Health inequalities podcast – talking with families

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Hi so welcome to the Royal College of Paediatrics and Child Health podcast. This is the first of a short series on health inequalities. My name is Helen Stewart. I'm the College's Officer for Health Improvement. I'm also a consultant in paediatric emergency medicine in Sheffield and a transport doctor in the North West.

I'm joined today by two of the guys from Liverpool who are going to introduce themselves. Ian, let's start with you.

Ian Sinha
Hi, I'm Ian Sinha. I'm a consultant respiratory paediatrician and at Alder Hey Children's Hospital in in Liverpool. And I work as an associate professor in the University of Liverpool and I co-direct the research group within Alder Hey called the Lab to Life Child Health Applied Data Centre.

Alice Lee
And I'm Alice Lee. I'm a paediatric trainee in the north west and I'm currently a clinical innovation research fellow in the Lab to Life Centre doing a PhD in respiratory health inequalities with Ian.

Helen
Thanks for joining us. So I thought we'd start by talking about what got you guys interested in health inequalities. What was it that brought it to your attention? Ian, I don't know if you want to start with that one?

Ian
Yeah, yeah., it's something that has always been visible to me is that both as a medical student and as a doctor, and even meeting before being a medical student, and I when I was at medical school at Newcastle, I had a really inspirational and mental in many ways, who was a community paediatrician called Tony Waterstone, who's just a great guy, and he was the person really who gave me the confidence to start questioning why we're doing all the things that we're doing, only to just send children into situations that make them sick. And when I started medical school in 1997, there was a shift in government from the Conservative to the Labour government and there was a real ambition to try and end child poverty.

And so while I was at medical school, opening up children's centres and Sure Start Centres. And so it was just an interesting time to be to be around and thinking in that space. And I think that's really what has sort of prompted my first interest in this.

And obviously as times's gone on as a respiratory paediatrician, I think it's 70 to 80% of what I see is just simply the manifestations of poverty in one way or the other, or complicated by poverty one way or the other. So it's just very ingrained in in what we do.

Helen
Definitely, I work in emergency department and it's a huge part of a lot of our presentations. Alice, what about you? What got you interested?

Alice
Very similar things really. So similarly throughout medical school and early in training, being very aware of, you know, the injustice of what I was seeing presenting to A&E, presenting to the hospital and the situations that we were we were sending families and children back into. And then during my paediatric training, you know. I think it sometimes is a bit corny, isn't it? To quote Michael Marmot. But the whole idea of why send someone home to the same environment that's making them sick.

Alice
And so I knew that that was an area that was interested in and spent some time going, you know, signing up to different programs to learn more about that. And eventually, fortunately, was put in touch with Ian by one of the respiratory consultants in Manchester.

Helen
Excellent. Obviously you're both interested, but why do you think paediatricians, as a profession have a role in addressing child health inequalities?

Alice
I'll let Ian go first there and then I can chip in.

Ian
If we think through health inequalities through the life course and Alice mentioned, so Michael Marmot and his team, who showed that, you know, there's an unprecedented worsening of life expectancy for particular groups particularly and the most deprived decile of people and especially in the we saw this early in in women. And actually when you start to trace that back when you trace back any of the health inequalities through the life course that track begins in in childhood. These children are on two separate tracks. You've got children who are disadvantaged and those who aren't. And it's not a case that they that they that these tracks diverge, they just start off in a different place.

And so what we're really seeing in childhood as paediatricians - if I think back to my clinics, all I'm saying when I do clinic or do a ward round is I I'm seeing a child in a snapshot of what their lifelong journey will be. Something's led up to that point and something will happen from that point onwards. And when we see children in clinic, you know, when I do my bronchopulmonary dysplasia clinic with babysit gone home with neonatal lung disease, you know - part of what we do obviously is keeping children safe now.

But I think as paediatricians, we are kind of bought into the idea that we should be thinking about the wellbeing of these children in 30 years time in 60 years time in 90 years time, we want children to live their best life. That's why we go to work and do what we do. We want them to live their best life, to fulfil their potential, achieve everything they

want to achieve and that requires a lifelong approach, and we're in a unique position as paediatricians because our adult colleagues who we know and love are basically just managing the decline of long health or gut health or brain health in adulthood. But really what they're doing is addressing things that went wrong 40 years earlier in that person, so we're the unique and crucial position to try and advocate for a lifelong change. When you get the biggest bang for your buck by investing in in, in making improvements early.

