

# FROZEN LIGHT

## Frozen Light Podcast

### Episode Seven-Interview with Stephen Kingdom Disabled Childrens Partnership

- 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 Music
- Lucy:** I'm Lucy Garland, and I'm one of the Co-Artistic Directors of Frozen Light.
- Amber:** I'm Amber Onat Gregory, and I'm the other Co-Artistic Director of Frozen Light. Frozen Light are a multisensory theatre company that tours sensory theatre across the UK for audiences with profound and multiple learning disabilities.
- Lucy:** So, thank you for joining us today. And on today's podcast, we have Stephen Kingdom from the Disabled Children's Partnership, and we were really interested in talking to the Disabled Children's Partnership because during lockdown, they have put out a survey which reached over 4,000 families of disabled children, and the survey was called #leftinlockdown Parents and Carers' Experiences of Lockdown. And it was absolutely fascinating, but also really quite sad reading about how parents and families and children with disabilities have really been left behind during this time.
- Amber:** What's been great about the campaign is actually when the results were released. It got a huge amount of media attention, which I think is one of the earliest times that people started talking about people with disabilities and learning disabilities during lockdown.
- Lucy:** So, we're really excited to have Stephen on today, so we'll just give him a ring.
- Phone Ring:** Phone Ring sound effect
- Lucy:** So hi, Stephen.
- Amber:** Welcome to the Frozen Light podcast. So, can you tell us a bit about the Disabled Children's Partnership and how the partnership of so many different charities working together came from?
- Stephen:** So, the Disabled Children's Partnership is a coalition of - well I think we're just about to hit 80 charities. I'm just sorting out a

couple of new members and that'll take us to 80 charities, which is another organisation which is absolutely brilliant. And we work closely with families to campaign for better support for disabled children and their families.

I think that the coalition came together in 2017, I think from a sort of sector concern that there was a real need for a strong voice for families, for disabled children. And I think with a particular focus on health and social care, that those were areas that were neglected, and children and disabled children were really falling behind in those areas. And the coalition's taken an approach of seeking to raise public awareness of the challenges that families faced, of the lack of support that families get, and through that to try and drive change and drive policymakers, government to invest and to improve services for families.

So, the coalition is led by 11 charities, and then we have the further sort of nearly 70 supporting charities. When it was launched in July 2017 there were about 35 members, so we've steadily grown over the time. And I think one of our strengths as a coalition is the variety of types of organisation we have. So, we have some big national charities like the National Autistic Society, like Sense, Scope, Action for Children, Contact who have that sort of that national view. And then we're down to really some quite local provider charities as well who provide short breaks and other services in local areas. So, we get a variety of views, a variety of experiences. Each the charities brings their own sort of parent base and family base with them in terms of those experiences, plus we work directly with families and with parents.

So, we hope from that point of view we get at a wide range of expertise and experience to bring to bear, and so put reality on the stories that we're turning to the public and government.

As for me, well I was, before this, immediately before this I was on a career break, cycling around the country, raising money for Contact. But before that I was a long-term civil servant, I worked on policy on education, children's services, and health over about 25 years, including working on the 2014 special educational needs and disability reforms as they went through parliament in 2013 and 2014.

So, I left the civil service in 2016, had a bit of a career break, and then joined the coalition, joined the Disabled Children's Partnership in early 2018.

**Amber:** And has your work become much busier due to all the research that you guys have been doing throughout this lockdown? Has that had a big impact on your role?

**Stephen:** Yeah, I think so. We've been we've been busy trying to get the message out, and I think we're really pleased at how the survey's gone and the amount of media attention it's got. And to be fair, the amount of engagement we're getting from government and from officials to discuss what we've found. So, in that sense, yes, it's been pretty full on over the last couple of months.

**Amber:** Because in, in May you reached out to over 4,000 families to ask how they'd been impacted during the lockdown. Can you tell us a bit more about the findings of the survey?

**Stephen:** We put the survey out on social media and more widely, and spread it throughout networks, and we had over 4,000 responses which was absolutely brilliant. But the overall picture that they gave is a pretty depressing one, a picture of families of exhaustion, anxiety, confusion, and fear. Parents reporting an increased caring load for themselves and for the whole family have come through very strongly, the sort of burden on siblings as well. They feel exhausted, stressed, anxious, and frankly abandoned by society.

