

FROZEN LIGHT

Frozen Light Podcast

Episode Thirteen – Interview with Bedford and District Cerebral Palsy Society

- 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*
- Amber:** Hi everyone, I'm Amber Onat Gregory one of the Co-Artistic Directors of Frozen Light.
- Lucy:** And I'm Lucy Garland the other Artistic Director of Frozen Light and Frozen Light make multi sensory theatre for audiences with profound and multiple learning disabilities which we tour to theatres and art centres across the UK.
- Amber:** This is the last interview episode we have on the Frozen Light podcast which feels sad but we have an epilogue episode coming out next week so we won't talk about how sad we are until next week because that's what that's for. And we're really excited today to be interviewing Bedford and District Cerebral Palsy Society. BDCPS as they are often known, are some of Frozen Light's regular audience members at Quarry Theatre at St Lukes in Bedford. So we are thrilled to be speaking to them today.
- Lucy:** We'll just give Rose and Ellie a ring now.
- Phone ring:** *Phone ringing sound effect*
- Lucy:** So hello and welcome to the Frozen Light podcast. Would you guys like to introduce yourselves and tell us a bit about Bedford and District Cerebral Palsy Society.
- Rose:** Okay, so I'm Rose. I'm the Children's Services Manager with Bedford and District Cerebral Palsy Society. We're a small charity that operates in Bedfordshire supporting young people with disabilities and their families. We've been going since 1954 so quite a long time now and services have kind of developed as families have kind of told us what they need and what they want.
- And we try and put in the right support for them. As I say I'm the Children's Services Manager and I've been there for 15 years so I look after the things that we do for children and young people.

Ellie: I'm Ellie, I've been with BDCPS again for five years. I did work there when I was at uni and I've come back again. They just draw you back in. So I'm the Activities Manager and I also do the social media and events coordination. So many hats as we all do.

Lucy: We love Bedford and District Cerebral Palsy Society. You guys have been coming to our shows since the beginning I think.

Amber: Since the very beginning.

Lucy: And we've seen some of your families really grow up so it's been so lovely so we're excited to have you on the podcast today, so thank you for coming.

Amber: So what happened to BDCPS when lockdown began and how did you stay in touch with families that you support during lockdown?

Rose: Once we kind of got into lockdown that meant that sadly our services, our direct contact services had to stop. A lot of the families, the young people that we support have very complex needs so a high proportion of them were kind of in that shielding category so couldn't kind of have that contact with us and their other support networks as well.

So we tried to find other ways that we could step into that support. So we did things like delivering food, medication, any other essentials or any other support that they kind of felt they needed. One person's essential is quite different from somebody else's just to kind of keep them going really. It's a difficult for them.

And then we moved some of our services as were doing much more now as we carry on through the effects that coronavirus is having to a virtual contact. So some of our clubs have – young people have met up online, so they love to see their friends that way because they're obviously missing all of their friends.

We do games and activities, and just keep it fun and kind of give them a bit of a break from that. At BDCPS we do support the whole family, we think it's really, really important that the whole family are supported. So we do have activities that we have for parent carers as well. Not far before lockdown we'd started a parent carer choir which was going really, really well.

Parents were really, really enjoying coming along to that and getting a lot out of that. That has gone online. That's gone virtual so it is still working. It's not quite the same but parents are still telling us that it that little bit of a break for them. Some have said it's still the best part of their week. They laugh more than they do the rest of the week. And really lovely

comments like that make you realise that even that virtual meet up in not quite the same way is still making a difference for them.

We've also teamed up with another organisation which is called Spectrum Arts and they do activities for young people as well. They work with some of our young people and we've had them into our play scheme in the past so we've had Jade who's absolutely amazing. She's come in and kind of done activities with our young people.

Really sensory focused activities and she's been running online sessions during lockdown and we've supported our families to have access to that. So we know that Jade is amazing at what she does so we kind of thought well let's not try and duplicate that, or if we've got something amazing go with it so we've kind of supported our families and paid for their sessions so they can access what Jade's doing, and she's doing some really lovely sensory movement and stories.

And lots of lovely activities with them, and will hopefully be coming into our play scheme this summer. She is the one person because of the relationship that we've got we've been able to work with her to access our summer scheme. So, yeah, it's a little bit different but we're trying to keep that contact, keep people connected so they don't feel isolated and do again what they need.

So it's finding out from families what works for them. What's going to help them. What's going to make the difference and that's what we try and do really.

