. Each day they come, my parents have got a dog and I've got who I call my grief puppy so after we lost Sam last year six months after that I decided to get a puppy because I needed something to express my – give all my hugs to and things.

Because Dan and I have a bit of a different relationship than I did with Sam and hugs are definitely much more on his schedule and they do occur and he sits on us completely but, yeah, most definitely that's on his thing whereas Sam and me we kind of came as a package. Often he would sit in this corner of the sofa and he would sit on my knee really because Sam was very small.

But obviously trying to look after my own grief puppy and support Dan was really difficult so the puppy, who's called Mr Bingley, I don't know if there's any Pride and Prejudice fans out there, but Mr Bingley loves a ball. He goes and stays at my house during the day most days so our friends come, they walk the dogs, they bring my parents' dog, Rory, back and Mr Bingley goes and stays at my house.

And they've also been supporting us with doing sort of going to the pharmacy, going to the shop and things like that but that has changed again recently because since the restrictions have eased slightly they've taken the decision to stop going to the shops in the hope that they will be able to support us in a more direct way, that's what we're moving towards, that I'll be able to go in my house and it will be another option for Dan.

Another sort of place that he can go to. Go and have his lunch somewhere different than just here and things like that. Obviously it's been really difficult, we haven't really had any guidance on what to do with the support workers so my mum leads the package and she has all the employer responsibilities of that.

And it wasn't until about 13 weeks into lockdown that we got any letter from Social Services with any guidance about what we were meant to do with them. About we couldn't furlough them, my mum was ringing the insurers and lots of different – so obviously we've got the employer responsibilities but with no information of what to do so obviously we took

the decision that they weren't coming into the house.

But it's very difficult to remotely support someone with multiple learning disabilities. Some of the team have been really great on – Fi, she's been writing some support plans of like craft activities and things to do in the home. There's a project that me, her and Dan had started before all of this where we were building a sensory board with like door knockers and things on.

And her and her partner have been building that at home and things so she's been doing some of those things remotely but for the first, for many weeks we were paying them and we didn't know what our responsibilities were really. Obviously we wanted to support them but it was really tricky and like I say we were just given no guidance.

And then after about 12 or 13 weeks we got a letter from Social Services saying the staff could be paid for, I can't remember how many weeks, but a certain number of weeks full pay but that time had come and gone by the time we received the letter so again not much help or guidance there at all.

Lucy: Has Dan continued to get the benefits and have you been able to get the money to be able to pay them, has that continued?

Sarah: Yeah, so Dan's packages, there's been no change to the packaged but obviously one of the many things that we've been worried about is that we didn't know – had no reassurance that that was going to happen either and no information about whether it was correct to pay them for not working and all of that kind of thing. So that's been really difficult and certainly for my mum who manages the package a really unnecessary additional stress and strain.

I don't know whether I'm allowed to say but she rang Social Services for guidance and the Social Worker responded with "We're all running around like headless chickens here".

Lucy: Helpful.

Sarah: Very helpful. So we've got a couple of PAs who just work a small number of hours for us that are key workers elsewhere. So one of our PAs is an Occupational Therapist and the other one works in the Morrisons Distribution Centre. So both of them right at the beginning contacted us and said "We know that it isn't safe for us to come in and provide any support for Dan".

That was a mutual agreement and their responsibilities had increased as well so that was fine, but then had a couple of people that we're their only job and so obviously we've been looking more closely at that. So they have

been coming into the garden now and doing some sort of things to help clear the space with Dan, make it a bit sort of more pleasant for us to spend the time in because that's the only place that he's been going.

And we've been trying really hard to keep a connection with the PAs. Dan is really significantly visually impaired as well as his learning disabilities and so obviously things like video calls and stuff are trickier to manage. I'm talking to you now on the iPad and Dan is used to if I would ever go like away for the weekend or something I'd probably do a bit of a video call. He's used to sort of the concept of it.

But we mainly use it for doing videos as a communication guide. So if we were going to go swimming we'd have a video of Dan swimming on the iPad to give him all the clues of like sounds and colours, and things like that, and obviously we don't know 100% what he's scaling out of that but it's what we can do to give him as many clues as possible.