Of course, a lot - you know, the context here is a lot of these families were not receiving the support they really needed prior to lockdown. We didn't come together to campaign because of lockdown, we were campaigning about lack of support beforehand. But it has just got significantly worse, and of those families who were receiving support, three-quarters have had that stopped altogether under lockdown. And that's resulting in families seeing a decline in their mental and physical health, of the parents, of the children, the siblings, real concerns about pressure on managing children's behaviour and impact on children's wellbeing, mental wellbeing, the strain of managing home-schooling, clearly a big issue for all parents has been. But I think, again, a whole magnitude more so for families of disabled children.

I'm not saying that their schools weren't differentiating or providing specific support they needed because of their child's particular needs. So, we were worried about the impact of that on their children's learning and communications, on their mental and physical health. And, you know, just simple things like their friendships have been negatively impacted. And on top of all that, real financial pressures on families, either or both through reduced income and additional costs on families.

**Amber:** And were you surprised by any of the results? Did anything come out in the surveys that you weren't expecting?

**Stephen:** I think, yes and no is the answer in terms of surprised. I'm not sure the themes were a surprise, I think we probably expected

those, but I think the scale, the scale of the concern and the pressure on families. As I said, I think that, you know, 76 percent saying that all support they were getting stopped altogether. That kind of scale was what probably surprised and shocked and frankly horrified us

**Lucy:** From your findings, how do you think the families could be supported during this time by society and, you know, the wider outside world?

**Stephen:** I think one of the simplest things I think we heard a lot about was just the feeling of being affected, the feeling of being ignored, and just to seek some acknowledgement of the position that families are in, and their position, and a feeling that, you know, whenever the daily press conferences, they really didn't talk to families with disabled children. They really didn't talk about disabled children.

Some of the messaging, I mean we heard a lot of talk, going back to schools, we heard a lot about how places would still be available for children with education, health, and care plans. Well, that was the theory, but the reality was completely different. Through most of the lockdown, less than 20 percent of the children with education and health and care plans actually were in school because schools were saying they couldn't provide for them, or parents didn't feel schools could provide for them, or the risk assessment said it was more appropriate for them to be at home.

So, while society might have generally thought, "oh, these children are all right because they're in school," that really wasn't what was happening. So first and foremost, some acknowledgement and some understanding of the position families were in, but of course that's not enough, you need practical support as well, and real action from government. Better financial support, making sure there is support, even caring, getting short breaks up and running, innovative approaches to that kind of support, in-home support, domiciliary support, getting those sort of services back in place as quickly as possible.

I think when lockdown happened, there was probably a bit of an understanding that would have an impact immediately, and maybe for the first month, but as that becomes two months and three months that support really needed to come back in. And what families need now is to see a really clear route map for them, with specific to them and their families out of lockdown, how things will progress, how services will come back in, how they'll be supported during the summer. And with schools returning in the Autumn, how they'll be supported bringing their

children back to school. And, you know, for many of the children, they may still not be able to go back to school in September, so what support will be in place then to help families?

**Amber:** I think one of the things that has come out from us doing this podcast and speaking to families is they still could have had access to carers that they had before, but they chose the safety of their family to not use that, even though they were told they could have that back at a later time. What I think was really tricky as lockdown eases is, as you say, there's been very little roadmap of knowing where to go. So, families are kind of doing their own research and their own risk assessments about when it's safe to have people back in their homes and kind of making their own assumptions based on their own personal breaking points really. There's been very little information on, "OK, so we've been told to not see anyone that we've made ...," you know, even though that 'anyone' is very important in our lives, we've taken that away, but when can you start that re-introduction and what's the safest way of that happening?

**Stephen:** I think that's absolutely right. I mean, the government's message seems to be increasingly use common sense. Well, common sense is an easy thing to say, and a much harder thing to judge in reality, and even more so when your position and your situation isn't common. I mean one of the things we heard a lot of parents said to us about what they would appreciate was things like how the rules around social distancing or social interactions worked. So, it would have been helpful if earlier they had been allowed to extend their bubbles, because losing the support of relatives who would normally provide informal support, that's another cause of increased pressure on families because they couldn't have grandparents come and look after the children, they couldn't have their own brothers or sisters come and look after their nieces and nephews. So, a bit more clarity on, as you say, on how that works for the individual family is really important.