Alice
You know, at least when I was in medical school, it was always classed as the wider determinants of health. And I think that kind of puts it in a niche interest box rather than what it is, which is, as Ian said, the vast majority of the reason we're seeing children and adults coming to hospitals and coming to GP services.

And so a phrase that we've co opted from one of Ian's colleagues is that they are now the core determinants of health and the core determinants of child health, and that's how we should be seeing these things.

Helen
Ah, interesting. That's really interesting approach because I think I read somewhere that the health service is only responsible for about 15% of health outcomes and actually so much more is due to those environmental social factors.

I think from my perspective as well, just remembering that is a crucial contact with the family that actually we all have responses to make use of to improve the child's health because that might be the only contact they have for quite a long time, particularly in emergency department and primary care so overwhelmed at the moment, isn't it?

So, how do you start to approach this with families? How do you start to have that conversation?

Alice
I learned a lot about this from Ian.

Ian
I mean you know when we think about how we communicate with people in, in, in general, sometimes we get it right. Sometimes you get it wrong and but the key thing is we've gotta be honest with people, don't we? You know, the golden rule is don't know anything that your patient doesn't know. And our family subscribe to that. There has to be a complete trust. And if there's something important that that could be impacting on their child's health, people have a right to know and as soon as we. Have that then things become a little bit easier to do. We're often told that people feel uncomfortable about asking about living situations and about finances and about poverty and things like this. And I guess that's the way that I look at it - these things, as Alice quite rightly says, other core determinants of health.

The analogy would be, you know, if I had a cough and went to a GP and he didn't ask if I smoked, I'd feel a bit short changed. This is the same thing. You know, if we know that there are things that can impact on someone's life, we should be asking about them. And conversely, I think we sometimes forget that the impact of what we recommend, of what we say and do to families has its own burden for them. You know, every time we say come

back to clinic in six weeks, that's a big chunk of their time that they're not earning, that they're paying for parking, travel, childcare, all these kinds of things. So it's really important that there's an open discussion about both those aspects, how their living circumstances might impact on their child's health and how their child's health might impact on their living circumstances.

And so I'll be honest, I've never really had a problem myself. No one ever questioned why I'm asking these things. I think it's important that we ask it to everybody and not a believer in the idea that we should target groups that we think might be poor and talk to them about it. Ask everybody, you know, we don't know who's struggling just cause of how someone's turned out. We've got some, you know, certainly in my life I've seen really rich people who look like they're wearing clothes straight out of the bin. And I've seen really poor people who pay so much respect for the NHS and the way they want to show that is by turning up immaculately. And so it's impossible to tell from what people look like. I know of families where there is a really high level of income, who's someone in the family, has got, you know, gambling problem and the money just goes. So there might be a huge income and 0 wealth. So we can't pick that.

Alice
No, I completely agree with everything Ian was saying that and I think especially for people who are feeling a little bit nervous about speaking about these things with families. For me personally, learning more about what we can do for families learning more about the community organisations has given me a lot more confidence in approaching these topics because I think sometimes as doctors or medics we were problem solvers, we like to fix things. So I do worry that sometimes we don't ask these questions because we don't have a fix for them.

And so it has helped my confidence from working with people in the community. That I know if someone comes says actually, yeah, I'm really struggling in this area, I know where to direct them and I can say, oh, my colleague from Citizens Advice or I know someone in Shelter who would really be able to help with that. And so that I would recommend people familiarising themselves with what support is in their local area.

Helen
That's great advice. I think that's probably applies to quite a few things, isn't it? People want to know that if you're opening up that difficult conversation, that actually there's a purpose and you can actually help in some way.

So do you have a have an opening gambit at a question that you kind of start that conversation with?

Alice
I can say what Ian tends - it's a really nice way that you approach things in the BPD clinic, actually that I've picked up and especially for new patients who are arriving at the BPD clinic, it's I think we're privileged in that situation where it's automatic to say how long were you in the neonatal unit? Were you working before you had your baby and do you have maternity cover and asking that kind of thing to see how long they've got off after their discharge from the neonatal unit.

Helen
Right.

Alice
And I've seen you do that a few times and that seems because it makes it a universal issue of having a new baby and the experience of being in neonates. And then filtering it down to, actually that can be really costly for families and how you coping with that.