We asked the PAs to call in on the day they would be working and just have a bit of a chat with Dan on the iPad and we've been really pleasantly surprised with how he's responded to it actually. We'd say that the PAs are all in the box now. So he picks the iPad up and sort of gives it a shake if there's no-one there so I think "Who can we ring?"

So you can definitely see in his eyes and he'll have a smile when he recognises someone's voice but I think that's been a huge thing for him because not only have we had lots of people that come and go in our lives, as is common I'm sure for people with PMLD, the staff that work for us, their lives change and people move on and you might never see them again.

And that's hard enough for us as a family when we know where they've gone and what's happened. We also had a PA that had worked for us for 14 years who was a really, really close member of the family. Was kind of more like a brother and he had a tragic bike accident three years ago so he was – had been part of Dan's life and then disappeared.

And then obviously our brother Sam passed away six months after our Granddad passed away. So Dan has had a lot of loss and we were really worried about this whole "Okay Dan, you've just got me, mum and dad now" to try and reassure him that these people were still there, and still there for him. So that's been really interesting to give that a try and see how he's responded to that, and he's definitely recognising people's voices.

There's definitely some positives that have come out of this time in lockdown. Obviously since we lost Sam I've struggled very much so with my grief both on an emotional and a physical sense. My energy levels have been really low and so supporting Dan in a direct sense had not been happening as much because I've found that I was needing what I call a

toddler nap.

I was having a sleep in the day. I couldn't make it through the day without having a sleep but Dan and I have spent some really lovely time together since lockdown because he and I sort of do a music session and do craft and things like that. That's one of the things that we definitely connect together doing.

Amber: You mentioned music there and you've sent us a lovely clip of some music that Dan's playing, so we'll play that now.

Dan: *Singing, vocalising and playing the piano*

Amber: You've spoken about the lack of advice you've received and we're now speaking on Tuesday 7 July, obviously there was the news about people no longer having to shield from 1 August with very little information other than that that's come out.

And it's been a bit of a recurring theme that in the podcasts people are saying we're not exactly sure where to go next. How do you guys feel about that?

Sarah: It's really scary and to be honest since the restrictions have eased we feel more scared now than we did before because when I was going out on my walks when the restrictions were enforced you felt like everyone was sort of working together on that. You could tell that people were keeping their distance and respecting that.

And now it really feels, there's more traffic on the road and everyone else seems to be getting a bit more back to normal and it actually feels more isolating now than it did before. I definitely feel we're very much forgotten about. People with PMLD weren't contacted for a long time by their GPs and things like that.

Our neighbours both had had shielding letters and Dan's level of support and risk from COVID I would think would be much greater. It's really difficult because now it feels like people that are shielding, their family members have been assigned into this well we all need to get on with things now for the economy and all of those things which is absolutely true.

But I saw a lady talking on This Morning and she said, you know, people who are vulnerable they just need to stay in and then the rest of us need to get on and get the country moving again. Well that's really unfair.

Amber: So unfair.

Lucy: Not nice, is it?

Sarah: No, it's horrible, and so now we feel more isolated than ever. To be honest at the beginning of lockdown it was quite easy and I know that sounds strange but I've heard other people say it but for myself, with my grief and things, going out and about and forcing myself to go to places took such a huge amount of energy it was like a reason to not have to do that.

So the pressure was taken off in that respect but also I think families that have grown up with people with PMLD they're used to making sacrifices or changes to their lifestyles or plans because of the people they love. It's just a daily part of our experience to, you know, not go to that concert or whatever because someone is ill and change our behaviour.

And I think the general public found it a lot harder because they don't have any of those restrictions. They don't have reasons why they have to modify their behaviour and so for us, you know, Dan is in front of me every day and I see the reason why I'm sitting on the doorstep every week and spending an hour and a half disinfecting our online shopping delivery.

You see people walk past and you can see them thinking what's she doing. Obviously people aren't taking it to that extent and they don't need to but it's really easy for them to forget that there are people like Dan that need protecting and even more so now because they're not visible are they? They're not out and about even more so than normal.

I've ordered some hi-viz, very fetching hi-viz vests that basically say shielding from COVID-19, keep your distance. So while we take these steps to going out with Dan when we make these changes in the coming weeks it's a massive glaring sign to say here we are and normally obviously you're trying to fit in. You're trying to blend with everybody else and you're encouraging physical contact and physical experience with other people.

