

FROZEN LIGHT

Frozen Light Podcast

Episode Twelve – Interview with Christine Singleton Founder of Skiggle

- 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:** I'm Amber Onat Gregory, a Co-Artistic Director of Frozen Light.
- Lucy:** And I'm Lucy Garland the other Co-Artistic Director of Frozen Light. And Frozen Light make multi sensory theatre for audiences with profound and multiple learning disabilities that tours to theatres and art centres all across the UK. Due to coronavirus we are no longer on tour so we're making a podcast to keep in touch with our communities.
- Amber:** However we are currently, and it's currently late July, we are planning to go back into rehearsals in September time. So we'll let you know how we get along. We are looking at the possibilities of touring at some point in 2021. We are really keen to speak to our audience members about how they might feel about that or what they may want in place in order to access theatre. Get in touch with us at info@frozenlighttheatre.com.
- Lucy:** Today we're talking to Christine who is the founder of Skiggle and also mum to Will and two other daughters. Skiggle is an online community of people and families that can support each other by sharing resources, medical equipment and they have an SOS service where if you run out of something and it's an emergency you can put out an SOS and somebody can get back to you.
- Whether that's you've run out of feed, you've run out of suction tubes, all sorts of equipment and the community supports each other through the sharing of equipment.
- Amber:** So let's give Christine a ring now.
- Phone ring:** *Phone ringing sound effect*
- Amber:** Hi Christine, introduce yourself please to the listeners.
- Christine:** I'm Christine Singleton. I am a mum of three children. My eldest, Will, is profoundly disabled. He's got complex needs through a brain injury that

he suffered when he was born and then I've got two girls who, one is coming into GCSE years which is not going well with her stress levels and the other one is basically like me, that just has to get on with it and life is thrown at you and you just take it. That's who I am. I'm married and I live in a chaotic house.

Lucy: But you also run Skiggle and I first came across Skiggle in an article in PMLD Link and just thought oh my goodness this sounds like an amazing initiative and something that I can't believe hasn't existed before. So can you tell us a bit about how the idea for Skiggle came about and a bit about how it developed?

Christine: Skiggle originally was set up because of my forgetful mum brain. So we went away on a few days holiday with Will and the family, and one of our carers and we have a fairly large Motability vehicle which was absolutely packed to the rafters with everything that we needed as a family plus what Will needed which is a huge amount of stuff.

We got to our holiday accommodation and we were unpacking and putting things away as best you can and we went "Where's his feed?" and everyone looked round and we went "Oh it must still be in the van". So they went out, had a look, they came back and they went "Mum, the feeds not here" and I said "Oh no, I've left it at home". We'd driven two and a half hours away from home.

So I thought right well we don't really want to get back in the van and drive home for it so I rang the out of hours doctors and basically they said "We can get you a prescription for the feed" because it's not something that you can just bob to a supermarket and collect. And she rang me back three hours later and she said "I'm so sorry, the options for this are you either drive home or you put Will into a regional children's hospital to get the feed".

Will is really vulnerable to infections and all sorts of things and I said "Well that's not an option for us" so my husband got back in the van and drove home and the feed was exactly where I'd left it. In the evening the carer who was with us as well, we all sat down to have dinner and we were all like "This is just bizarre that the only way you can get something is to take your child, who is extremely medically vulnerable, and put them into a hospital situation when they're not actually needing hospital treatment".

So that night we all went to bed and the morning after my husband came down and we were sat having breakfast and he said "I've got an idea, there should be somewhere that you can just send a message, like Facebook, and say 'Can you let me have a tub, a carton, whatever you need'". So we Googled it, nothing. We Facebooked it, nothing. There was just nothing out there.

So that's where Skiggle came from. We just thought if there's nothing there I can't be the only forgetful parent or carer who needs something who's got no option of getting it. And when you actually look into it there's a lot of people that forget things when you go because we've got such a huge amount of things to take with us and basically we started it from there.

We went off to a university. They made us the website that was our original website and has been tweaked several times since. It's a non profit organisation. We then thought well this should be bigger than just the SOS service which is what we developed initially which is where you sent out a message to any user and say "Have you got some feed?" and so then the user would have a look in their cupboard and go "Yes, I've got four cartons that you can have" because you can't sell anything because you're provided with all this stuff from the NHS you can't profit from it. It's not legal to do so.

