Making SEND Everyone's Business

Hello and welcome to the Making SEND Everyone's Business Podcast.
This podcast is part of a SEND training package for Level 4 health professionals and developed by the Council for Disabled Children, and it's also commissioned by NHS England for SEND Leads in the South East region.
And to access the e-learning, which is available on the CDC website, please go to learning.councilfordisabledchildren.org.uk.

Hello, my name is Joe Fautley and I work as Project Assistant in the Health team at the Council for Disabled Children. I'm an autistic person myself, who also has dyspraxia and anxiety. Over many years, I've been involved in various projects which enable autistic people to have a voice in decision making and to make a positive impact on society.

For example, I featured on videos which have been published by the NHS and are available on the NHS YouTube page in which I talk openly about my personal experiences of autism. And also in my previous role I co-delivered training sessions to professionals across England about supporting children and young people with SEND.

And so today, we have Dame Christine Lenehan who is with us on this podcast today. Christine is the Director of the Council for Disabled Children who is going to talk about what we mean by SEND being everyone's business from a strategic point of view.
So before we do that, here is a little bit about Dame Christine's background.
Christine is a former disabled children's social worker who has been involved with supporting disabled children for 40 years, including authoring a number of government reviews. She liaises with the government regularly and is, if not one of the, most respected figures in SEND. During her time as Director, she helped establish the long running Every Disabled Child Matters campaign and published a recent review into the care of children and young people with complex health needs, called 'These Are Our Children'.
And also co-chaired the children and young people's health outcomes forum and served on the Board of Healthwatch England until 2015.

Thank you very much Christine, for joining me today to share your insights.

It's a delight to be with you, Joe. Good to be here.

Thank you very much.

So we are now going to start with the basics.
And so the first question I have is, can you in a couple of sentences explain what we mean by making SEND everyone's business?

Thanks, Joe. I think that the answer is that children with SEND don't live in boxes. They don't live in isolated services. They don't live in isolated places. They use all of the systems that they work with. So, as well as the SEND specialist systems, for example, in the health service, there are also going to use dentistry. They're also going to use universal health services, they're going to turn up in hospitals, they're going to be in early years services. So it's really, really important that everyone who works with children also understands there are children who have SEN and disability and actually just thinks about what is it that I can do in my role. Sometimes, you know, we make our world so specialist, that we stop everyone taking a part and you know, thinking about your experience, Joe, you know you live in a world which is not just about autism, but in a world that's much bigger than that and everyone who comes into contact with you and everyone who comes into contact with young people just needs to give a bit of thought to what is it we can do that makes a difference. And if we do that, the outcomes for children and young people will be so much better.

Thank you very much.

So we're now going for our next question. And so I'm now going to ask about what are your reflections on the engagements and involvements of the health system in SEND, so since the Children and Families Act which introduced new duties on health in 2014.

I felt a bit sorry for the health system at the time, Joe, because as that was coming in, health was being reorganised under the Lansley reforms and a lot of the health staff we

were working with didn't know what job they had where they fitted in the SEND system or who they're responsible for. So they've done an amazing role in coming through, you know, a period of really difficult time for health and finding the space to do that.
I think some of the things that have made the difference are crucially, things like the Designated Clinical Officer and Designated Medical Officer posts. I think that's made a huge difference in the system as a sort of connecting wire between the different services. I think the other thing is like all of the systems we work with, we have some amazingly committed, passionate people who work in health and make a difference. And I think what the 2014 Act did give them with, for example, health advice in Education, Health and Care Plans was that very specific role in working with children with SEND and those that are keen on that, I think have embraced that.

Thank you very much.

So for our next question, I'm now going to ask about Level 4 professional lead teams have functions around influencing and affecting change and of course teams and services in relation to SEND. So what has in the past allowed the change to happen and also how can this group apply that learning into their current roles and teams?