And it's really weird that now we're like keep away from that person, sort of stand back. It's so much more difficult to socially distance with someone in a wheelchair than it is if you're on foot. The last walk we went on before we went into lockdown was so stressful for mum and I that that was kind of when we decided that we weren't going to take Dan out again.

I mean we were sort – we went to somewhere where we thought would be quiet. We could see people coming up ahead and we were moving over to the side but there was a lady and she approached, and she was trying to stroke the puppy and we were like “No, you need to keep your distance. My brother is vulnerable, we're trying to shield”. That was hard enough when it was kind of more prevalent and now I think people are just – they're fed up with it so they're getting back to normal.

But unfortunately for us that's not an option. So, yeah, we've got our nice

fetching hi-viz vests coming soon hopefully.

Lucy: They sound great but I think you're right. I think that point about people, you know, and I know how active you are, have been with your brothers, getting them out and about and doing stuff, and trying to access everything and now people will become invisible again and like you say forgotten. Like forgotten in three months. We're all getting back to normal and people are now allowed to say "Well the vulnerable can just stay inside". So that's acceptable in the name of COVID and that's horrific.

Sarah: Yeah, and obviously we do. We choose to protect Dan in that way but it is isolating and it does feel sad to kind of, to hear yourself described that way by people talking on the telly, you know, "Oh it's okay, they can stay in". It's really demotivating. So I guess one of the reasons why we have started to get a new routine for Dan.

So Dan has noticeably because the PAs aren't here has been wanting to spend more time directly with us. Obviously he has high level support needs so we are with him almost all the time but, for example, after each meal he will normally take us up to his bedroom and he'll have some time just tapping his favourite toy and spend some time in his room.

Now the breakfast trip is now just eat my breakfast, he takes us upstairs and then more often than not by the time you've got back downstairs he's back on the landing. So it's good because he's still getting that exercise of going up the stairs but he still needs to do that part of the routine but he wants to be back near us. So he does spend a little bit more time after lunch having that time.

But definitely he needs us, even when he's standing at the keyboard he wants you right with him. He wants to hold your hand and things like that. He's definitely asking for that closeness and reassurance which is obviously understandable. And one big thing that we had to do, I mean Dan would normally, he's non verbal but part of his communication is very physical.

So he can walk around the house with support and if he wants to go out he would normally walk us to the front door and he often do that. He'd have his breakfast, go upstairs, come back down, have his morning smoothie, and then when he was ready he would take us to the front door and he didn't do that for a little while and one of my biggest worries actually was, secondary to COVID, was a worry that he would lose a lot of the confidence that we've been working really hard to build up on him going out and about and him feeling settled in the car and things like that.

Lucy: So we've heard from Annie Ferguson that you've been doing a creative challenge. I mean everything you talk about sounds super creative but can you tell us a bit more about how this idea came about and how it's shaped

this time in lockdown?

Sarah:

Obviously there's been loads of great resources popping up as lockdown came about with people sharing sessions. So we tried to do it on Zoom or on Facebook but they didn't really work for Dan because if they were time specific and that didn't work for Dan, you were trying to get him to come into one room and things like that. So it was more looking at once we got our music routine settled it was then looking at how could we make each day a bit different.

How could we create sort of, you know, something new for each day rather than feeling a bit like the Groundhog Day effect and personally myself, my mum, our friends, have found this thing the 25 day drawing challenge and we did that and it was a nice way to connect through like WhatsApp and share what you'd done that day.

But not particularly practical to sort of include Dan in. So often I'd share a picture of him doing something relevant to the theme and then after that my mum designed a two week cooking challenge because that's more in her area of expertise. And again Dan enjoyed certainly sampling that and Dan and I created a very amazingly delicious gluten free biscuit based lemon meringue pie as part of that.

That gave us some focus and interest but we wanted to get some more variety and focus, and motivation sort of for each day. Jeanette and I, my friend that's living in my house, we spoke with their children and chose some different themes that we thought we might like to work on and we settled on the be creative challenge so that it was more flexible and more open for people to interpret as they wanted.

So you don't have to be particularly arty or you don't have to be able to cook. You can either learn something new or try out something, or you can do something you're really comfortable with. So hopefully it's not sort of as exclusive really. And Dan and I have rediscovered loads of toys and activities and things that we spent some really nice time enjoying.

