

DD: Can you describe yourself in three words, please?

JL: Parent, a paediatrician and an optimist - when you're called Joy, you're doomed to be an optimist.

DD: Hi everyone, welcome to the Global Health Lives podcast, I'm Delan Devakumar and today I'm with Professor Joy Lawn, a researcher and academic in newborn health. Joy is a professor of maternal, reproductive and child health at the London School of Hygiene and Tropical Medicine and Director of the MARCH Centre there. Joy, it's great to have you on the podcast today.

JL: Pleasure, Delan.

DD: I first came across your work when you released the neonatal mortality series in The Lancet and I was working in New Zealand at the time, actually, doing neonatal intensive care and I remember reading your series and just being amazed by it. I read every word, there was the epidemiology in the public health, and the economics, and things I'd never heard of. And people ask you about the papers that have changed your career, and for me it was this one. I distinctly remember we had a regional paediatric meeting in Wellington and I was doing the journal club, and I presented this and I was actually following a consultant who was talking about head lice and I came on to talk about these global, neonatal mortality statistics. And soon after I had a meeting with my supervisor, the head of NICU at the time and he just said to me, "Go and do this, don't bother with intensive care," which I must admit may have been down to my intensive care abilities as much as anything else, so, for me, it was a real privilege to meet you several years later.

JL: Just a small person.

DD: I wonder if you could start by telling the listener how you were literally born into the field of newborn health.

JL: Actually, the first time I told this story and really used it was after that neonatal series. I went to a meeting in Uganda, which is the land of my birth, and I was presenting to their first ever newborn, stakeholder meeting and they had tens of thousands of newborn deaths a year, but it hadn't been visible, it wasn't on people's to-do list, and I had done the talk on the neonatal

series in a few places, normally you show slides and talk about the data. But I actually started with the story, so I talked about a woman in the bush, in northern Uganda, in obstructed labour, in a hospital, no running water, no electricity, she's there during the night. In fact, the woman in the bed next to her died during the night. And in the morning, they were able to find a surgeon who had seen a caesarean section but not done one, the woman was anaesthetised with chloroform, the surgeon washed his hands with water from a jug and she went out and the baby came out that was alive - and that was me, in the bush in northern Uganda. And my mum and me both survived. And the reason we survived was because there were other people - my dad, friends, who said my mum shouldn't die, I shouldn't die. And telling that story in Uganda, and seeing the response, I learned so much because data counts, yes, but stories that connect your head and your heart when you have somebody in front of you, are things what people change practices on

DD: Yes, it's so important, isn't it? Those narratives can convince people, that can push people into different directions. So, you were born in rural, north Uganda and you lived there till you were an adolescent, your mother was a teacher, your father a bishop in the church and then you went to boarding school in Kenya with your two younger sisters.

JL: Yes, it shaped my life, my parents were remarkable. So, you know, this area in northern Uganda, which in those days and possibly still now, was kind of like punishment zone for civil servants if you were really not in favour, that was where you got posted. And my parents had gone out separately, they were married there. I was born there, both my sisters, although my dad was so nervous he packed my mum off to some maternity waiting home in Kampala, a very long time before my mum gave birth the next two times. Yes, but, you know, my parents had a very deep ethos of service without making a fuss and standing behind other people and before people were thinking about that kind of approach. Yes, really kind of equitable service and enabling people, that was very deeply in how they lived all the time. And, yes, we had lots of fun things, despite, you know, not having lots of, we had a few books that we shared, but also a lot of things that really gave you a different, maybe deeper priority in life. You know, very early memories of being in a famine zone and knowing that, that people were literally dying because they didn't have food, very much shapes what you choose to do with your life. So, I was about six when I thought going into medicine would be a jolly good thing to do.

DD: Oh, really, so young.

JL: And I stuck it out and did it.

DD: And it was also a very difficult time, politically, in Uganda under Idi Amin, and your family literally had to escape the country.

JL: Yes, so during the years of Amin you couldn't even get salt or sugar in the shops, there was nothing available but also people didn't talk about what was going on, you wouldn't talk to your neighbours because something may happen. And my dad and some other church leaders were part of writing a letter that became public, pointing out that there were a lot of people being killed. And that was, within three days of that, one of the other church leaders was shot and my dad was the only non-Ugandan list of signatories. Somebody was sent to kill him, actually, the local army commander who then refused and had to run away himself. And a police officer arrested my dad, basically for his own safety, smuggled him up to the capital and managed to get a deportation order signed for being a spy, which was quite, could have been quite amusing. Yes, he got out alive, my mum didn't know that he was going to survive, when he left in the police car, and my mum had a week to pack up the best part of 20 years, their home, all the time that they had been together.

DD: And from there you left to another politically unstable place, Northern Ireland, and the rest of your adolescence was in Northern Ireland, and then you went to Nottingham, and to Nottingham University, did your medical studies and clinical paediatric training there. But you always had this yearning to go back to Africa, is that right?