That's a really interesting question, Joe. And I think the basics of what allows change to happen is always the same. You know, when I see the team now working in areas around the country, we keep coming back to some fundamentals which allow change. And the first thing is actually understanding the nature of the children we've got. It sounds odd, doesn't it? But quite often we will work in an area and people will not know how many children are there and what their needs are. So there is something about basic data which I think that matters.

And it's not just about basic data, it's then how we can share that data. So the heart of our multi professional working are those relationships across the system that enable us to look at how many children have we got.

What is it we're providing and do we know if whether we are providing is effective, so some of the things we've been looking at on outcomes for children, so the measurements

for effectiveness. You know, we can spend a lot of money on the wrong thing. So when I first started my professional world, as you've outlined, for example, we spent a lot of money on institutional care, residential services, intense support. Our knowledge base these days is far more about how we intervene early at diagnosis at assessment. So it's about how we can look at our system and understand the pathways that exist and where those pathways are about change and they are about the use of data and they are about also, very much, I think we might talk more about this later, how we listen to the needs of the people in the system so we can draw huge drawings when we're working with systems. But the sheer amount of people in the system, so also what you're having to think about is it's change for who's sake?

As a professional, a change in a process might look lovely for you because it saves time. But does that change make a difference to the lives of children and young people? Let me give you an example that should be simple, but isn't.

If a child has a physical impairment which means they need a wheelchair, then we know the average child throughout their childhood will need seven different wheelchairs and that's the sort of average assessments. And yet trying to find out how much we spend on wheelchair services and how we understand children's needs is really difficult. And yet we know that, for example, for those children, if they have a wheelchair, that can take them in school, that takes them home, that supports their mobility, and that supports their independence. That the outcomes for them can be much greater. So it's about thinking that process through in order to understand change.

Okay, thank you very much.

And so for our next question. So establishing partnerships with various agencies and partnerships is key for this role. So partners includes the local authorities, the VCSE and parent carer forums and provider collaboratives.

So have you come across any creative ways of working in partnership with other organisations to improve the outcomes of children and young people with SEND?

So I think partnerships at the heart of this, you know we do a lot of work don't we in the system and people regularly said to me so do you know what's the best practise in the system? What can we find? And do you know what the best practise is? It's about having the right people in the right room at the right time, with the right approach. So if you take the work that the Council's been doing in Rochdale, for example, that was based on a partnership coming together.

Key I think to those partnerships are the engagement of parent carers from the outset, on good days and on bad days, you know partnerships are about what we can do and what we can't do and within the constraints of the system, because let's never pretend we're going to meet the needs of all of the people all of the time. We have a shared understanding of the best things that are possible. Partnerships are also built on good practise. I think there is some really good regional networks out there and obviously what we now have in the change nature of ICBs is we have executive leads for children, executive leads for SEND, executive leads for learning disability and autism services. We also have regional networks who have been working quite a lot with regional palliative and end of life care networks, for example for children. So it's understanding that actually we tend to live our lives as professionals in programmes like I'm on an autism programme, a placement of life care programme, commissioning programme or whatever, and it's understanding, especially within health. First of all, our own interrelationships. Who works with children and where do they come together? Sometimes we have a habit of subdividing children. You know, we have a transforming care programme. We have a SEND programme. Hold on, they're often the same children, often with the same needs. So how within health itself, do we integrate into our own partnership?

And then at the heart of this, how do we work with one another? And one of the things I found really interesting about, for example, the dynamic between health and local authorities is that each are very worried about the other. Each are worried that costs will transfer to them. Responsibilities will transfer to them. Each are worried that the expectations of them cannot be met. And yet, actually, sometimes we have to be brave. Sometimes we have to go, of half of those open conversations, which says this is what I can bring to the table, what can you bring to the table and also then with parent carers. You know sometimes, people get very worried about working with parents because they think,

almost, we have to do everything they want and we don't. So what we have to be clear about is what is our offer of support or joint offer of support in order to do the best we can to meet the needs of the children in front of us. So it's about getting that vision. That's why I think that the work we do on outcomes workshops is so important because I think what you're doing in that outcomes workshop is you get all those partners in the room and you start to have that conversation, not about rushing into we must fix this and we must fix that. But you get a conversation which says what do we all bring and what do we want? You know? And they're often simple things, aren't they? You know, we want our children to be happy, healthy and independent. OK, that's great. So what do each of us have to do in order to make that happen? What is the most important from a parent and child point of view? And then going back to where we started, what is the data and evidence that will tell us that that is what we're doing?