Things that were in the cellar that we haven't used for ages because it fitted with a certain theme. We made some little videos and things like that and it's made us feel more connected to others because we've been sharing it on the WhatsApp group and things. It's been really nice and there's a real range of people that we're sharing.

I mean day one was brilliant, it was pond life was the theme and Dan and I made an edible pond. We made pond gravel. We used gluten free Oreo style biscuits blitzed up in his mini blender and melted butter. We had lime jelly. We had mandarin orange slices, that I always think look like goldfish when he has them for lunch, so they were popped in there.

We made Dan's gluten free and he doesn't chew so obviously thinking about all of these things for what we're safe textures and what was gluten free. We dyed some Soba noodles with green food colouring for pond weed. We had a chocolate pudding around the path for mud and then we had green desiccated coconut for the grass and we made chia seed frogspawn.

So many different textures, so many nice smells and things to taste. We just really had a great time creating that together. Day two was favourite meal I think. Shapes we did. We got some beautiful shapes, toys and things, and it was a lovely warm day so we got a big basket full of warm water in the garden with lots of different shaped toys and things like that to experience and play with, and things.

So we've done all sorts of different things. So I'd love it, obviously you guys are going to share the challenge sheets so it would be really if other people sort of found some really great times and experiences following it. And some people have just dipped in and out, joined in with certain days.

Lucy: So we'll put that on our show notes and link that and if anybody does do it please send us an email and we can pass it on to Sarah. It sounds really, really fun.

Amber: You've previously been to a Frozen Light theatre show with your brothers and we know you're a huge theatre lover yourself. What do you miss about live performance at this time in lockdown and what do you think the accessible theatre sector adds?

Sarah: One of the things that I'm really missing is my connection to Sam and the memory of Sam because a big part of me going to theatre and concerts, and shows, was as a shared experience with Sam and so since we lost Sam dad and I have been to quite a few things, and it's really helped us feel connected to remember when we went to this other – but one big thing that for me, because it's Sam I brought to the Frozen Light home, and then when you were doing Isle of Brimsker was just after we lost Sam.

So I actually came with a friend of ours who also has support needs and I didn't bring Dan. I mean that's something I absolutely want to look at and work at, at building towards is how to help Dan in those environments because as strange as it may sound, you know, even tailored theatre for profound multiple learning disabilities, you know, Dan is much more worried and anxious about going to different places and things.

And things that are outside of his control certainly to do with – his acquired visual impairment has made things like that more difficult. I'm saying to him "Sorry Dan but there's nowhere, you're not getting out of it, I'm going

to try really hard” he’s coming to the next tour.

Lucy: We would love to meet Dan and anything we can do to help with that anxiety let us know because we’re always trying to develop things like that.

Sarah: Absolutely. That’s as much of a challenge for me as it is for you guys. I’ve done some training in – I did that oily cart residency and it was a big question that I sort of have been pondering is how to make these experiences accessible for the Dans, for people that maybe even no matter how many sort of brilliant things you’ve done, and that’s I think my favourite things about your shows.

Where’s the times when things didn’t go to plan. There was one lad that sort of joined you on stage and that’s just, you know, it was just fluidly accepted in part of the performance and someone else it was a bit too much for them and a friend of ours sort of went and sat further away. It was so wonderful to watch you guys sort of respond to that and check that it was okay that you followed her.

But it didn’t mean that because she wasn’t sitting in the semi circle that she was then excluded from the experience. Those kind of things are much more important than just the physical access. So much allowing people access into those experiences is being flexible. Sort of allowing people to respond in the way that they want to.

I think having the accessible theatre and things, it’s a great role modelling for some of the support workers that might be, or family members, that might be bringing people of how to open up different sensory experiences and things for them. I mean that’s kind of the way I’ve grown up in this world. So that’s how we experience everything really. If we go to the supermarket I’m scratching the lemon peel to smell and feeling it, and all of that kind of thing because you can get sensory experiences everywhere.

I mean B&Q is a brilliant place to get sensory experiences with buckets of pegs and sponges in bags, and the light aisle and things like that. But I definitely think for people to see what’s possible and make people challenge how they’re interacting with the person they’re supporting.

