

# The Skies We're Under

## Season 3 Episode 1 - We're Back!

Rachel (00:01.906 )

Welcome to the Skies We're Under podcast, posted by me, Rachel Wright.

Rachel (00:11.79 )

This podcast is created by and for parents of people with disabilities and the many practitioners who support us. It's just for all of us who are trying to get from one end of the week to the other whilst bridging the gap between the life we expected and the one we're actually living. Hi, I'm Rachel, the founder and director of Born the Right Time, a qualified nurse, the mum of a young man who loves music, swimming, pointless and has complex disabilities.

I wrote the memoir, *The Skies are Under*, and I'm delighted you've joined us for another episode of *The Skies are Under* podcast. The plan this week was to do the podcast with Sarah Clayton. She's the CEO of Simple Stuff Works, postural care geek, mum of four, and the parent of a formidable young woman who is a survivor of a brain tumor and has medical complexities and learning disabilities. I was going to surprise her with an interview with our very own sea-loving, swearsy, vegan Lucy Parr.

She's an assistant ed psych and the parent of a young man with a genetic condition, which means he lives a very complex life. We are all here to share stories of fellow parents, get some useful information and connect with each other so we can all feel a little less alone and a little more understood. As you will hear, none of the plans went to plan, much like the rest of our lives.

Rachel (01:32.846 )

So here we are, season three of the *Skies We're Under* podcast. And the plan for season three is, okay, it's been over 250 days since we last did an episode. And I've decided to do the next season on the day that I'm full of a cold. So nasal cavity are us. And the plan is we're making our episodes a bit shorter. It's going to be half an hour. The dog walks are going to have to shrink by one whole 30 minutes. So you have 30 minutes worth of exercise. So whether that's your jog, whether it's your dog walk, whether it's your bath, whether it's the really long poo that you do when you get in to try and avoid your family. And that's really long poo, 30 minutes. But whatever it is that you do, to listen to the podcast, your journeys, whatever else, this is going to be 30 minutes rather than most of other episodes were an hour. And how it's going to look is we're going to similar format to last time.

We've got a quick introduction. We'll do a bit of what's the weather like, a bit of catch up, and then there will be a really short interview, a 10 minute interview. We don't have time to read books or to scroll the internet or to find out information that we don't have in our heads. So we're going to have some people, we're going to have experts. So some will be parents, some will be parents and professionals. It might be somebody who knows loads of stuff about just something we need to know. And then there'll be opportunity to connect with each other.

So there will be time for people to ask questions, to leave Speakpipes, to leave WhatsApp messages or email audio files and ask questions. Tell us something that you want to celebrate that you don't think anyone else is going to understand or a story of you wouldn't believe what happened to me today, whatever it might be, where we can connect and engage with one another. So first of all, Lucy and Sarah, how are you both?

Sarah

How long do you want me to talk to you for about 250 days worth of general crawling? Around the internet. Right. So, Abby is settled into residential college. Loves it. There's been, yeah, we're having a great time. We're working out Amazon and she keeps getting stuff delivered, which is all quite fabulous. I no longer have any children at primary school.

Can we just have a moment to celebrate the fact that there are no more half of vegetable days. There's no more bloody, none of it, none of the crap, but I'm a bit upset. more World Book Days. No more World Book Days. I'm slightly devastated because there's not a WhatsApp group anymore. And I was completely reliant on there was a particular person in the WhatsApp group that basically was my PA.

Her daughter has gone to a different school and I don't think it's appropriate for me to get her to read my newsletters to then remind her. So, I'm reading my own newsletters and that's upset me. Frankly, it has upset me. I've been on holiday, had a successful -ish holiday and we went north. We thought it's too hot for us south, so we went north.

And that resulted in what's called Holiday Fuck That List. Do you want to know my Holiday Fuck That List? So all the way through the holiday, I added to the Holiday Fuck That List. Right, are you ready? Yeah, we're ready. Right, UK. That was at the top. Just fuck that. Self catering. Driving. Yeah, absolutely fucking self catering. Why would you do that to yourself? Driving. Queuing.