So the SOS is where we went originally with it but then we thought actually, do you know what, here's a parent. I'm given a huge amount of things for Will, so things like continence products. He has a tracheostomy to breath so you get tracheostomies and suction catheters. You get dressings. You get all sorts of different things. Feeding equipment. We get a huge amount of stock.

I thought do you know what each time something changes in Will's life we are told just to throw those items away. If you're up-sized as they call it on a tracheostomy, these cost about £150 each, you have a box, it's in a sterile wrapper. It's got an expiry date on it. You look after it because you potentially need to put that into your child so why can't you pass that on to somebody and that's where our marketplace came from.

I thought well if I've got all this stuff that potentially I'm going to put into landfill which is just not acceptable in my eyes, I'm very big on recycling in my house, and I'm trying to bring my children up in the way we need to look after our environment, I thought I'm putting a huge amount of unnecessary waste into landfill and as my smallest daughter says "You're killing a dolphin mum and that's not acceptable".

And I said "No, absolutely it's not acceptable". So that's where the marketplace came in is that we then can put on the things we no longer need which then can be shared around with other parent carers. What we've actually found happening, and I didn't know this because my area seemed quite good on you ask for something you get it, but if I said "Could I have an extra tracheostomy this month because Will's pulling it out" or whatever you'd get that extra one.

But I've found a lot of people in different areas, particularly down south

seems to be quite bad, is that what we would get maybe two or three of they're restricted to one or they don't get at all, or they're made to buy things and so this is where the marketplace really comes into it's own, that if I've got excess of say three feeding syringes I can pop those on the marketplace and somebody who doesn't get the supply at all, or someone who's short.

Or not had a delivery can go on the marketplace and take them from you. The SOS side was initially where we went. We thought there's going to be a huge market. Actually the SOS isn't going to be used that often whereas the marketplace will be used every day. And I mean today we've had at least six new members today and it's only 2.30 in the afternoon.

So there are people using it all the time trying to find different things. So that's where it started and then obviously last August we worked very hard, and there's only two of us in the charity, there's myself and Helen who is one of Will's day carers who work on the charity and we made a decision that we would try to be a charity and oh my goodness that's a test of strength and determination.

And we actually got to be a charity in August of last year in England and Wales. We need to now to get to be a charity in Scotland but we don't know if we've actually got the emotional strength to take on Scotland. So now we're a fully fledged charity as well which has taken us on to a whole new level and we're doing really well with the charity. We're really proud of it.

Amber:

I mean it sounds like a very specialised freecycle type of model which is, and again freecycle is very, very popular. It's been around a long time. It's a tried and tested model. So it's so great obviously because the things that you have on your marketplace are things that you wouldn't come across usually in freecycle so again it's so interesting to hear how bespoke it is.

And in our last podcast episode we were speaking to Reflect PMLD who are a day service provider but the focus for them was again all about providing something that was really bespoke for a very specific kind of group of people's access needs and this feels similar in the sense that because it's so specialised it actually is getting to the people who need it the most.

Christine:

Yeah, and that's one thing that we actually are potentially struggling with. Because it's so unique and so bespoke I don't think people really understand it. So you're programmed all the time to throw everything away. You go into a hospital setting and they just, if it doesn't work, it doesn't fit, it wasn't what they wanted they just throw it away.

So you're programmed into this throw away culture. I think you're mindset is I can't share this. Well I don't see a reason why you can't share it because

people have said to me “Oh well where has it been stored?” and I think hang on a minute, yes I get what you’re saying, where has it been stored, but I’m going to give that to my son. I’m going to put that into his body.

I am not going to leave it out to get wet and disgusting am I or allow the dog to sniff it, or whatever. It’s going to be put in a place where I know that it is clean and sterile, and dry, and safe to use. So why can’t we move these things around, there’s absolutely no reason for it. For me it’s very much like any of the other selling sites.

If you’re going to take something it is down to you to check that you’re happy to use that on your son or daughter, or your mother or father, or whoever. So recycle, recycle. That’s where I’m going and freecycle is basically I think where my head already goes. I freecycle everything. I’d freecycle my children if I could get away with it. Maybe not.

Amber: My partner’s a doctor at the NHS and he talks a lot about waste within the system again just from an environmentalist point of view how it doesn’t make any sense and if he ever goes and does any work abroad again you don’t necessarily see that kind of waste in other countries which don’t have as many resources as we do here in the UK.