Now I'm always very clear that as I've worked with children over the years and their needs and the systems' needs have become more complex, that we are now at a point where no one agency, however good that agency is, can meet the needs that are presented to it. So the only way we can meet needs is through partnership. So I would be really keen that any of the professionals listening to this podcast went away thinking: So who can I partner with? Who else is gonna have the same interests as me? Who else might be able to help me? You know, if you think Joe about some of the new partnerships even we've been making lately, understanding the world, for example, of youth justice and the amount of neurodiverse young people that have ended up in the youth justice system and thinking, how do we make the partnerships with youth justice then that hasn't been a partnership we've made before, but we've had to go out, think about it and work on it. And actually when we've done that, we've been, you know, well received as somebody who may be part of the solution.

Thank you very much.

So for our next question, one challenge we hear from level 4 professionals is being able to raise the profile of SEND in local or regional health system meetings and making SEND visible in broader children and young people's programmes in the NHS. Why do you think this is a challenge?

I think that's a really interesting question, so let's step back a bit.
Children have always been marginalised in the NHS. The bulk of the NHS service is for people who are elderly. You know it has less traction with children's services and always has done and politically always has done. You know, I spent a number of years chairing the children and young people's health outcomes framework with Professor Ian Lewis and we were looking then at what does a good health system look like for children.

And that had a bit of space. And that was great. But that was a sort of rare political insight moment that passed. And I think that within our marginalised system for children, then clearly children with SEND are a marginalised group. So we need to understand that and therefore it's really important that we are the people who lobby for that and change that and nationally, for example, we use different mechanisms. We look at the relationship between DfE and the Department of Health and Social Care.

And NHS England and we look at the children's opportunities within that. So on a number of times we go and present to the Children and Young People's Transformation Board, which is still, I think, a key national lever for making sure children's issues are on the placement and I'm really pleased that SEND has been a big programme for the Transformation Board and it's one of the things we can work with. I think at a local and regional level it goes a bit back to partnerships, doesn't it? I remember years ago going back to the wheelchair example. I was being part of a huge group looking at transforming wheelchair services and what I had to be able to do was make friends and interests with other people on that group who were representing children. So if we think about children and the challenge for children in the NHS, you'll be looking at people who represent children's mental health needs, children's palliative care needs, you know, children's needs within the public health system or whatever. So I think definitely at a regional level, I want all of you to think who are likely to be my allies for children, who are the people who are gonna help me make a difference because there is something about that. There is also something that's really important that sounds sort of odd, but actually that the system forgets, which is that children grow up to be adults.

And actually there is part of very, very clear messaging from children's services about the

difference we can make when we intervene early, how we can support children to be the healthiest adults they can be, so that as they become adults, they are not putting a strain, if we use that terminology on the health system that's already overburdened. I think the other thing that we need to be clear about is when you are thinking about your regional and local, you are going in with solutions.

You are going in to say we have a plan that supports community therapy waiting lists. For example, we have a plan that supports some of the more complex children and the way we have developed that plan is that we have worked with our partners, whether they're partners in the local authority or partners in the voluntary and community sector. And that is what we are bringing. So there is something about that. The other thing I would want us to feel empowered to do at level 4 is to be able to say to local and regional networks as agendas are at early stages of being developed and thought through, that actually we would always want an agenda on children and we would want to assure our place at the table.

The other thing that's coming down the track, of course, is the world of the SEND Improvement Programme and we had the first ministerial meeting on that this week and I'm really pleased that there are colleagues from the NHS on that board.
And both from PCB level and from regional level and from national level and the first item on that agenda was local inclusion partnerships. So the government is seeking to legislate, not currently, but is seeking to legislate a mandatory programme of activity locally, which is likely to increase a mandate on health to take part. So the accountability systems for health are likely to get stronger so it's worth us thinking about that at this stage and being clear about that locally.