Helen
Interesting. And what about when you're in respiratory clinic? With the older families where you've not necessarily got that hook in with the maternity leave?

Ian
So the hook in the asthma clinic is a different one. It's more a biological hope. So the hook in the asthma clinic is asthma is a disease of airway inflammation. There are various things can drive airway inflammation and actually quite a lot of those things are related to poverty. And for the last 30 years, we've got hung up on, you know, rightly we've focused on parental smoking, and that's a really important thing. There's a whole load of other stuff - poor quality food can drive airway inflammation. So that gives us a route to say it's nutrition might be leading to the FeNO [Fractional Exhaled Nitric Oxide] being up. And you know something like 60% of our severe asthma clinic is overweight or obese so that gives us a route to say, well, I wonder if we think about nutrition as being something that might contribute to your asthma and I wonder if that ultra processed food is important.

Alice took the lead at our end on developing some work for the RCPCH toolkit and one of the things she came up with was this a cost clock capacity analysis. In other words, simple things that we think are simple that we say to families: just eat better. Go on, you know, go and eat better. Actually, when you sort of break down that process, there's so many different steps and there are so many different barriers that that gives you a route into, say, well, I wonder why nutrition is a problem. And you know what all roads lead to poverty. It does for that.

Similarly for housing, we say to people, well, if you've exhaled nitric oxide, that's a good marker of airway inflammation that's persistently high. We know you're taking your treatment. We know you're not smoking. We know this, this and this. I wonder if there's something in the home that might be triggering that. So there's a biological and clinical route in there. When we see children on intensive care, the route into talking about stuff, And then someone bumped into me yesterday, we were reflecting on a case that we had of a child who literally went on ECMO because of a respiratory infection and when we traced it back, the house was absolutely completely uninhabitable, al because of the mould and our route to that is to say all children get chest infections, hardly any of them go on ECMO. Are there other things?

And, you know, parents don't feel judged at that point, because they're part of the circle of that team, you know they're a central part of that team. It's not us and them, not us, asking them. I'm sure when we get it wrong, it's perceived by paren, us was asking them, you know. We have to do sensitively. But this is very much about putting together as much information as we can to help that child, and we're all there for the same reason. So the hook is whatever it is that you're seeing that child for - unless you're seeing them for gout - there's a 99% certainty that there is some evidence that that disease could be, you

know, contributed to or is associated with or increased rate or different type of phenotype, whatever it is with not having as much money. And there's 100% certainty that whatever it is that you do will have an impact on that family's finances. So yeah, there are always ways in and doing it early and doing it sensitively is important.

Helen
So basically finding a medical element of that childcare and exploring it that way, rather than just coming out and asking.

Ian
Absolutely.

Alice
I think yeah, the work that so the parent champions that myself and Ian work with as well. You know they have been really instrumental in helping me approach these topics as well in the hospital and also so much of it is avoiding that stigma and being really careful that you're not perceived as being voyeuristic or trying to put them in their place, and that links into what Ian was saying, is that actually if you're sharing knowledge with them so that you are on the same page, that does help to address that stigma and make it so that actually here is what I know you need, you tell me what you know and let's work on this together.

Helen
Yeah, I mean, that's definitely been our challenge in ED in that we've created this leaflet for resources, but how do we make sure the right people get them? Because as you say, we can't profile people and say ooh, you look poor, here's this leaflet, but also people who don't need it don't want it. And we were giving it to everybody, but it ends up on the floor. So that's been a real challenge to work out how to make sure people who need it do get that information.

Alice
And what's your approach been there, Helen?

Helen
Well, and what we've done is we've created a welcome to the emergency department leaflet. So that kind of kills two birds with one stone in that it explains the process, explains what might happen. It explains why there might be a wait where the toilets are, where the water fountain is, but then also the link is on there. So that actually if we point people in direction of that, then they get the information as well. So it's still in a PDSA cycle, we're still working on it but yeah, it's something to be aware of, yeah.

Ian
There was some work that I I spoke with an anaesthetic trainee from your neck of the woods, Helen, who was again interested in going back to what you said earlier, and probably a similar thing to ED, she said, you know, we wanted to know as an anaesthetist, what can we do about this? And we were just shooting the breeze and talking. And actually one of the key things that came out was that in the same way that you said, you know, we might be the only person, the only professional that has touched base with a particular family. You know, we kind of realized that an anaesthetist taking someone for

an appendectomy or whatever they're taking for might literally be the only person that looks in that child's mouth for their entire life, you know?