So again it’s an interesting thing to think actually when you have a lot of resources you kind of think that waste is okay.

Christine: It shouldn’t be and that’s what really sort of bugs me because Will as I said is on a specialist feed and I worked out that a year for our family to eat is about £2-3,000 for a family of four. You can go to the extreme and I kind of averaged it out including Christmas and all the rest of it. Will’s feed for a year is £18,000. That’s where you really have to think actually that’s a lot of money.

£18,000 would pay for an intensive care bed and a nurse for 24 hours. That’s where it really hits hard and you think actually can we really afford to just throw these items away. No you can’t. We won’t have a free NHS if we do continue to throw away like this.

Lucy: Absolutely, and as you say those things are really expensive and they can also help people. I think what you said about being a postcode lottery as well I know when my grandmother became quite disabled we were only allowed a certain number of continence pads. She needs more and we couldn’t get anymore.

Christine: And that’s what really irritates me and it shouldn’t because this is not how it should be. So Will has a lot of actual physical equipment like a medical bed and a standing frame, and a wheelchair, and things like that. Now everyone who is in the special needs world will be nodding their head going

yes and you get told it's too expensive and you can't have this model because that's not within budget.

Well actually if they didn't throw quite a lot of things away their pad allocation for people that genuinely need it would go up. We would be allowed not the all singing all dancing beds or wheelchairs but the one that is more suited to our loved one would be accommodated because the money would be being put back in to the service.

Because you're not throwing things away. So, for instance, I had a delivery of milk for Will that was clearly somebody else's, I'd never even heard of the feed so you wouldn't feed that to him because it doesn't match what he needs and I rang up the delivery company and they said throw it away.

So I costed it out and that was just over four grand. Now £4,000 is the price of a new bed which I'm fighting for, for Will.

Lucy: Oh my goodness!

Christine: All it had done was come out of a delivery van and I have a delivery area if I'm not in where they can leave it securely and they'd put it into my secure area and I came back was like oh what's that, I wasn't expecting a milk delivery. So I rang them and I said "I'm sorry, I think you've delivered to the wrong person" he said "It's what we class as contaminated".

And I thought hang on I've not even touched it how is it contaminated and they told me to throw it away and I thought well I'm fighting for a hospital bed for my son but I can't have it because you haven't got the money. Well you haven't got the money because you've just told me throw four grand of feed away.

And so you're in that vicious circle. So that's where Skiggle comes in. So the more people that join us as members, and whether they use the SOS service or whether they use the marketplace service you're still doing your part to recycle. You're still doing your part to actually make the community for the people with disabilities better.

We all need to unite and I think that COVID has clearly separated the community. I think there's been a very hard line drawn between us and we now, as a disability community, have to pull together and go actually we need to do something about this and take some of the responsibility for your actions really.

And that's not saying that we're all throwing stuff away unnecessarily, it's because we're told and we're programmed now to do that.

Amber: Where do people find you, where's the best place to reach Skiggle?

Christine: So our main place is skiggle.co.uk so that's the website. Now on the website you can find what we do, why we do it, our blogs, because we're doing monthly blogs now which has been something that I think is quite a good way of downloading how you're feeling at the moment. And even my daughter, my latest blog was my daughter was reading over my shoulder and she's written a blog.

We have a Facebook page as well which is chat and support which you're welcome to join and talk to us on. We also have an Instagram page. We also have a Twitter page and we've just opened up a YouTube channel which is going to be Will's Journey. So it will have little adventures for him and things like that. I think you would like the YouTube channel.

We had a lady who sung Will Hallelujah. It's one of his favourite songs and she actually made him a personalised message and sang to him over a video link which is very special to Will so we play that a lot.

Amber: You mentioned COVID and we're recording this on the 22 July, a lot of the country has started to come out of lockdown, can you tell us a bit about what you're lockdown looks like. You're latest blog post talks about being reunited with your daughters and husband after 84 days having made the challenging decision to separate as a family on 12 March. So where are you guys at now?

Christine: On 12 March was when the Prime Minister Boris Johnson said "We're going to lose some loved ones" and we were all sat having dinner at the time and everyone just looked at each other and we went "Not in this house we're not" and we made the decision then that the girls and my husband, because they were still at school and at work, were going to move in with family.