Lucy: And we should just say that Jade has worked with Frozen Light before, she was a performer with us and we absolutely love Jade. We love Spectrum and we love what they're doing. So that's really exciting to hear that two organisations are working together and it sounds like you've managed to continue with a lot of your activity even in this really challenging time and also adapting what you do which is really lovely to hear.

Amber: We've heard so much in the podcast from guests who have felt really, really isolated during this time particularly families who just feel forgotten so I think that whole family approach is just so important and being able to continue an activity like doing the choir and again we've heard time and time again about how people are using music to get through this time so that feels really, really important as well to have a community that also involves something like music that brings people so much love and joy is really, really wonderful.

Can you tell us a bit about some of the frustrations that your families might be experiencing during this time?

Rose: In kind of what was normal times they were already subject to incredible amounts of pressure through the amount of care and not being able to access particular activities, and obviously this has just escalated that and made it more intense and really pushed families further into that really. So, yeah, it's just that kind of – that this obviously is a really, really difficult time for them.

I kind of think that in some ways it's kind of helped that – we're all kind of experiencing that isolation of not being able to meet up with families and friends, there's places that we can't now go. We can't go out because there aren't toilet places that are open and that kind of thing. And so for us we're kind of just getting a brief glimpse into what it's like for these families in normal circumstances really.

We've only had to put up with this for a few months whereas these families, this is their life this feeling of isolation and not being included.

Lucy: I think you're absolutely right about that and that's what we've heard time and time again on the podcast but one of the things we've always liked about BDCPS is that connection with families. When you guys come and see our shows it's always with people, young people always come with their families and not just their mum, it's like mum, dad, brother, sister. We can never fit everyone in.

We have siblings sitting on the floor and parents all around. So it's really, really lovely and it feels like an organisation that not connects the young people with disabilities but also their families and creates a really great support network and you can tell that through what you guys are saying.

This year you guys are running a summer play scheme which is something that you do every year but planning for this year it must have been very different. What's the process been like and what do you expect the summer school to be like?

Ellie: As you say very, very different this year. It's really been hit and miss I think the whole time whether we were even going to run and even back in January, February, March even we were saying "Oh in the summer we'll do this" and we almost had summer planned. We had our trips planned. We had Harry Potter world booked thinking it would just all go back to normal.

And it didn't go back to normal but we just feel really lucky that we actually can run something and giving the parents and families that respite that they need. So we've organised it in a very, very safe way. I think we've probably gone over and above in our safety measures and we've got the bubbles.

So we've got two bubbles on site, same team of staff, same young people.

Obviously we couldn't offer the amount of spaces that we normally would. We'd normally have around 30 on the scheme a day plus all the family activities and things and obviously that's not going to happen this year. It's just not safe to do so. But we feel like what we're doing is better than having nothing in place.

And I think so many families are really looking forward to having that break and joining in on the on site activities. So we're running for four weeks rather than the normal three this time. So each bubble has two weeks on site each and then we're working with Jade from Spectrum Arts for that. She's helping us create like a bit of a story in terms of we've got this idea of this, the storm and the rain and things which is the COVID side of things that has come in.

And then the rainbow and then at the end of the rainbow is the hopes and things so we're incorporating that in a very BDCPS way into a story that's going to be filmed and hopefully shared, and we'll include the families because the virtual activities that will be running alongside it that enables families who just cannot attend, some young people are far too vulnerable and at risk, so they'll be able to join in with some of the activities.

We've got little home packs we're going to send to them, and then a really big extensive virtual timetable. So they'll film bits and hopefully put it altogether and it will just show what we can do even in these circumstances.

Amber:

Really interesting to hear that you were doing a mixture of stuff in person and stuff online, that's a model that we're actually looking at exploring for when we are able to tour again because I think, I'm sure you must be in the same position, but we want to make sure that we are able to create accessible activities for people who are able to come and look for things to access but to make sure that those who are still shielding that they aren't left out due to their needs to have to shield.

So that's really interesting that that seems to be a model that's starting to come up and I wonder if that's something that we'll see in a lot more places.

Rose:

I was going to say I think the virtual side of things was something that you we almost felt kind of forced, obviously the situation kind of almost forced us into that but you just start to recognise the benefits and the reach that you can have through doing things that way, and just reach people that you perhaps wouldn't reach before.

And as we said we're a really small. There's only five of us that are on the permanent team and we're obviously supported by a huge bank of amazing staff and volunteers but in terms of our team we're really, really small. So being able to offer things at different times and we don't have our own premises. So we're constantly constricted sometimes by when we can run

and getting the staff for it.

