## Transcript: Public Health Research and Me

##  “Interventions to promote social and emotional resilience in children and young people affected by parental substance use”

## Host and Fuse Public Partner Victoria Bartle speaks with Fuse Researcher Cassey Muir

**Victoria Bartle:** Hello and welcome to our podcast ‘Public Health Research and Me’. This podcast is led by public partners from Fuse, the Centre for Translational Research in Public Health, and brings together the five northeast universities of Durham, Newcastle, and Northumbria, Sunderland and Teesside in a unique collaboration to deliver world-class research to improve health and well-being and tackle inequalities. Fuse is also a founding member of NIHR School for Public Health Research.

So my name's Victoria Bartle and I'm a public partner collaborating with Fuse on creating this podcast. And I've been involved with research from a patient and public perspective since I had to stop working in twenty sixteen due to multiple, long-term health conditions. I really love being able to influence health and social care research and I know that the input from every public partner makes research more focused on benefiting us all.

So today I'm going to be talking with Cassey Muir, who's an NIHR School for Public Health Research doctoral student. God, that's a good title. I'm very jealous, that’ lush! As well as a Fuse Associate Member who's based at Newcastle University. So, hi Cassey, thanks for joining us.

**Cassey Muir:** Hello!

**Victoria Bartle:** If you just want to start with telling me a little bit about the projects that you're working on at the moment.

**Cassey Muir:** Yeah, of course. So, hi everyone, I'm currently a final year, PhD student, where I focused on young people who experience parental alcohol and/or drug use. And my PhD aimed to answer the question: “How can we support young people whose parents use substances?”

So to answer this? Firstly, I conducted a qualitative systematic review of young people's experiences of parental substance use which is looking thoroughly at all the published work and findings where other researchers have chatted to young people on their views and perspectives. And from this identified thirty-five unique studies, covering the views of over seven hundred young people from across twenty different countries, the youngest being four years old and the oldest was thirty. So, yeah, it's like very big, wide range, and the findings from this bit of work then led into my own qualitative field work, where I interviewed twenty one young people, aged between fourteen and twenty-four from across England, and forty-four practitioners who provide support to young people who have experienced parental substance use.

This work was really trying to explore young people's experiences of support, their support needs, and ideas for future intervention.

**Victoria Bartle:** Oh wow, that sounds absolutely amazing.

**Cassey Muir:** So much work over the past...!

**Victoria Bartle:** That's brilliant, though. I've been reading your research in preparation for this interview, and I've just been blown away with how engaged you are with the topic. And I was just wondering, like, what drew you to children and adolescents and young people's mental health and parental substance abuse?

**Cassey Muir:** Yeah. So I think I've always just really had an interest in young people's mental health, and when I was younger I used to always read like Jacqueline Wilson books which very much kind of depicts the lives of different families and childhood experiences. I also really like reading sort of self-help books, and one of them being, I think, was called ‘Chicken Soup for the Teenage Soul’, which had like little stories from across the world of different kind of things that young people felt, and how they had experienced things. I then went on to do psychology at degree level. Obviously, you know, piquing my interest more with mental health. And during that time I was a peer mentor with ‘Children North East’, which is a local charity who support families and children, and I worked one-to-one with young people who’d experienced some form of adversity to become more confident, independent, and really just supporting their social, well-being.

**Victoria Bartle:** Oh, that sounds amazing!

**Cassey Muir:** I think those experiences really shaped kind of me to want to focus on children and families, and also when I was a teenager, I also experienced substance use within the family, and know kind of how it feels to feel alone in that situation, and like you can't ask for help, and that there isn't much support out there, or you just don't know about support. So that made me really kind of want to work in this area.

And then fast forward, an opportunity arose to do this PhD work with a team who I like really admire and got on well with, and it just felt quite serendipitous to just go for it and apply. And here we are now.

**Victoria Bartle:** Oh, congratulations! That sounds so amazing. Like, just the work that you've done with children and young people, and it sounds like you just get so much out of that. And as a person who's experienced parental substance, misuse myself as well, it's, it is quite isolating, and you don't know what's out there, and you don't know what's available and like, I was a lot older when it impacted me so it's... I just think your works absolutely phenomenal.

So obviously I'm engaged with research from the public perspective. So, could you tell me a little bit about how you got the public involved with your research projects and kind of what impact that had on it?

**Cassey Muir:** Yeah, definitely. So I mean, first of all, I just really loved collaborating with young people on this project who've got lived experience, and it's really kind of grounded my thoughts and driven my analysis and ways of thinking throughout. And I've also had the opportunity to work with Adfam with their chief executive Viv Evans, who's been an advisor and supervisor on this project.