So they actually moved in with family. They only came home four weeks ago and that was I think one of the toughest decisions we've had to make as a family because when you have someone as medically complex as Will the slightest cold can fling you into intensive care with pneumonia. That's the top and bottom of it.

This is not being flippant about it. People will go "I've just got a bit of a cough, I'll come round for a coffee" and I'm like "No, absolutely not. You stay away and once you're clear you come". So to make the decision with COVID it was a silent killer is how we said at home and as my girls said we are going to lose Will at a very early age. I mean as I said he will be 17 soon.

But every year has been a battle to get him to that so why would you put him in danger with COVID, that nobody knew anything about. When we first started out on the COVID journey in March even the health people had

no idea. So to make the decision we talked to all the care team because Will has a care team.

We talked to the care team, we talked to the family. It was decided that they would move away and they would go and live with family which was incredibly hard. *(Crying)* It was absolutely dreadful. To pack my girls clothes in a suitcase and – sorry.

Lucy: We can't even imagine the situation you're put in when you've got to, you know, send two of your children away for the sake of another one of your children.

Christine: I think the worst thing for me was packing their suitcases and actually not knowing when they were going to come home. Now this was potentially if anything happened to Will that was going to be the last day they saw him. And that sits so heavily on your shoulders because you're genuinely thinking gosh this could just end our family of five instantly couldn't it.

And I think that was the worst bit for me personally. I mean I've done the long hospital stays with Will. Nine weeks in intensive care is just one of the normal things that you do. But this was to divide our family and potentially them not see Will again. And that takes a lot to get into your head really and I have to say that we have the most amazing care team here.

So we have three night carers and we have three day carers and we talked to all the care team and two of our day team had to step out because one was working in the community, so she works as a support worker, so she was still at work supporting. So she made the decision before we actually said anything to take that step back.

So that again, so we'd had the blow with the family separating, then she said "I can't come to work Christine, it's putting too much risk for Will" I said "Fine". And then we had another blow literally about 10 days in, I couldn't believe it, one of my night carer's daughter was possibly diagnosed with a brain tumour so we were kind of like (a) it was a shock because this little girl had got potentially a life threatening illness.

And also it took out a carer instantly. Now with Will he's very much a creature of habit. Everything is in routine because if you knock out his routine it takes him days to recover. He can't pick himself up that easily. So we lost two carers really quickly and Will didn't see them. They just disappeared from the care team. So he'd lost his dad, his sisters and two carers.

That was five people within 10 days and I know that he does suffer with his mental health. If we're away from home in hospital you can see him declining but this hit him really hard and you're talking about a child who,

he has got understanding and you know he's got understanding but his understanding isn't necessarily as good as ours.

So to explain to him that one of the carer's daughters had potentially a brain tumour, because I told him because I tell him everything just in case he does understand that's fine. And then I said the other carer can't come because she's still working with all the people outside and she needs to make you feel safe.

And he was like "Okay, I get it" but to not have his dad and his sisters when he probably needed them the most was really difficult for him. Really difficult. And I think our journey through COVID has been – you think you're doing okay and then it's like being hit by a train and you think goodness me, how do I get myself through that next day because today has been really tough.

And we have managed it and I think the care team have been able to support each other. So I'm part of the care team and a day where I was perhaps having a particularly bad day, Mother's Day was really hard, then the other carers would go "It's alright, we'll do" and then they would maybe go down and have maybe a bad day and it was a cycle.

And I don't think we're out of it because I can't come out of lockdown with Will until the end of August, that's what I've been advised. So I've basically been in the house and garden with Will since 12 March and not set foot out of there. So it's been tough. It has been tough. But I think the COVID journey has also showed strength. It's showed that you think you can't but actually you can and if you can still have a laugh, which we have, and tears, which we have.

And the days where I'm not at my best and I look I might shout at somebody the carers know to just hide it's shown strength that I didn't know that Will had, and I didn't know that I had, and I think the COVID journey for a lot of people has probably shown different sides to themselves and I've learnt a lot about myself.

And I've learnt patience which I'm probably not the most patient of people so I've learnt patience, and I think the COVID journey has just been an exceptional one to go on in a lot of ways and if we can come out of this as a full care team, a full family, we've done exactly what we needed to do.

Lucy: And your husband and daughters are back with you now?