Thank you very much.

So for our last question of the podcast, the Local Area SEND Inspection Framework has changed and has a stronger focus on outcomes and we have provided a summary of the requirements and what this might mean for level 4 professionals. From the initial inspection outcomes, what are some levers or enablers this group of leaders

can make use of to support their systems ahead of inspection?

New inspection systems are always really interesting and I think they take time to sort of bed in. So at the moment the team here at the Council for Disabled Children have been watching each of the inspection reports and actually measuring them against one another so we can start to see trends and issues and whatever. And that's suppose, you know, let's start with a really difficult thing.
There is one of the things that the inspection system is now looking at is waiting lists for community therapy services. I don't think there is an ICB in the country that does not have a waiting list. I think that's really clear and for all the reasons we know about post covid and workforce and everything else. But in the inspection reports we've seen, there are three, as you know, three inspection levels, mainly positive for families inconsistent for families and system failure and we've been looking at the difference for their community therapy services between local areas, ICBs as an absolute key part who have scored positively in those areas and have failed. And I think the issues have got to be it's not about pretending that these challenges don't exist. You know, we were talking to the inspectorate the other day and they were saying yes we really want to inspect against a system we would like to see. But we know what we're expecting against is a system that is. So, if you for example have got community therapy waits within your area then we want to know what the action plan is. Do you know what the length of the wait is? How are you keeping people informed about that? Are there other activities you are doing so for example if you take a waiting list for children on the diagnosis for autism pathway are there other things happening in your early years services in your school services and your support services that will support children who have those needs while that pathway is going through and are you actively looking to manage that pathway by for example looking at your recruitment strategies looking at if there is a different range of professionals that could support that, so that's one of the things we've been looking at. The other thing I think for us that we're really keen on two other things. One is a sort of specific, I am really pleased now that one of the things that inspections will look at is the dynamic support register.

So if we think about children who have the most complex needs, you know my professional life over the years is by the time that I stopped working in practise in my local

area, I could walk round the local special school and look at children's needs and think that child's going to be out of authority by 9. That child's going to be out of authority by 11. You know, it's not that we don't know children who have the most complex needs. It's that we allow them to become too challenging for the system to deal with. So the dynamic support register which picks children up early, who have those needs and where there is likely to be a high likelihood of statutory intervention and then doesn't wait for it to go wrong but thinks about how are we going to support these families. I think it's really important and I'm also pleased that this inspection system makes it very much a multi agency tool rather than something that health do that's really important and that's the third point for me.

I've been working with a couple of the areas that have been inspected and one of the things that's come back really strongly and it goes back to the theme really throughout this podcast, Joe, which is where is your shared vision, your shared partnership, your shared governance. So in a sense, if you think about your roles, you will be responsible and accountable, and it'll be great and you'll be doing a really good job.

But unless that good job is shared with your colleagues across the system, your colleagues in the local authority, your colleagues across the system, then actually we are not going to get good outcomes. And I think one of the inspection thing is doing is it's looking at that. So you know if you think about it as a lever, Joe, and your local authority area is not playing ball in the way that you would want it to be, this should be a really strong lever in terms of being able to go to people and saying we are going to be inspected.
The height of that inspection is outcomes for children and the only way that outcomes for children are delivered effectively is if, in particular, statutory agencies work together. So I think what we've been interested in looking at and one of the tools I'm sure we will develop is that are you ready for inspection and the questions and that will be that.

Do you understand how to work together? How are you evidence it? What does your shared governance and shared partnership look like? And if we were taking pathways for specific groups of children, like those for example, on the DSR, then how are you demonstrating that partnership? And really importantly, can families and young people see the demonstration of that partnership in practise? Because that's what the inspectors will

be looking for.

Thank you very much Christine for joining me on the podcast today.

Thank you, Joe. It's been a pleasure.