Rachel

Are we so good at queuing in the UK? Yeah, I know. What are you talking about? We love a queue.

Sarah

Right, no bacon sandwiches from mobile vans. That's on there. I haven't looked at it for a while. I've not looked at it for a while. And to be honest, I don't know why that's on there, but maybe there was a really bad sandwich. Right, ready? Castles, cathedrals, monuments, museums, war, death, history, boards with information on that you have to read, etc. That's just a UK holiday. I'm not finished. It's outside. So obviously you've got to be inside reading shit. Right, no, well, right, I'm not finished. Listen, cold, waterproof clothing, sharing a house, dogs, carrying stuff to a beach, windbreak, brackets, sea waterproof clothing. Local leisure centres, changing rooms, washing up and my final one is buying milk.

Or summed up accurately at the top was UK. So I've done that. So that's what I've done. So obviously we've booked this year's holiday. We're going to Cornwall.

Rachel (06:46.51 )

Oh, so no doubt. That sounds like you're still going to have, it sounds like you're still going to have the carrying ship to the beach. Oh, I think it's all UK. I mean, it's there, isn't it? It's all there. It's a self -catering UK holiday again, but nevermind. Not for the wedding. Anyway, Lucy, what have you been up to?

Lucy

Well, I also went on holiday to Cornwall and that was fun. But Brecken had just had his VNS, which is a, you know, kind of a brain pacemaker for want of a better description. And so he couldn't go in the sea, which was very sad because it was very hot. And we were near Bude and we took him to the beach one day, which was a massive fail because all he wanted to do was go in the sea. And we had to not let him in the sea. And yeah, you can imagine that didn't go so well. Other than that, I think, you know, when you think, oh, it can't get any worse and then it gets fucking worse. That is my life. I don't even know where to start. My fuck that list is increasingly growing. Fuck that, local authorities. Fuck that. I work for one as well. Yeah, local authorities. Fuck that. The real shit show that is currently the system where there's not enough placements for everybody. And so the easiest kids get placements and the

more tricky kids. I mean, if you're going to take a...you going to take an easier kid or a tricky kid for the same amount of money? Obviously an easier kid. Fuck that. Fuck that. Just general. Yeah, there's lots of things, but I'm cross and angry at lots of things. So fuck that to a lot of things. And the only reason I'm still alive and making it through and crawling the shit show of life, if we're going to use the cruel word, because that was quite fun.

And I do feel like that is because occasionally on a Wednesday, I go to Wings Wednesday at my local pub and there's two for one fucking cauliflower wings and I love it and it's cheap. And then there's a band and that is my weekly survival strategy is Wings Wednesday at the BT not sponsored by the BT, but that is, that is exactly where I'm at. So yeah, Brecon has been served notice on with no current plan.

We have four weeks. No plan. No plan. Explain what's served notice on me. Okay, so Brecken is in a residential provision. The second one that he's been to. There have been a kind of whole host of issues, not solely the setting by any means, lots to do with the local authority, not putting in enough support, you know, not listening, all of that kind of stuff. And we've got to a place where they just don't feel like they can be needed. And Brecken's needs have evolved, to be fair.

He's now basically a PMLD child, which is profound and multiple learning disabilities, but he walks around and insists on moving all the fucking time. He also has seizures and osteoporosis. So there's like a massively lethal mix of things there, which I totally understand is difficult to manage. But yeah, he has been severed, which basically means the placement have said to him and us and the local authority, we can't meet his needs anymore.