So it's about just taking all those opportunities. It would be really interesting to see what comes out of that of that work in ED in Sheffield as well. I think there's a lot to learn from there. And Alice, with the parent champion model that she said, you know, these are women that have got both credibility and reach that that we don't have. These are people that we got a grant to work in children's centres in Liverpool talking to other mums, new and expectant mums about smoking, housing, breastfeeding and poverty, bronchiolitis, people's rights - you know, all these kinds of things that impact on child health and childhood respiratory health. They've been really useful because they've fed back to Alice some of the terminology that we kind of take for granted as being acceptable. So you had some good examples.

Alice
Oh yes, so recently the parent champions themselves can also directly refer families to the perinatal Citizens Advice scheme.

Helen
Oh, brilliant.

Alice
But what the feedback that we got was that they, families don't like the word ‘refer’ because as soon as they say I can refer you to someone, they were saying that a lot of families like no, I don't need any referral and it's the fear of I'm going to be criticised for this situation that I'm in.

Helen
That's very interesting. We got similar feedback about the word ‘vulnerable’ actually from some of our parent groups. They don't like being referred to as vulnerable, and that's the young people as well, particularly. They feel that is a stigma. And actually, as someone pointed out, we are all at some point in our lives could be considered vulnerable. There's always a period in our lives where our mental health might not be great or we've got an illness or we've lost a job or there's always, everyone has the potential to be vulnerable at some point in time. And they don't like that phrase, so it's really is really important to get that information from families, isn't it?

Ian
Vulnerable is a great example. It's something that we think and I get by great example. What I mean is a great example of why all these things, however little, however big, have to be codeveloped with families and with communities. Because actually the families with the least, in some ways, and you know the the least one over, because they are so strong, they're so resilient, so resourceful, so intelligent, so good at getting through with, you know, billion walls in front of them that we surrounded by barriers and. And so, yeah, I think vulnerable is a is a great example of a word that we use as a throwaway word, which is incredibly.

Alice
It's so weighted, isn't it? That word?

Helen
If you ever had a negative reaction to bring you up any of these conversations?

Alice
Personally I've not had a negative reaction. I think quite a few of us have experienced and including the parent champions have experienced and what Ian was saying - is that actually, because there is so much stigma related to deprivation and poverty that you may not get, you know, the way that you approach it, you may not get the response. You may not get the person to say actually I'm really struggling and I do need this help. And that is more challenging in terms of building up a rapport. And I guess we're more privileged because we're seeing children again and again in clinic to get that insight.

Helen
What about you, Ian, have you ever had a negative reaction?

Ian
In context of what Alice has just said, which is very important, that we... By the time people get to tertiary services that they often treat us a little differently, they've, you know, speak to us about different. And I totally get that and it's wrong and I do feel sad about it, but it does make my life a bit easier.

So it all comes back to the stuff we were taught in first year medical school. How do you speak to people? What are their ideas, concerns, expectations? How do you communicate? What do you look like when you communicate? How do you sound? It never comes down to this was seen as a very sensitive topic.

Alice
I guess that goes back to what we were saying about the paternalistic aspect of medicine as well. And yet a lot of the families that we've worked with have said if I'm in the hospital with my child and I'm worried I don't want a telling off and I don't want a telling off behind a curtain where I know the whole of the rest of the ward can hear me.

Helen
Ah, yes, of course, yeah.

Alice
Which just even increases the stigma or even more so I think choosing both the approach and the setting and making sure it's not paternalistic.

Helen
Lovely. Well, thank you so much for taking the time to have this tab today, guys really appreciate it. It's been so interesting and hopefully give everyone something to think about.

If anyone out there is interested in learning more, Ian and Alice have both worked really hard on our toolkit, which is on available on the website. There's some stuff in there about having difficult conversations as well as some other information which will be covering in future podcasts. It's at www.rcpch.ac.uk/shiftthedial or at www.rcpch.ac.uk/health-inequalities. So thank you so much. And no, it's been it's been a real pleasure.

Ian
Thank you very much.

Alice
Thanks for taking time with us.