I went to a relaxed performance of Chitty Chitty Bang Bang with Sam at the Lowrie and there was a young guy behind us who was non verbal but was enjoying the music vocally and in the interval I turned around and I said “Oh I’ve heard some great singing from behind here” and the support worker said “Oh that will be me” and I was like “No it wasn’t you, it was the gentleman sat behind me”.

And she went “Oh it can’t be him because he doesn’t speak” and I was like trying really hard to say “Well how he was joining in with the music was

singing to me and I was really enjoying it". Also I've found that things that I've taken Sam to in the past that are designed for people with learning disabilities there's still a massive range of learning experience for the people running those workshops.

In how to make them suitable for people PMLD because I've been in many situations where the people, facilitators, group leaders are much more used to people with moderate learning disabilities that can follow direction and there's an expected way that they're going to behave. And I've taken Sam in those situations and it's been a real challenge for them to kind of accept that Sam joined in who wants to play the keyboard.

And I was like "Sam wants to play the keyboard, he loves the keyboard" but they had coloured stickers on the keys and you were meant to play blue then yellow then orange in a pattern and Sam just two hands dah dahhhh and it went on for ages and it was coming out of the speakers and, you know, they wanted me to lift his hands off and sort of direct him to press the right colours.

And that's a real shame because actually Sam was demonstrating a way to experience the music and showing them a different way to do it. You can't expect if something is even designed for people with learning disabilities that it's going to be accessible.

Lucy:

That's what we find, is it can be accessible for most people but it's always people with the most kind of profound and multiple learning disabilities that are still left on the sidelines and that's why we really felt with Frozen Light that it needed to be something specifically for that group of people who really have access to, you know, very little things made especially for them.

And I think it's a really good point as well with Sam and the piano, actually instead of forcing what we, a neurotypical person wants to happen in that situation, let's listen to what the participants are saying. Sam was saying this is how I'm going to play the piano and the panic of "No, no, you're not doing it properly" actually let's listen to Sam and let's learn from him, and learn what that is.

Sarah:

Absolutely. Having those spaces is a great opportunity for siblings and families to have shared experience if places are more tolerant because when I was growing up it was I went to something and we had to create something for it to be something – there's only 17 months between Dan and I but provisions were very much separate.

So having those places where we could do things together is really helpful. And I think just being present in the venues and things like that it's encouraging the tolerance and being able to contribute. I have had

experience, really sad experiences of – I took Sam once to a cinema showing of the Billy Elliott show. We didn't actually make it past the adverts because a member of the audience complained to the staff that Sam was making noises and it was distracting him.

Well Sam was sat on my knee and I could still hear what was going on and it was only still the adverts but we really felt pressured in that environment to not be there, and obviously that person felt that their experience was more important than Sam's or than ours. I took Sam to Lion King and one of our friends was there as well in a different part of the theatre and someone who was sat near her complained that she was making sounds.

And the theatre staff responded really well and asked them whether they wanted – my friend asked her and her support workers whether they wanted to go into one of the boxes and actually that worked out really nicely for her because she had more space. It didn't make any difference to the noise I could hear her where I was.

But, you know, the approach that going to something like the Lion King which is a family show that people should have to sit and be absolutely silent to be able to get any sort of enjoyment out of it, it's a real shame. It's only by us being more present and being around in those environments but, you know, understandably you've got to be really confident to be that kind of advocate.

Dan and Sam are my brothers and I have always been fiercely protective of that, and so the confidence for me in standing up for them in those situations is huge but for people who are new to support work and things it's a real challenge to stand up for the people that they're supporting and say "This person has every right to be experiencing this and actually I'm not going to get their fingers and press the buttons in the order you want me to because he's showing you something".

"And you need to learn from that". So it takes a lot to be that advocate, to be that voice for the people you're supporting.

Lucy: Absolutely Sarah, and it's so horrible that we do have to stand up to people but that does take a lot of confidence and people need to be really empowered to do that. It's really difficult.

Well thank you so much Sarah, it's been so interesting talking to you today. And now I hear Dan is about and is going to come and play for us on his beautiful dream drum which is a drum that you guys use a lot. So let's introduce Dan.

Sarah: Here we are, Dan.

Lucy: Hi Dan.

Dan: *Bangs dream drum (a tuned metal percussive sound)*

Sarah: That's it.

Amber: Maybe on today's podcast Dan can play us out with the drum.