So actually the virtual thing just allows you to expand beyond that into different times and reaching people that we wouldn't reach. So in some ways it has been a really positive thing to come from the way that we do our services. So hopefully going forwards it will be very positive.

Lucy: And that's what we've been hearing from quite a few people. You know there's a lot of times when people with quite complex health needs can't leave the house outside of COVID and have been asking for this virtual stuff from before this. So for everybody to have started thinking about what that is that's really brilliant and I think it can help make things accessible for people in the future.

Amber: BDCPS have been Frozen Light's audience since our very first tour when we toured tunnels and actually I think it's one of your guys who has all of our posters on their bedroom wall which, you know, is my ultimate claim to fame. I just had to put that out there. But just wondering, you've obviously taken this huge step to doing the summer play scheme, do you have a plan, or how do you plan to develop a plan on how you may be able to approach trips out safely in the future.

For example, if we were able to tour to Quarry Theatre at St Lukes, I mean I guess I'm asking for any advice for what you might expect or what kind of steps do you think you would need to take to make sure that the trip is safe for the families that you support?

Rose: I kind of thing that your shows already lend themselves almost to that post COVID, post kind of going out on trips and things because it is so intimate and it's so individual. So each person has their own space and their own interpretation of what's going on within the activity that you're creating. So I mean something like would be much more, it's much easier for us to think about how we could take on something like going to see one of your shows.

I guess kind of getting out into the community and some of those activities are much, much harder really and will take a lot more planning and just much more consideration and just seeing how things develop really. I think as I said our partnership with Jade that we have it's working with people that we know and can work with, and trust to develop around our young people's needs really and taking those sorts of steps before we then just go out into the more general community really.

Lucy: It's that constant risk assessing isn't it that's going to have to be done more and more which is a lovely load more paperwork for everybody to do. I suppose on that note are there any changes that you hope will support people with PMLD in the future influenced by this time in lockdown?

Rose: It is very hard to have a concept of how things are going to be really. It is very difficult to kind of, we're very much at the moment thinking about the kind of here and now and how we support now, and obviously that will adapt as we move forward. I think as I said earlier it's kind of around some of those things that our parents are going through and some of those hopefully, as I say, that some of us have now got a little bit of empathy into what it feels to be, feel so isolated.

And not be able to go places. So hopefully some of that will translate into more opportunities for our young people because hopefully people will understand a little bit more how difficult and how that impacts your whole life and your wellbeing. If you are isolated and you can't go out, and you can't see your friends, and you can't go particular places that hopefully that understanding will have some positive changes.

Lucy: And I think that's been a theme that's come through is that hopefully people will start to have some empathy because they've been in – a lot of people with this COVID have actually had to experience what it's like to feel quite isolated and unsupported, and alone, and that hopefully some of that empathy can pass on to people's lived experience. Ellie, have you got any thoughts on this one?

Ellie: In terms of the whole thing in general it's been a bit scary and I think it is still quite scary for us and for everyone else, and I think it just makes you think about how you reach everybody. We are all alone but we're alone but we're alone together if that makes sense. It is what Rose said of just finding ways to reach people and it's made us realise as well the families that perhaps aren't engaging in certain ways and how we can adapt and we can include them.

Amber: I think you guys answered it a bit before as well in your response about how you've adapted your own organisation with that mix of online activity and in person activity as well in terms of how you've been able to reach more families in those ways as well and I think again that's something that's come up a few times with things like people having the ability to have medical appointments and things like that online.

So again I think we're all very aware that online does not answer all our problems because everyone is kind of desperate to spend time together however it can reach some groups of people who would have found it harder before.

Rose: I think there's some stuff around the kind of create, I've seen stuff about creative activities as well that I agree with. During lockdown we've all turned to much more kind of creative activities and the benefits that that gives us so it's recognition I think again of the value of those types of

activities, and the kind of things that obviously you guys do, and the benefits that that has for people and for our young people as well.

So they're kind of seen as nice to have, as that extra rather than I think now people are kind of appreciating more that it is more important. It does affect people's wellbeing and their mental health to be able to access arts and music, and crafts and these kinds of things. So again for our young people some activities are out of reach for them so being able to access these sorts of creative activities is really, really important for their wellbeing and their self esteem.

And their confidence, and kind of helping them achieve their potential really. So hopefully people will see those sorts of activities as more important as well.