Christine: Yes, and Will's hating it because he's having to share. He's got quite used to being on his own so them coming back and demanding mum time and I'm busy doing other things now and he's kind of like "Mum would normally" and I'm not doing that now. So he's having to share and he's not – he is

very good at sharing but I think after three months on his own he's kind of gone I like this only child thing, it's quite good.

Amber: And you said that you received advice to shield until the end of August, where's that come from, is that through kind of your personal clinicians or is that general advice that you've had just because everyone we've been interviewing for the podcast has had such a range of advice or no advice?

Christine: I was going to say a lot of people that I've talked to have had no advice which is really scary. No, so basically all of Will's consultants, we've had a huge amount of interaction with our consultants because the NHS have actually done really good on the video calls which I'm thrilled about because they've not abandoned me.

I think a lot of people feel abandoned but my consultants ring me at least fortnightly to three weeks to see how he's doing because he's so medically complex they daren't just take their finger off the pulse. Initially they said the shielding would end at the end of July and the R rating was just tinkering wasn't it. It wasn't just coming down as far as they thought it was going to do.

And the R rating stayed and plateaued for a while and they all came back to me going "Okay, can you do another month?" and I said "Yeah, that's fine, I'll do another month" well once you've done four you may as well carry on might you. And so they said the end of August but we're going to re-evaluate that again because he's got a very low immune system so why would you risk going out too soon.

So I don't think the end of August is necessarily the end of this. I think we're coming into, I crudely call it snot season, but that's where I think the consultants, definitely the respiratory consultants and the tracheostomy, the ENT people are all saying if people can wear their masks, which some people are going I don't want to well that's just a bit selfish in my opinion but there you go.

If people wear masks and protect themselves then I feel I can protect Will by him having his face mask. He has a tracheostomy covering so I've got him the best protection I possibly can and then I can bring him out into society. But at the moment if people are not prepared to wear face coverings then I have to think is it safe for him at this time.

Lucy: And I think that's the big question facing all our families that we've spoken to and it's such an impossible horrible decision to have to make. Tell us have there been any new things that you and Will have done together during lockdown?

Christine: Quite a lot actually. So Will has done some absolutely fantastic times with

the music videos. As I say we've had people sing him songs and things so he's really loved listening to those and really his genre of music is quite extreme, he loves a bit of classical, he loves a bit of hard rock. So he's absolutely loved watching music video so I've been YouTubing music videos for him to watch and things like that.

So he's really got into his music. The other thing that he's enjoyed is just basically catching up on his films and things because his sisters often take the remote "No, we're not watching that" and so he never gets to watch what he actually wants to watch. So he's caught up on a lot of films that he's like to watch and musicals, he loves musicals.

But also one thing that I've learnt is that hair dye is not important or a haircut. And he's had to get used to that. Whereas I'm cutting his hair so I as a previous job before I started running the charity used to be a dog groomer. So I've had to bring out my dog grooming skills and Will presently has a haircut that any dog groomer would be proud of. We've learnt to do that.

So Will's quite shocked at the moment because I said to him the other day "You look like you've just escaped from prison". So we've learnt lots of things and we've learnt to think out of the box. Play time is different than it was because we've had to wear full PPE. So we've had face shields on so there's no getting really into Will's face because you've got to stand back all the time.

So we've learnt to think out of the box but also we've learnt that we can read each other better emotionally because we've not been able to do kisses or cuddles because I am a risk to Will as well as Will being a risk to me. So there's been no cuddles and no kisses, and we've now got a way that we can do cuddles and it's called leg hugs.

So we just hug his legs and he thinks it's great so that's going to be our new thing now, that we don't actually do kisses and cuddles, we do leg hugs instead and he thinks it's brilliant.

Amber: I mean I love the sound of a leg hug. This is great. I think this should be adopted as a form of physical affection globally. I love it. It's brilliant.

Christine: You might get an odd look though if you did that in the supermarket. But it's just you can't go near his tracheostomy because of the virus so we've had to adapt and go different so leg hug it was.

Amber: And what a brilliant way to adapt. You've spoken already a bit about how you felt supported through Will's consultants throughout this time which is really great because again that is something different from what we've heard from some of our previous guests but we have heard time and time

again from people that they have felt very isolated during this time.

And as a PMLD community people have felt quite forgotten, what other kinds of support do you think could have been useful you guys as a family and Will at this time that you may have not received?