**Victoria Bartle:** Can I just butt in there? What's Adfam?

**Cassey Muir:** I was just about to tell you! (laughter)

**Victoria Bartle:** Yeah, All right. Sorry! (laughter)

**Cassey Muir:** Oh no, it's fine. So Adfam is the only national charity tackling the effects of alcohol drug use or gambling on family members and friends. So it's been really great to have them involved and their input and their knowledge really in this area, in this field and their connections to services.

**Victoria Bartle:** That’s brilliant.

**Cassey Muir:** At the start of the project. I was really lucky to collaborate with a great North East-based charity. So they are called PROPS Family Recovery Service, and they work with families and children who have experienced family substance, or friend substance use, and they had a group of young people, and they sort of used that group as a way of kind of helping advise on my project. So those young people had lived experiences. They already knew each other. They knew the support workers, and they really helped kind of structure the start and kind of come up with the kind of decisions at the start of my PhD.

**Victoria Bartle:** Wow.

**Cassey Muir:** It helps to identify how we could approach young people so kind of going into services, developing some of the materials, the kind of changing the colours, and whatever else other information needed to be on the recruitment materials. They also helped come up with the project name, which is SPRING, which is kind of both an acronym, and also has a connotation to resilience that kind of bouncing back and new, you know, newness to it.

**Victoria Bartle:** Yeah, it's nice and positive. It's lovely, yeah.

**Cassey Muir:** Yeah good positive word to kind of talk about what we're, what the research was. So, initially, I'd kind of start off, and it was looking at obviously support, and it was going to be looking at resilience, and I took some initial findings to them from the other research. So the systematic review that I was doing and it was really trying to think about what was missing in the research to date. So we looked at kind of other authors’ themes, and trying to see what, yeah, if there was any gaps or what I should focus on.

And what young people had said was that they didn't seem to be much around how like young people can feel different to their peers, and how they felt isolated and like they had to keep everything hidden from others. And with a separate conversation with the public partner from Adfam, she also mentioned that stigma seemed to be missing from the current literature in this field. And obviously that is exactly what the young people were describing, the sort of experience of stigma. So that really guided the project at the start, and helped to explore both resilience and stigma, and how that linked with support.

**Victoria Bartle:** Sorry every response I give is just “Wow! Wow!” I'm just really enthused about your research. It's really exciting and innovative, and I know some researchers don't like the systematic review sections of the research project. But just from what you've been saying, it was really important to do that, and then speak to people with lived experience to see where the gaps were, and then they've helped you identify them. And now you're doing research that's actually relevant to the people who are living it and going through this every day. So yeah, that's kind of what we hope for PPI (Public and Patient Involvement).

**Cassey Muir:** Yeah, Exactly. Especially that it, the young people with lived experience, and you know the practice side with Adfam, both having very similar views that something was missing. So it definitely felt like the way forward, but obviously as with everything with Covid and the pandemic, that advisory group, unfortunately, had to kind of end due to obviously restrictions and everything going on but I started up my own group. After kind of doing some of the interviews with young people, I ended up getting a group of young people from across England, and we met online to discuss other findings – so the interview findings and so on. And to start prioritizing some of the intervention ideas. They also helped spread the word of the study, and got their friends involved in the interviews, which was really great to see that the project meant a lot to the young people taking part and that they were, you know, wanting other people to take part in it as well. So I think that was, you know, really, really useful.

**Victoria Bartle:** Yeah, I know, that's amazing. You can see that they obviously were engaged with it, and impacted by it, and especially if they wanted to carry on doing it through Covid and lockdown, and everything. Like, there was so much stress and just... It was just an awful period for everybody. And then for these kids to want to be involved is just phenomenal to show like the impact of what you're doing, that it does actually touch people's lives like, really importantly.

**Cassey Muir:** Yeah, the Young Person Advisory Group also kind of changed my perspective on resilience. So, I think that was mainly that they just didn't really like the term, and they said it was kind of overused and to them it usually meant, and in their kind of experience, that it was young people doing well at school, and that's kind of how they perceived what it is to be resilient. But to them they thought of resilience in terms of kind of surviving versus thriving, and professionals need to determine whether a behaviour was then a young person surviving or thriving.