**Lucy:** Because we've spoken to a lot of families who have taken the decision to completely shield, but not necessarily got the letter because they're thinking that their thoughts is that somebody thought another agency was going to send the letter and the letter never got sent. But then suddenly on August 1<sup>st</sup> they've been told, "oh, you don't have to shield," and families are just left going "I don't know what to do, and I'm just going to try and do what I think is best for my family."

**Stephen:** Yeah, and I think that lack of trust point is massively important. And I think some of the communications, you know, it feels like the order they've gone is really unhelpful, so talking about that relaxation, or, sorry, ending of shielding on 1<sup>st</sup> August, well more guidance is promised in June and July on what that means, but

that hasn't come out yet. The announcement was made, and I don't think a lot of professionals knew what it meant, so families would be phoning their paediatrician or phoning, you know, their therapist or who they trust, and they wouldn't know the answers. And actually, I mean my advice to families is as the information goes out is to talk to your trusted professionals and listen to them because they know your family, they know your situation, and they can give you that professional advice.

But they weren't ready. Those professionals weren't ready to give that advice at the time government said shielding's going to end on 1<sup>st</sup> August. It's incredibly difficult for government and it's incredibly difficult communication, but it does feel that it could have been handled better and particularly families in the hardest situations, and the same goes for adults as well, seem to be those ones who the messaging hasn't been tailored.

**Amber:** And one of the aims of this podcast has been to document the experiences of the PMLD community in lockdown. I know that you guys have also been collecting stories from families, is this something that you do all the time as the Disabled Children's Partnership, or is this something new that's come out of lockdown? Can you tell us a bit more about the stories that you've collected and where we can find them?

**Stephen:** Well certainly you can say it's something we always do. It was only where the campaign started from was very much about telling family's stories, so the initial phase of the Disabled Children's Partnership campaigning was called Secret Life of Us and we had a series of blogs and videos, families telling their stories in their own words of not having the services and support they need. And we carried that on to our second phase 'Give it Back' campaign, and now #LeftinLockdown is our latest hashtag. The publication of our survey finding had lots of quotes and snippets from families within it, and we just started adding more blogs to our website, [disabledchildrenspartnership.org.uk](https://disabledchildrenspartnership.org.uk) - under the Secret Life of Us banner, but we're adding more blogs to that of what life in lockdown's been like, and what it's like to be left in lockdown. We've got about three up so far, we'll put plenty more up, and we'll be sharing them on our social media. And we'd really encourage people to email us with their stories so we can share those as well.

**Amber:** And who do they email?

**Stephen:** Email [disabledchildrens.partnership@mencap.org.uk](mailto:disabledchildrens.partnership@mencap.org.uk).

**Amber:** Just out of interest in terms of who your audience is for those stories, what is the audience you guys are aiming for, and who is the audience that you get?

**Stephen:** Yeah, this is - I mean going back to the sort of start of Secret Life of Us, this is obviously always the hardest thing that you - you know, we've got a decent Twitter following and we get decent coverage on social media, but there's an element that you were talking to other people who understand more than what our aim is to talk to people who don't have the understanding and raise awareness in the general public. One of our key statistics, which I think came from some Scope work, but I may be wrong on that, when we launched was that 43 percent of the general public say they didn't know any disabled people. A really shocking finding. And trying to increase that understanding amongst the general public of the realities of life was a key aim of the partnership because by doing that you put pressure on politicians and policymakers to make change, that was our sort of logical theory of change to drive change.

So that's always a struggle. I mentioned our Give it Back campaign which we launched in June last year particularly around funding for social care. We did that in partnership with The Sun newspaper, and I'm sure there'll be some people who think we shouldn't work with The Sun newspaper, but that's been absolutely brilliant because by getting stories in The Sun, and they've published a whole number of stories about families, that gets us to an audience we wouldn't otherwise reach in the general public, and we had a really, really good petition which The Sun helped push, which we handed into the Chancellor, as the Chancellor was then back in the Autumn, and we got signatories on that who were the kind of people we wouldn't normally have got to. So, having those kinds of media partnerships has been really good, and The Sun has have continued pushing through our work during lockdown as well, so that's been really positive.

**Amber:** I think that's something that we found ourselves with this podcast. We really do want to use this podcast as a way of staying in touch with the PMLD community, so of course we want that community to be part of the audience, but as theatre makers, we would really love there to be a wider audience of theatre programmers, theatre makers who are part of the audience of this podcast, but it's really tricky because that's not what we're talking about. We're talking about a certain group of people in society and their experiences, and one of the funny things about the theatre sector is obviously often so much is about theatre, as it should be, but very little focus on audience, and actually without audience what is theatre anyway.