Lucy: I hope so and I think that's a really good point. I think since it's not been there, theatre and live music, people have really missed it but that's what people have turned to and we've heard over and over again in this podcast when we've said what's got you through and it's like music. Music, craft, creative activities and realising how important that is and I hope that that reflects in how we support the arts to come out of this crisis.

Amber: I think in last week's episode we also had someone who had got through it through film binge watching as well.

Lucy: Yeah, absolutely, and then we heard wonderful stories about Coronation Street and all sorts so I think it's all really, really important and I'm really happy that you may that point Rose, thank you.

Amber: Well that's all our questions guys. Thank you so much. Good luck with your summer programme, it sounds really exciting.

Lucy: Did you want to tell the listeners where they can find you online?

Ellie: So our website is just BDCPS.charity and then our Facebook and social media tag is just @BDCPS. You can find us on Instagram, Twitter and Facebook so, yeah, check us out.

Lucy: Yeah do, and you share loads of lovely things about what you've been up to so I'm excited to see pictures from your summer play scheme.

Amber: And we'll link all of those links on to our show notes so that people can check them out there as well.

Lucy: Brilliant. Well it's been lovely to see you and take care. Have fun on your summer play scheme. I can't wait to see the film and hopefully we'll see you again soon.

Rose: Bye.

Amber: Bye.

Ellie: Bye.

Lucy: Well thank you Rose and Ellie for coming on our final episode. It was really great to talk to you and catch up and find out everything that you guys have been up to. It's so exciting I think that BDCPS are running a play scheme as of next week. So I'm really interested to see how that goes and to hear all about it.

Amber: I absolutely loved the sound of their COVID inspired sensory story about a storm in collaboration with Jade Cook of Spectrum Arts. I mean that just sounded beautiful and actually explaining COVID and exploring what it means to people can be a really, really challenging thing so I think to be able to do it through the sensory exploration of a storm is such a wonderful idea.

And we are recording today on 23 July but this won't be going out for some weeks so I think by the time this is airing hopefully that video will be on their website and I will then link it on our show notes.

Lucy: I'm excited to see that and really excited to hear that they're working with the lovely Jade Cook at Frozen Light Friends. So that's really exciting. I think what I really liked is the point that Rose made at the end, and I think it's so true, that the arts have really supported a lot of people through this and that's people with learning disabilities, non disabled people alike. I think everybody has found comfort and solace in the arts be that music, film, TV.

I think that needs to be shouted about. We need to not only talk about the economic value of the arts but we need to talk about what they do for people's wellbeing, for people's sense of self. For people's sense of community and sense of belonging and I think that's really important, and really important to ensure that we get that back. That people can continue to create and things can continue to happen not only recorded but live.

Amber: Completely and, yeah, and looking forward to a time that hopefully we can do live performance again but perhaps cross it with an online offer as well like they've been able to do at BDCPS. I think that's going to be the new normal for a while and actually feels like it might be something that could hopefully work for people who are still shielding.

I think the big takeaway for me is how do you stay in touch with people who then aren't able to now still access that summer camp or that theatre

show when other people are able to do that. So I think that's something that at Frozen Light we will be really interested in exploring further.

Lucy: And probably something we should have explored before because I think there's quite a lot of our audience who probably even before COVID couldn't come to the theatre for various different reasons. So I think it's actually really exciting that we're going to explore, I'm not going to tell you what it is, but some sort of digital virtual offer which will accompany our tours and we're really excited about that so do keep your eyes peeled.

Amber: So up next on the podcast is nobody.

Lucy: Oh my God as if you just said that.

Amber: It's so sad, but next week we will be having a rounding up episode where we will be looking back at the time that we've had making the podcast and all the wonderful interviewees who we have met. So do still please tune in next week to catch our round up. We hope you have enjoyed listening to everyone that we have interviewed.

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Amber: You can get us on Facebook at facebook.com/frozenlighttheatre. On Twitter @frozentheatre and on Instagram @frozenlighttheatre, and on YouTube you can find us by searching Frozen Light.

Lucy: So I don't think this is the end of our podcast journey. I mean I'm not promising anything but I think these conversations have been really, really important to us and I hope they've been important to the people that we've interviewed and the people that listen and I think there's still a platform for sharing people's stories and it's really important to increase the visibility of our audience.

So maybe it's a different format, maybe it's in a year's time. I don't know. But I don't feel like the Frozen Light podcast is done.

Amber: Well on that note see you next time.

Lucy: Thanks for listening. Bye.

Amber: Bye.

Jingle: *Jazzy piano music with scatting*