Christine:

I think, you see I've been very lucky in my support and I've heard some horrendous things from people and how it is isolating but I set myself into a very different place and I think having done 17 years of Will's life where I've spent weeks and weeks on my own in hospital you learn to get used to the isolation. You shouldn't have to get used to the isolation but you do learn to live with that isolation.

So I've been actually really fine. And because my carers have been coming and going, which I'm extremely lucky by the way on that, because more care companies just pulled all care from people and so they had no support at all. Now we actually have been very lucky that I've only lost two carers, one because she couldn't help as her daughter was quite poorly, and she hasn't thankfully got a brain tumour, I forgot to say that.

She had to step out and she's worked with Will 11 years so she was a huge person to go. And then other one was taken out for her commitment with work. Now for me I felt completely supported and I've not felt lonely at all. My outreach nurse has been fantastic. She was actually pulled out of my service because she is a paediatric outreach nurse but she's also trained in intensive care.

So obviously all the people that were trained in that had to be pulled to the intensive cares. So I lost her. Now she's my absolute sounding board. Before you get to a consultant I bob her a text and I'll say "This has happened, can you help?" and she even going through the ICU she'd bob me a text and go "How you doing?" and I'm be like "Okay, yeah, I'm fine" and then I'd say "I need to get this into hospital" and she'd go "I'll come and pick it up on my way past.

And she would just go that extra mile and just help me. So I don't feel unsupported in that way. The one thing that's been the most stressful with support, and other people have definitely felt this like I have felt it, is we, me particularly for Will I've had relentless phone calls asking for equipment back.

So they wanted to take – Will is on an oxygen concentrator because he forgets to breathe at night so he has continual oxygen and they asked for my oxygen concentrators back to provide for the intensive care departments. They also told me that – I have two feeding pumps for Will because he's fed by a gastro-jejunum tube so he's fed into the top end of his bowel because of other complications he's got.

So I have two feed pumps which I run simultaneously and they basically said "You can't have two, you need to give us one of those back". I didn't. I said "No, not on your life". I was told that tracheostomies which we change every week for infection, so I've done that since he's had his tracheostomy which was 2008, all of a sudden I had to prolong the life for up to a month and I was like hang on a minute, so you've just decided to change it.

Then he has suction catheters. I got told that my deliveries wouldn't be coming. We had to downsize on our tracheostomies or not have any at all. Now I know this has happened to other people but these are life saving things. You can't go "Oh, okay then, we'll not bother having that". It's not like not having potatoes for your dinner. This is real life saving equipment that was being withdrawn and I know why it was being withdrawn, because it was all being stored in what they called the super hubs.

And the super hubs are warehouses throughout the UK that the hospitals, so the NHS Trust, can just dip into and pick anything out of. PPE, what a nightmare that was. Basically that's the side I was forgotten on, me personally in my journey. To get a box of gloves I was told "No, you can't have any gloves". Okay, so I've had gloves, we suction [unintelligible 00:36:36] with gloves for infection risk and all of a sudden they say you don't need them.

Why don't you need them? How can you just change something that you've said forever to all of a sudden just fit your way of thinking and what you've been told. It's all upper Government so Matt Hancock on the news will say "Yes, PPE can come, you can have this, you can do this, that and the other" and the next one was just a closed door and it was forget about the disabled people at home, the carers. The parent carers.

You're not important and I think for me what happened was the NHS got first pull, obviously. The second pull was because the nursing homes all got really cross and angry and wrote into the Government saying this is unacceptable. They then got second pull on PPE. And us at home are just completely forgotten.

And you can't get – I mean if I had to go and buy some gloves now, well prior to COVID off a website like Gloves for Us or whoever you would be paying between £3 and £5 for a box of gloves, that's including VAT. You go to any of these sites either there's no stock available for you or you're paying up to £25 for a box of gloves.

So (a) why are we not being supplied them because we need them, and don't tell me that the NHS, whoever orders our stock, doesn't get a container load of these of 50-60,000 boxes. Or why have the Government

not stepped in and said there's got to be a cap on gloves. I know this is all about business and profiteering, I get that. I used to be a businesswoman.

But we need help in that. We've got to protect our loved ones and they left us high and dry.

Amber: And it sounds like, you know, the support that you had and the support that you got was that kind of localised support, people who knew you, people who knew Will whether carers at home or medical professionals, people who knew your case, you were able to rely on that support but anything that was kind of from a bigger systemic point of view is what was taken away.