He needs to, you need to find another alternative solution. Or another fuck that list, fuck that that we're having him at home. I love my child very much. And it's because I love my child very much that fuck that am I having him at home because nobody nationally can seemingly meet his needs. And yet by some magic, myself and my husband, just us are supposed to manage this child and make sure he's safe and meet his needs and do all the things just us. So yeah, fuck that. And work and live and look after other children. Currently he's two to one, he's assessed as two to one all the time and he has nursing support as well. So I'm not quite sure how suddenly we're supposed to do all those things. But I've said no to them, drawn a hard line, which feels fucking awful. But equally, I know it's the right thing to do. I'm not compromising everyone's sanity and safety, least of all, Breckins, but it's horrible when somebody is saying to you, you need to have your child at home and everything in you as a mom wants to go, yeah, of course I want to have my child at home. But his level of need is such that it's just not possible. So fuck that too. Yeah. So it's just, I'm in the middle of a storm to be honest, and I'm not quite sure how that's going to pan out, but yeah, there we are.

Welcome to the shit show. Exactly. So that's where I'm at.

Rachel

Well, my son became a man, just magically one day last year. Wow. Magically turned 18 and suddenly everything changed and nothing changed. Except obviously he's falling, gradually falling out of all the pediatric services that have kept him going for the last 18 years. So that transition is, I think I remember hearing about transition into adulthood really early on in my son's life and how hard it was, all these different transition things and how they were trying to improve it and look at this. And yeah, as far as I can tell, still just carnage, carnage. The amount of time.

Yeah. Is there any joint thinking or not at all? You just kind of, no, yeah. Not that, I mean, there is only me cajoling, coordinating case working and like, yeah, just trying to drag people together, kicking and screaming. So that's, that's his life and our lives. We have more people living in our house because you know, we're a little bit bored. So we have another couple of people and one of those people is a toddler. So we are back to safety guards on kitchen doors and yeah. Stairgate. Oh no, you're in a bungalow. I'm in a bungalow. Yeah. But there is a stairgate cause we do have some stairs. Yeah. We have, it's a, I don't know, some different thing where there's some upstairs and there's some downstairs, but still mostly bungalow. So yeah. So we have a toddler in the house. So that's fun and

games. And we have chickens. So chickens are, they kind of make me feel like I'm in Jurassic Park. You know the scene where right at the very beginning and you've got them, they kind of run along over the over the hill and then dive behind the rock. Yeah. And they kind of come over. That's how I feel walking to my office now because they're like come around my feet and like they're pecking their heads.

(13:57.912 )

It's such a shame if we're going to have to clip this for social media because it looks so good. But it feels like I'm being chased by some prehistoric animals. How many chickens do you have? We have four chickens. How big are they? They're monstrous. They are huge. They're like dinosaur size. They are. You jest. Have you been pecked at the leg by a chicken before? No.

Have you? Right. Yeah, it was then, don't judge, okay?

Lucy

It was one of Brecon's favourite activities to sit by the chicken coop and stick his fingers in and get pecked. Apparently hilarious.

Rachel

Yeah, well, okay, maybe he's a little bit more sensory seeking than I am.

I would love Lucy, I want you to tell us something that we need to know. Okay. Okay. You've got five minutes. Five minutes of a conversation now. I want you to tell us what is it people need to know. Okay.

Lucy

People need to know, this is a really important thing. People with children with special educational needs and disabilities need to know they don't always need an education healthcare plan, an EHCP. And there's a lot of like kind of rumour going around and misinformation, I guess. And I'm talking as a parent, but I'm also, and I wish I knew this as a parent at the time I needed to know it, but I didn't. But now I do. I'm a professional, I work as an assistant EP. So I know this stuff in the SEND team for my local authority. And you would be amazed at the things young people should be offered under universal support. So when we talk about support for SEN children. We talk about universal support, which every single child should be offered. And then we talk about SEND support, which is the next level up, which is children who maybe struggle and have difficulties in some areas, either cognition and learning, sensory and physical, communication and interaction, or social, emotional, mental health needs. Those are the kind of four main areas of need. And then at the very last level, we have children who are on targeted support and that is plan level. So kind of targeted statutory support, which is over and above what you would expect on universal support or sense support. I'm just going to tell you a few things that should be included at quality first teaching level. When we talk about quality first teaching, we're talking about universal support. So this is stuff every single child, no matter what their level of function is or level of need, should be offered as a universal offer in every single school. So, provision and support that should be available, things like broad and balanced curriculum, quality first teaching, quality feedback on a regular basis. But then we get to total communication approach. So, total communication approach, you may have seen on EHCPs written down, that is not an EHCP level intervention, a total communication approach where you're using...sign and where you're using PECs and where you're using visual time tables and all those things. That is a universal offer that should happen at universal support level, which blows my mind, honestly, because the amount of times we write reports as EPs and we're still kind of adding in the provision section, oh, this child should have a total communication approach. And people instantly think that that should be kind of plan EHCP level.