**Stephen:** Well, that's a big question at the moment, isn't it?

**Lucy:** Working with The Sun is absolutely who you should be working with, because we can all shout really loudly into our echo chamber who are all going to agree with us and be the same, but,

as you say, you need to be reaching that 60-odd percent of people that don't - haven't met someone with a with a disability.

**Stephen:** It's been a really positive partnership, and I think it's helped because they've obviously got political connections as well, particularly with the Conservative Party, so that's got us more access to politicians than we might have got otherwise. So, it's been a really positive partnership, and they've been really supportive. And actually, you then learn there are journalists within The Sun who have their own personal experiences and real commitment to the issues because of that. And we got as far as having a specific question asked at the - by The Sun journalist at the daily press conferences when they still happened, so that was great, I mean great to get the question asked, and I have to say the answer from Matt Hancock was pretty poor, but it at least got the question asked.

**Lucy:** So, we create theatre primarily for adult and young adult audiences with profound and multiple learning disabilities, and are aware that adults with learning disabilities can be hard to reach. Are you aware of any initiatives that are researching the impact that the lockdown has had on adults?

**Stephen:** Yeah, I am. Mencap actually are doing a survey at the moment, it's live at the moment, you can find it on their social channels, particularly focusing on social care, I think, but still, same kind of issue, same kind of surveys as we carried out. So, it'd be great if people have chance to fill that in.

Certainly, my experience is quite often when we put any message out about what's happening with children we get responses back from some people saying "it gets no better," often from family members, you know, "my son is now in his thirties and we still have this problem," and from individual, you know, people with disabilities themselves. So, we certainly hear those same messages about adults as well. And, as I say, Mencap are carrying out a survey at the moment.

And actually the Office of National Statistics I think have published some information from their Lifestyle surveys about the impact of lockdown on disabled adults, and that showed that compared with the general population, disabled adults are more likely to report that the crisis has affected their wellbeing, are more likely to be very worried about the impact of the crisis, and they are more likely to be spending too much time alone. So depressing findings there as well I'm afraid.

**Lucy:** What I do like about the Disabled Children's Partnerships and the Secret Life of Us is those films are really positive, and it's about showing that positive message. And I think what's a shame is that



lockdown has taken us back into like a negative space. Is that something that you guys are finding or working with?

**Stephen:** Yeah, it was a definite deliberate plan in Secret Life of Us to show that positive, to show both sides of it, and we - you know, you're always very wary and very concerned about slipping into pity pool, and even those kind of traps to fall into, so we were keen to show both sides.

But we had, even with the Give it Back campaign, we were trying to be a bit harder edged about the realities, and showing the difficulties, and being really clear in all our messaging, it's not about having a disabled child, it's not about being a disabled child, there's no reason inherently why if your family has a disabled child your life should be terrible and the child's life should be terrible. What we're saying is that society is not providing the support that it should be. That is the problem. The problem isn't the child, the problem isn't the family, the problem is the support that they are entitled to and should be getting isn't happening. And that was true before lockdown, and sadly it's even more true during lockdown.

**Amber:** I mean I think that response really feeds into the social model of disability and looking at how as a society what can we do to make life equal and fair.

**Stephen:** Absolutely. That's exactly it.

**Amber:** It's been absolutely fascinating, Stephen, I've really, really enjoyed this chat, and actually I haven't come across the Disabled Children's Partnership until lockdown, and until this survey came out, which it really did get quite a lot of press and maybe we can link some of the news clips and stuff onto our show notes.

**Stephen:** I was going to say, yeah, we were delighted with the coverage we got.

**Lucy:** And, Stephen, is there anything else you would like to kind of promote? Where can we find you? How can people get more involved?

**Stephen:** The main thing is, you know, follow us on social media, we're particularly - it's mainly Twitter and Facebook, particularly Twitter, follow us on there and share your stories, and we'll try and help amplify the messages.