And it's just, for someone who has kind of created a charity in supporting and sharing this medical equipment, and much needed things, it's just horrific that when you actually need something that and that's been taken away from you it's kind of ironic given everything that you've given to so many other people isn't it?

Lucy: They were going to take Will's oxygen, what were they going to do?

Christine: I know, but it's basically taking away the physiological rights isn't it of a human being because you're taking away air and you're taking away feed. And as Helen said one day because, I just sat one day when I'd had, I think I'd had four or five phone calls and it was back to back and I just said "Do you know what, I'm not in the mental state to keep answering the phone at this point".

They'd rung for my oxygen machine. They'd rung twice for my feed pumps. And almost, not got nasty, but it was almost like "No, no, you need to give it us back now". Then I got told about my tracheostomies and I just sat and I put my head in my hands on the kitchen table and Helen went "You alright?" and I said "No, I'm not alright". I said "What are they doing?"

And she said "Well basically they're just accommodating the hospitals for people that aren't yet sick aren't they? And I went "Yeah, that's exactly what they were doing" and I know there was this huge panic around the COVID situation because we've never ever been in this situation before where they had to get the beds, and they had to get the ventilators and all the rest of it.

But they literally went bang, stop everything else. Well we still have to live.

Lucy: On that note are there any changes that you hope will support people with profound and multiple learning disabilities in the future influenced by this time in lockdown?

Christine: Yes, I think that we as a disability community and people with disabilities in the future need to work together. We've not been solidly been working together. I think we have all been battling our separate battles and what we need to do is we need to come together and we need to fight the war which is being left out things.

Society don't believe that we're important and I think that COVID for me has got very dark lines straight down the middle. Able bodied people who have no reason to be upset by the COVID and they carry on with their normal, and are quite cross that they can't go to Spain on holiday and then there's us which are the disabled community and I think now this should be bring everybody together with the disability to show our strength of who we are as human beings.

Show that we've got the battle scars. We've got the war wounds. We've been through a journey and we've come out of the other side and we should all be united with each other to ensure that no-one is left behind. I know we can't leave our homes because we're vulnerable but like I'm talking to you today there's social media. No-one should be left behind now. We should all be united.

Lucy: Yeah, and that's we hope to achieve a little bit of with this podcast, just getting people's voices out there because we are aware that our audience and the community that we usually work with were being forgotten and ignored, and like you say people with PMLD are so invisible anyway and then especially even more so when you're locked in your homes.

Well we love Skiggle and the idea behind Skiggle and we will put all the information about that on our show notes should you need that and if there's anything we can do to support Skiggle on our, well hopefully when we can tour again, journeys around the UK do let us know but it's been brilliant talking to you Christine.

Christine: Thank you very much for your time.

Amber: Well thank you so much Christine. That was a really, really insightful episode and we really appreciate your generosity in talking to us about your family's experience during this really, really challenging time.

Lucy: And your honesty about what it's like to go through this and I really think that will help support other families hearing those stories.

Amber: I think making that decision to split your family to protect someone in your family really is such a powerful message about the power of love and family, and it was really incredible to hear about everything that you've been through with that.

Lucy: But also I loved learning more about Skiggle, what an amazing initiative.

Amber: Yeah, super cool and just how it fits so well with environmentalism. You don't necessarily always see the learning disability sector and the environmental sector kind of going together hand in hand. So it was really, really cool. It felt very, very different from anything I'd come across before.

Lucy: And like a really supportive network for families who may have things that they can share or things that they need and people that can support them in getting it. I thought it was really great.

Amber: Yeah, so do check out our show notes. We will put all the details about Skiggle in them and it just sounds like the bigger the community is the more successful it will be. Also guys I mentioned it last week but please do check out BOP On The Wire which is Birds of Paradise's podcast. It's a podcast that interviews disabled artists in Scotland hosted by Robert Softly Gale and Jack Hunter. So do check it out.

Lucy: So thank you for listening to us today. You can listen to the podcast at www.frozenlighttheatre.com/podcast or all the usual places you get your podcasts. Please do rate, review and subscribe.

Amber: You can get us on Facebook at facebook.com/frozenlighttheatre, on Twitter @frozentheatre and on Instagram @frozenlighttheatre.

Lucy: Thanks so much for listening and we'll see you next time.

Amber: Bye everyone.

Lucy: Bye.

Jingle: *Jazzy piano music with scatting*