And I guess, as a kind of example of that: so a young person may be seen as resilient at school when they're doing well, getting their homework done, getting good grades. Yet, the young people had said that that may also be a survival technique, which needs to be looked at. So, is the young person trying to seem like they're doing well, so they don't get singled out? Or are they putting all their effort into school work because they don't want to focus on home life? So they're doing their homework, just so they they've got some time to focus on something else?

And then what may seem like resilience to the outside world may actually be the young person trying to survive which can then limit their opportunities for support, and, you know, continue it to be hidden. So you know, just thinking about it like that, and from their perspective, really helped me kind of think about resilience as well in terms of this, and how that also links to stigma, and you know, and trying to make it seem like there may, that there might not be any issues at home, or that there might not be any problems.

So yeah, it's definitely been absolutely fabulous having them involved. And they helped present the findings of the project to over one hundred practitioners online.

**Victoria Bartle:** Really?! Oh, fantastic.

**Cassey Muir:** We has a big sort of Fuse, Adfam and NIHR School for Public Health Research online event where it was well attended. And then, yeah, they shared their experiences. They helped me kind of develop some of the workshop activities, and one young person from that group has reflected that the group, just being a part of that group she's realised that she wasn't alone in her experiences. There were other people that had similar experiences, and she'd never had that opportunity, so that it kind of, it gave her that opportunity to need to meet new people.

**Victoria Bartle:** Yeah. Oh, that that's so fantastic! What you've just been talking about kind of makes me think about like masking behaviours of people with autism and different, like neurodiversity, and trying to behave in a certain way to fit in with society, because that's what's expected of you. And then you go home and kind of it all spills out, or if you're in a situation where you're dealing with substance misuse at home, then you don't have the opportunity for it to all fill out at all, and so stigma is going to be a huge factor in how we address this as society, and like how we approach it to help children and young people. So what kind of conclusions did you come to then? How are we meant to improve things?

**Cassey Muir:** Lots of different ways. And I think there’s definitely lots that needs to be done, and the majority of kind of interventions and support currently focus on the parents, and trying to reduce the risk to the child so trying to, you know, improve or reduce sort of drug use or alcohol use. And you know there is definite need for that. But we also need to think about, “well, how can we support the young people as well?” Because my research was finding that young people in times when their parents maybes weren't using, or they were in treatment, that can actually be really anxiety provoking for young people, and they start to worry about: “Is it going to happen again?” so that they still, you know they still need to have the support in place.

As well as that, there are very limited number of evidence-based interventions for young people currently, which are very kind of low effectiveness so they don't really have that great improvements for young people, and that's not to say that there's some really great support services across the UK - because there definitely are - and they're doing really great work with very little funding, and I guess that is one issue that you know, does need improving. There’s currently no requirement for local authorities to offer support to young people who experience parental substance use, and therefore service provision is patchy across England depending on which local authority you live in, it depends if there is support for a young person.

I think that's just not enough. That's not good enough.

**Victoria Bartle:** That's really surprising to me. I didn't realise that there was no like need, not ‘need’, but there was no service provision that you had to provide. Like that just seems…Yeah, it doesn't seem right to me.

**Cassey Muir:** There were obviously some areas with really great commissioners, who commissioned services and got like lots of access, whereas there's other areas that don't have that. And a lot of the services are generally quite silo-ed. So, they're kind of working on their own, not really linking up with other services in the country, and especially to kind of learn from that, and to find out, you know: “What works? What doesn't? How can we engage commissioners?” and things like that. So I think more needs to be done with, kind of, you know, the networking and sharing of resources across services too.

I think one of the kind of key areas as well with my research, and that I've tried to focus on, is that young people are not kind of passive in their experiences; that trying to recognise that young people are showing agency and tenacity, to find ways to support themselves, to protect their siblings, to try to control the uncontrollable. And this is really usually without any formal support in place. They're doing this for themselves. And it's to kind of not take away from that. And to really make sure that support that they *can* access allows them to, you know, exercise their agency and choice.

So, for instance, young people as kind of intervention ideas, or resources had said that it would be good to develop digital applications or websites that young people can access, especially teenagers and young adults. They can access them at any time of the day. They can choose what topics or sessions they want to go through. To hear about other people's stories that are similar to them. And that this could act as a gateway to in-person support, so to help reduce the stigma of speaking out and accessing support, kind of, you know dip their to in as such. Or it could be used alongside, you know, in-person practitioner support as just a way to help engage. There are obviously issues with digital poverty, and you know, things like that, but I think it's more of a suite of interventions and more needs to be done in terms of supporting young people.