And it really isn't. It should be happening all the time. Reasonable adjustments. So reasonable adjustments meaning if a child can't wear their uniform because of sensory issues, then they should, it's a reasonable adjustment to make to say they don't need to wear

their uniform. If your child has social and emotional mental health needs that they have time out, that they are able to take brain breaks, all of those different things, like really,

Loads of things can be met at a universal level and schools have to go through this thing called a graduated response. So they have to show that they are putting in place all the support that should be available at universal level and at sense support level. And it's really quite a high level of support. So if you have a look on your local authorities website for graduated response document, they should have a document on there somewhere, or you ask your caseworker or whatever, ask your school for, okay, well, what's the graduated response look like for this local authority? And on there, you should have examples of this is what should be available as a universal offer. This is what should be available at SEND support. And this is what should be available with education, health and care plan support.

Rachel

My kind of...concern about the universal level thing is that like you say, people don't know and you end up in this fight of, oh, but I think you'll find this is what my child or young person is eligible for. And partly, how do you know what you don't know? So how do I know what are the kinds of things they could be thinking about unless somebody else has assessed and has said that that's possible? And I...

Whenever I hear graduated response, I feel like it's perpetual trauma. Like I'm sure, there's something about, we will try something until it fails. And the impact that that failing has on the young person, that they have not been sufficiently regulated, that they have not been sufficiently supported, that they have not been. And then we'll try a little bit more until we're proven again that still they're not supported and still they're not, you and it feels like there's this need for there to be crisis before stuff gets put into place. And that really worries me. Yeah.

Lucy

No, I think that's a really fair point. And I think that not knowing what you don't know on your local offer in theory, again, this is in theory because not every LA does this well. Unfortunately, but in theory on your local offer, there should be a kind of document or some information about the graduated response, about what that looks like. I agree with you completely that graduated responses, it's kind of a deficit frame system. How much can we force a child to fail before we need to put some support in place? That isn't always the case. If you've got a high level needs child, so actually,

The children that really need an education health care plan don't necessarily have to go through that whole plan do review assess cycle, which is what local authorities expect for children to go through. If you're open to portage, if you have been assessed by a child development center, if you're open to any kind of health professional, you can fast track that process. I'm not sure people know that. I'm not sure maybe that's...supposed to be known. I don't know. But there we go. But yeah, I agree. The perpetual trauma of let's try something until it fails and let's put something else in until it fails. And then eventually when we've done that for two whole cycles of failing, then we might consider assessing your child for an education healthcare needs plan. Another thing to note is, so the legal test for asking for an education healthcare needs assessment is literally your child may have special needs, special educational needs, that's it. So if there is evidence to suggest your child may have special educational needs, you as a parent can put in a request and if you look on IPSEA or Sendai ASS or any of those helpful websites that we can put in the clever comments somewhere resource section. You can get a template for that letter and you as a parent can put that into the local authority. They usually can't say no to that assessment, which is... But they do. But they do. But they often do. They often push it back and they say there's not enough evidence, but you just appeal again, annoyingly, and it's really annoying, you appear. But I think...what then comes out if you go for it, if you ask for an EHCP, you don't necessarily get a plan, but it puts on everybody's radar that your child has XYZ needs and as part of that process, an EP has to do an assessment. So an EP goes into school, assesses your child, observes, gathers information from school, gathers information from you as a parent and writes a report that says these are the additional needs of that child and this is what