**Lucy:** And what are you on Twitter?

**Stephen:** We are @DCPCampaign.

**Lucy:** Brilliant, and on Facebook?

**Stephen:** I think we're @DCPCampaign on there as well.

**Lucy:** Perfect. Well thank you so much, Stephen, thank you for taking the time to talk to us.

**Stephen** No, as I say, thank you for inviting me, it's been great.

**Lucy:** Thank you, Stephen, for coming on today, I really enjoyed that episode.

**Amber:** Yeah, I felt it was extremely informative, and a huge thanks to Stephen for being so clear with the findings of the survey, and telling us about the journey that the partnership has been through during this time.

**Lucy:** And I think what is interesting, you know, is this, the Disabled Children's Partnership wasn't set up for the lockdown, it was set up in 2017 to really fight those inequalities and injustices that children with disabilities face in lack of access to care and support and health services that they need. And those things should have been getting better, but due to coronavirus and due to the lockdown, those things have got worse. And I think what we really need to do is to ensure that when we come out of this lockdown things aren't worse than they were in 2017, you know, that we use our learning from this time to make things better for people with disabilities.

**Amber:** Yeah, and me and Lucy have been talking a lot about how some of the restrictions put in place from a health point of view haven't necessarily considered the needs of disabled people. I think a good example is yesterday I was at my local kind of like corner shop, and they've changed the exit and the entrance, and now there's steps on the entrance and the ramp is only at the exit, whereas before you could use the ramp for entrance and exit. And it's just little things like that that can have a huge impact in someone's life. And just like Stephen was saying, we want things to be getting better, and we don't want lockdown to have things spiralling back to a time when things were worse.

**Lucy:** And I also think it runs the risk of becoming acceptable that for safety reasons disabled people are excluded, and I think that is completely and utterly unacceptable. We have an opportunity to actually make things better and, you know, that's just one example that Amber said. I saw an example of a pub who's put in little glass or plastic pods that people can sit in to keep them socially distanced, but to do that it says they're not big enough for wheelchair users. I mean it's completely and utterly ridiculous, and people are being excluded in the name of coronavirus safety, and I think that's outrageous.

- Amber:** And bringing it back to the theatre sector, we're currently recording this on Friday 3<sup>rd</sup> July, and the theatre sector is, you know, kind of in tatters at the moment, wondering what will happen next. And really in regards to access, there's a long way for theatre to go, but since the introduction of relaxed performances in particular in 2009, the access rights for people with learning disabilities to access the theatre have started to improve hugely. And since the time that we've been formed as Frozen Light over the last seven years, we've seen a huge increase in artists and organisations thinking about diversity within audiences which has been really great to see. But there is a huge danger that due to coronavirus and due to the horrendous funding situation that theatres have found themselves in already that access will not be the most important thing on the agenda, just trying to stay open will be. And we need to make sure that when theatres are able to open that all audiences are still welcome and there are still programming for everyone's needs.
- Lucy:** Yeah, I think that's an absolutely crucial point. You know, the work we make, accessible work, is expensive, and venues are going to be in tight financial situations, but we need to make sure that people aren't excluded because of that in the name of finance or in the name of safety. It's incredibly important. And as a theatre industry, we do have an opportunity in this time to actually make things more inclusive and to make things more accessible, and to really look at those things so that when hopefully it all does open up, it is a more inclusive place.
- Amber:** So up next, on next week's podcast, we have Sarah Walker who is, in fact, an audience member of Frozen Light. She's a family carer and she's been to several Frozen Light shows with her brothers, so we cannot wait to have her on the show.
- Lucy:** So, thank you for listening today. You can find us on all the usual places you'd find your podcasts, Apple podcasts, Spotify, Google Play, and all your other podcast apps. You can also find it on our website at [www.frozenlight.com/podcasts](http://www.frozenlight.com/podcasts). Please rate, review, and subscribe.
- Amber:** You can contact us on email at [info@frozenlighttheatre.com](mailto:info@frozenlighttheatre.com). If you'd like to be on the podcast, or if you've got any feedback, we would absolutely love to hear from you. And you can also find us on all the social media channels, so you can get us on Facebook at [/frozenlighttheatre](https://www.facebook.com/frozenlighttheatre), or on Twitter [@frozentheatre](https://twitter.com/frozentheatre), or Instagram at [frozenlighttheatre](https://www.instagram.com/frozenlighttheatre).
- Lucy:** Thanks everyone for listening today. Take care, and bye.
- Amber:** Thank you. See you next time.

**Jingle:** Jazzy Music

[End of recorded material at 00:28:11]