Dan: *Plays dream drum (a tuned metal percussive sound)*

Lucy: That was such a cool drum.

Dan: *Plays dream drum (a tuned metal percussive sound)*

Sarah: Woohoo!

Amber & Lucy: *Clapping*

Lucy: Well thank you so much Sarah and Dan.

Sarah: Thank you.

Lucy: Thank you, really exciting. Really exciting.

Dan: *Laughing*

Lucy & Amber: Laughing

Amber: Yeah really exciting

Lucy: Do you want to play anymore Dan or have you had enough?

Dan: *Plays dream drum (a tuned metal percussive sound)*

Amber: Thank you Sarah and Dan for coming on the Frozen Light podcast today.

Lucy: Thanks guys. We will see you soon. Bye.

Dan: *Plays dream drum (a tuned metal percussive sound)*

Sarah: Thank you.

Lucy: Bye.

Amber: Bye bye.

Lucy: Well thank you so much Sarah for coming on the episode and what a treat

to be played out by Dan on his dream drum. How much do you want a dream drum?

Amber: I haven't even heard of a dream drum before.

Lucy: They're very cool, and just so you know it was green as well which made it extra cool.

Amber: And actually Sarah has sent us a link to the dream drum so we will put that on our show notes.

Lucy: What I really enjoyed hearing from Sarah today was her passion for theatre and how many opportunities she took her brother Sam to in the theatre, and music, and how important that was in their lives.

Amber: And also really, really interesting to hear about issues that they have come across when going to the theatre. I mean we certainly always want our Frozen Light shows to feel like the audience are able to move around the space. To make noise.

And all of that is built into part of the show but I do think it's really interesting as a society for us to question how we can make sure people with profound and multiple learning disabilities can enjoy mainstream shows without people having to worry about having to stay very, very quiet. I know I've had issues before with taking my little ones to the theatre.

Even going to see a kids' show if your kids are noisy people start tutting at you and we've really built that into our culture which people always refer back to Shakespeare's time when it was normal to scream at the stage and throw stuff on to the stage, and that was part of the fun. I know The Globe still want that kind of atmosphere now. So why is that lost in our society in so many other theatre shows?

Lucy: And I think what's a shame is that a lot of theatres are actually working really hard towards that relaxed model and having more relaxed audiences but it's actually the fellow audience members that complain and ask for the people making involuntary noise or any noise to be removed, and how do the theatres deal with that is a really interesting question that I hope we can support them with.

Amber: And I know that a lot of theatres are having to train their front of house staff in dealing with these issues coming up which is great but again surely it's about looking at society. I think once, I think it was Kirsty Hoyle from Include Art, said "Instead of having relaxed performances should there not just be quiet performances" kind of like the quiet coach on a train so that if you really, really want to be a very quiet performance then you buy a quiet performance ticket.

And all the rest of them can be for everyone else who doesn't mind a bit of noise.

Lucy: I think that sounds like a wonderful idea. I think Kirsty, if you're listening, you should champion that one. I know you're good at fighting.

Amber: It also came up in the interview just how seriously Sarah and Dan, and their family is taking shielding and I think for us as an organisation it really makes us think about how we will go forward as a company that works so closely with people who so often have underlying health needs and a lot of our audiences we know through doing this podcast as well have been shielding very, very significantly.

So again I think we mentioned it at the start of the show but please do get in touch. We would love to hear from you because we really want to be able to provide and offer, for people with profound and multiple learning disabilities during this time, another thing that keeps coming up episode after episode is that people feel really isolated and lonely during this time.

And forgotten by society particularly when they're shielding so again as a theatre company I know we need to get our creative hats on to think about how we are able to reach people who might feel really isolated during this time to provide some sort of creative engagement. I don't know what that is but if anyone has got any ideas please do get in touch.

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Lucy: You can listen to us on all the usual places you'd find your podcast, Apple podcasts, Spotify and all the usual podcast applications. Please do rate, review and subscribe.

Amber: And you can find us on social media on Facebook at /frozenlighttheatre, on Twitter @frozentheatre and on Instagram @frozenlighttheatre, and on YouTube our username is just Frozen Light.

Lucy: So thanks everybody for listening and we look forward to you tuning in next time.

Amber: Thanks everyone. Bye.

Lucy: Bye.

Jingle: *Jazzy piano music with scatting.*