**Victoria Bartle:** I guess if there's no like necessary provision from local councils that a lot of it will be delivered by charities and like third sector providers? So kind of ideal world scenario: what do you see the role of say, like you were talking about digital poverty and, other forms of exclusion, and I'm assuming that, like the criminal justice system would come in at some point, and education is going to be massively important for like teachers to help identify children who are at risk? But also just society in general to make sure that we're able to identify these issues and put something into place to support these children and young people. And, so, I'll give you a magic wand. Here you go! What would you like to see in terms of like structures and systemic systems to help tackle these issues?

**Cassey Muir:** Yeah, I mean, I mean, we definitely have to create sort of resilient systems around young people. And you know a lot of my work focuses on “what can we do for young people?”, but within that, you know, they've also talked about things with regards to you know, system change, poverty, and you know, having fairer access to resources, and I think in general, with regards to sort of what the young people had said, as something that would be useful to them, is training for other professionals or adults, who may encounter young people or children.

So within the health and social care sector, within the justice system, within the educational system around, you know, parental substance use, the impacts to young people, how young people cope, what that may look like that sort of you know the “thriving versus surviving” examples with regards to the educational system, and to really try and take a trauma-informed approach from supporting young people. You know to think about non-stigmatising language, respectful relationships you know, trying to create safe spaces for young people to open up and allow them to kind of help make decisions about their own support. So I think that was really one way; that it was a prioritized intervention from both practitioners and young people that doesn't, isn't directly for young people, but is something that they want that would actually be really helpful. And to kind of, you know, try start and have that systemic change for the best.

And I guess, within sort of educational establishments, a lot of the, I guess, the highest priority for young people and practitioners was to develop more educational resources for children and young people. So this was very much to kind of co-produce them with young people. They wanted it as early as primary school, like early prevention - have these conversations early. Try to reduce that stigma from a young age, you know. If it's talked about in primary school, talked about through secondary school, it becomes more of a norm, and you know a dialogue within the schools, for both those experiencing it and those who aren't. And I'm currently working with a national charity to develop resources to be used within schools, and that's really a focus on the emotional impact of living with parental substance use, and how that may show up or not show up in school. So, that's going to be an add-on to kind of normal kind of curriculum, and you know, teachers can use it and play the video. And I think it'll be useful in terms of other areas. It doesn't just have to be parental substance use because we're focusing on the emotional impact and emotional and social wellbeing.

So I think that’s a really good way of getting into schools and trying to change that system.

**Victoria Bartle:** Yeah, that sounds absolutely phenomenal, like the impact that that could have to just reduce the stigma and to normalise it, like you said to normalise different situations. So yeah, not just parental substance misuse, but anything that's kind of seen as “out of the norm” that then becomes stigmatised because you don't talk about it. So if we open the, open the lines of communication, then it could just have a huge impact on people's wellbeing and just general mental health.

**Cassey Muir:** A young person had said that, you know, if someone just had those conversations earlier on at primary school, secondary school, that they wouldn't have felt…they would have felt less alone. They may not have accessed support. They may not have, you know, gone down formal support route, but then they would have felt less kind of that internal stigma or internal shame, and they would have felt like actually somebody cared. You know, somebody was talking about it. Somebody wanted to help, and I think that's really important for these kind of conversations that, you know, it might not increase referrals to services, but actually it might decrease the sort of internal stigma and shame that the young people might face.

**Victoria Bartle:** Yeah, it just… like you say normalising it means that you can talk to your friends about it, and you won't experience that stigma. But yeah, knowing that it is a “thing”, that it exists in the world, that it's not just you and your family, or your environment, or whatever - that it's, it's bigger than that. That there's other people who are experiencing it.

I mean you talk about all the different intersecting factors contributing to stigma, and discrimination, and from a disabled person's point of view, I find that so interesting because you can just see how socioeconomics and gender and age, and loads of other things intersect to form inequalities. So, what do you see as the biggest impact with regards to your research on, like, social inequality?

**Cassey Muir:** Yeah, I mean definitely. There are like many intersecting factors for young people who experience parental substance use, and it very much links to another project that I'm working on, which is called ORACLE which is overcoming adverse childhood experiences, and that's sort of focuses on parental substance use parental mental health, domestic violence and abuse and poverty, and how those kind of overlap. And there are lots of kind of overlapping and compounding issues which can all lead to stigma and discrimination.

And colleagues on that project found that poverty can amplify children's experiences of these adversities, which can lead to kind of worsening of outcomes, especially with poor mental health, and that you know more needs to be done with regards to policies around poverty and improving financial situations, and especially with the kind of you know, the energy crisis and the cost of living crisis at the moment is, these things are really going to impact the most vulnerable first, so definitely more needs to be done.