provision they need to be able to access learning. Now that report, we have just in our local authority been told to kind of start structuring it as this is what universal support they need. This is what sense support level they need. And this is what kind of targeted provision they need, which is really helpful, I think, because then actually, when panel were making decisions, we very clearly stated, and it's really helpful for parent to see, oh, okay, they it's not that they don't need support, they do need support. But actually, all of their support follows it falls under universal provision. Yeah. Or send support level and you can use that document and take it back to the school and say, but this is the provision that you should be providing. And that's the ideal. And in theory, in practice, we know it's all different and hard and difficult. But that's the facts and how it should be.

Rachel

Thank you, Lucy, we will get you back to tell us how to actually make that happen. Cool. That theory. Any thoughts on that, Sarah?

Sarah

I'm a little bit blown away by that because obviously B is now 22. And I just wish I'd known that because I just thought that stuff like total communication. Yeah, you're like shaking your head and I'm just like, what they should have been doing that because it was always...

it always felt like that was kind of behind a magic door. And that we need to do special things to get behind the magic door. Yeah. And actually, there wasn't a magic bloody door. No magic door. It should be happening anyway. It should have been a lot of things should be happening anyway. Yeah. In an inclusive environment, which is what we're striving for as local authorities to have inclusive schools and inclusive environments. But yeah, and I think that the whole thing of it's just another barrier, isn't it? That without that knowledge, that there is this universal offer without that knowledge, you just feel powerless because you think that you've got to do another thing first and that you've got to reach this particular, you've got to get over this particular hurdle before anything can happen when actually there's an awful lot that could probably happen. I'm going to go and have a look on my local authority website and see what there is because I know lots of people that live locally to me. who would be very interested in that piece of information. Fantastic. Thank you, Lucy.

Rachel

Right, we are going to finish up. This will be the part of the show where we have someone phone in or we have an email or we have a something. I'm going to play our first Skies Runder podcast voice note.

Michelle (Caller

My name's Michelle, love the podcast, so I'm ringing in to say something really insightful for you all to talk about. Isn't speakpipe really easy to use, by the way? Anyway, I hope that was a really insightful thing and will be really helpful for this week's podcast. Take care, see you soon, bye!

Rachel

So if you have anything more powerful to say than Michelle, please do phone in. Either use a speak pipe and there is a...

Sarah

Sorry, sorry. Can I just stop you? What the hell are you on about? You've done it like three times. You've written it on our little thing of make sure you're ready for today. Bloody speak pipes in there. you've gone on about what are you on about? I'm imagining like a pan pipe situation where you say your words over the pan pipe engine pipe. Is that it? Oh, I got that wrong.

Rachel

There is a website called Speak Pipe. There'll be a link in the show notes or the blah blah blah blah place that Rachel will have as Lucy referred to it. And it's just a way that you can record up to 90 seconds of recording that comes to the show and then we get to hear you whatever thoughts you've had. So it might be something, like I say, something someone's done and you're like, you would not believe what happened to me today. It might be that you need to share something, like a little mile stone, a little thing that's occurred that you think no one else is going to realize what a big deal this is. I need to tell somebody and celebrate it. We want to hear about it and we want to celebrate it with you. You might have a really burning question that's as strong as cystitis without any cranberry juice in the house. Maybe you've discovered something that you really want other people to know, or you just want to connect with the podcast and be part of the community we're trying to create. We would love to have you, and if you really think, I don't want to listen to my voice, you can do the old school email. That's us ladies. Can you believe it? It has been so lovely to have you both on the podcast today.

I'm so thrilled that you have surprised me with a Lucy today. Surprise! Surprise! It's so lovely. Little therapy sesh, little therapy sesh, we love it. Yep, so we will be back week on week, whining in your ear holes, hopefully giving you some useful or less useful information. And hopefully you'll join us too by communicating and connecting on the podcast as well.

Thank you ladies, thank you everyone for coming back and we will see you all soon.

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