But you know, young people had described times when they were not only kind of stigmatised or bullied for um, having sort of parents who use substances and a stigma that's around substance use, but also because of the financial situation of their families. You know if they can't... if they're not wearing the best clothing, or they're not having the right equipment for school. Definitely more needs to be done and Children North East, as an example, they're doing something they've called “poverty proofing” and an example of this within the sort of school system is by kind of going in and making sort of the school aware of how they might be unintentionally promoting stigma or limiting young people's access or opportunity to participation.

So kind of including how they deliver free school meals, how they plan non-school uniform days, especially if it's kind of with a donation, kind of making that bit more like in a bucket instead of kind of going around every person in the class, or having a non-matching sock day. So, instead of kind of you know, if non-school uniform, and trying to think about how that kind of can impact on PE kits as well, and activities outside of school, and really trying to, you know, promote an environment where there isn't stigma because of the poverty, and you know that can support lots more families than just sort of looking at it from the parental substance use. There's obviously a lot of other families who would benefit from that and children who’d benefit. So, I definitely think that's kind of, from the research that I know, so far is the kind of biggest impact.

**Victoria Bartle:** Right. But I've just realised that I've been stigmatising it all the way through in my language, and you should have challenged me because I've been saying substance “misuse” all the way through, and it's substance “use” isn't it? Sorry. So I apologise, and I'm learning. So its “substance use”.

**Cassey Muir:** Yeah, there's always, I mean yeah, it happens. But it's being, it's being aware isn't it? Acknowledging. And yeah, I think that's that's another way of moving forward as well.

**Victoria Bartle:** So I apologise for that, and thank you for teaching me something today. So, looking to the future, kind of, where do you see the areas for further research in this kind of area of study? And have the children and young people that you've been involved with pointed out stuff that you want to look at in the future?

**Cassey Muir:** Yeah. So I think, I mean, one of the main ones that I haven't really explored is that I think more needs to be done regarding younger children, especially as sort of primary school age was, you know, prioritised as a, one of those main areas that we should be intervening at. So, I think more needs to be done with including younger children, getting their opinions on how we can do this, kind of, you know, go into primary schools and teachers and staff, and think about how we could, you know, utilise some of these methods and education resources within primary schools.

And I think you know, thinking about the emotional impact could be one way of doing that, because there could be lots of different children experiencing different types of emotions for different reasons. I also think that further research is needed exploring that system wide change. So you know, thinking about tackling policies and the cost of living, how that can impact outcomes for children and young people.

And then also just needing to further develop and co-produce resources for young people within the educational system or the digital apps or websites, and think about, you know, how best is that accessible for the young person? And then sort of pilot it and feasibility test it across sites. So I think they’re the kind of main things, but definitely kind of thinking about how could we target and get into primary schools and start that conversation with younger children?

**Victoria Bartle:** It sounds like you're going to be busy for the rest of your career with all of this, fixing all of these problems for us. So, if you had one message for our listeners to take away, what would it be?

**Cassey Muir:** I think, put simply, it would be to be kind. You don't always know what somebody is going through or has been through, and there's just there is so much sort of hidden trauma and hidden things that people don't talk about, and that we should always be kind and compassionate to people, and not using kind of stigmatising or derogatory language or views. And I guess if we could help just one person to not feel alone today by just engaging in this conversation, then I think that's worth celebrating, because, you know, you're not alone. There are people who have experienced very similar things, and there are people who want to help, and hopefully, we can, you know, develop even more services and interventions that can be useful for young people as well.

**Victoria Bartle:** Well, that's just such an amazing message to end on. That was lovely. Thank you so much for your time, Cassey, and good luck with all of your research in the future. I've thoroughly enjoyed learning about it, and from my perspective, just to see that people will be helped, and that they are being helped is just amazing, and really touches my heart. So well done, and thank you so much.

**Cassey Muir:** Oh, thank you for having me and letting me ramble you for the last twenty or so minutes.

**Victoria Bartle:** Not rambling at all. It's been amazing. It's been really, really interesting. Thank you.

**Cassey Muir:** Thank you Victoria.

**Victoria Bartle:** So, if you're a fan of our ‘Public Health Research and Me’ podcast, please subscribe on your preferred streaming platform. Let us know how we're doing with the rating or review and share with your friends, family, colleagues and networks. Thank you, and we'll see you next time.