JL: I really wanted to go to medical school and I picked the only medical school that I could find that allowed an intercalated degree in Africa, it was like my sole criteria. So, yes, I went to Nottingham, did an intercalated degree in epidemiology, was meant to be looking at HIV in rural Kenya but actually ended up examining a cohort of pregnant women about where they wanted to deliver and why, and why not, and where they delivered and why and why not. And traditional birth attendance, I learned so much from that, totally failed to publish it but I got the bug.

DD: So, can you tell me how you then went back to a different part of Africa?

JL: Yes, so I came to the end of medical school, really excited about doing paediatrics. So I did my house jobs, did paed, got my membership, I met a doctor who qualified from the year

above me who had done a trans-Saharan track, yes, we thought that going to work in Africa for a couple of years would be a good idea. I had a mentor at the time, Professor Sir David Hull who set up The Royal College of Paediatrics and I discussed the idea with him and he said, "Don't be crazy, if you have to go, go for a couple of months, get it out of system, don't go for a year, definitely don't go for two. You're throwing yourself away, I'll give you any job you want, just don't do it." So, we went. [laughs] We went for two and stayed for four and it was the making of both of us, that was why how I ended up in global newborn health and how my husband, Steve, ended up in TB and HIV.

DD: And you were working as a clinician, essentially, in Ghana, is that right?

JL: Yes, just a wonderful set-up. The Ghanaians are the warmest, most fun people. We learned Asante Twi, we were on a local university's contract, so it was a twentieth of what we earned in the UK. So, it was also just, you know, four years, we kind of had chicken for Christmas and beans and yams the rest of the time. Yes, but you really understand, in a different way, why doctors go on strike, they're earning less than bank clerks, they've got everybody in their family coming to them, it's tough. Yes, it was a deep learning in lots of directions both what we saw and learned clinically. Many deep friends and friendships.

DD: And then, after Ghana you had a couple of years in the US, at the Centres for Disease Control and Emory, with Steve who was working there as well. And then you moved to South Africa where you spent eight years of your life, and I guess at this point in your life you were getting more and more involved in newborn health and neonatal mortality, can you tell me about some of the work that you did during that time?

JL: So, yes, you know I was just really finding my feet in Ghana with ideas for research and developing protocols and helping to enable postgraduate teaching, when Steve applied for a Wellcome Trust fellowship to work in Ghana on TB and HIV, and Wellcome Trust decided that it would be much better for him to go and sit in a lab in the US for a couple of years. And I remember being in Ghana, it was the days before email and phones and Steve had been at this Wellcome Trust panel in the UK, and I got this fax in this business centre around the corner from the hospital and I got this fax and I literally cried. And the guy behind the table, he was like, "Oh, has someone died?" And I was like, "No, we've got to go to America." And he was like, this woman is definitely even more mad than I thought she was, because, of course, every Ghanaian wanted to go to America.

So, we went, and Steve worked and we went for two and stayed for four, which seemed to be our pattern. Steve worked in several different city labs and, for me, I was leaving Ghana where I could really see that every day you could make a difference for newborn care, but there weren't numbers. WHO hadn't released any numbers, there was no guidelines, no funder wanted to know anything. So, you know, I landed in the US thinking, *well, you know, I'm not going to do my US clinical exams, I'll get the opportunity to actually, make an opportunity out of this, I'm landing with a two-year-old and a six-week-old*, Steve went out to work on day three and how am I going to do something. So, I was able to do a Master's in public health, I was able to work at a WHO collaborating centre and it really helped me to make that pivot, which I think is a difficult pivot to make, as a clinician, into a public health approach, thinking of a bigger picture, the numbers. You know, how do we make a bigger difference? Yes, I really felt a sense of hope that if you got better numbers that people would suddenly see this big topic and things would happen for newborn deaths.

DD: I think for me, personally, that was the thing that really struck me, I didn't know much about this at the time, but I just had no idea. I didn't know the numbers of babies who were dying, making that visible, even for a young doctor as I was, was quite a big thing.

JL: You know, you think that a big number will get a big response, but that's not always the case. So, having a big number isn't good enough, you also have to show what you can do. So, as I was leaving the US and we moved, actually wanted to go to Africa but we ended up coming to the UK for a few years, Steve finished his training and I was starting to do more with WHO on numbers and estimates, and one of the big things was the child cause of death pie at that time. Even though, at that point, more than 40% was in the neonatal period, there wasn't a slice showing that, so it was completely lost. There was a slice called, "Other" that, actually, was the biggest in the pie. So, yes, your kind of graphics 101 of the slice of your pie chart says other and it's the biggest one, it's not very helpful, and there was another slice called, "Perinatal causes" that meant nothing to anybody.

So, you know, I kind of had this dive idea that if we then split that pie where you could see the percentage that was neonatal, but also within that you had things that people could do something about, so, neonatal infections, tetanus, birth complications, pre-term births, then you would get people to say, "Well, it's not just a big number, but you can do something." It's a nice idea but I'm not sure it worked. We got estimates, that was my PhD, linked to The Institute of Child Health and UCL for neonatal cause of death estimates, with WHO for 195

countries of the world. So, we got it, but, actually, that still doesn't make people do things. So, a big number, four million causes, still doesn't change things, you have to show people what they can do. And especially, at that stage, most births were at home and almost all the evidence was about what you could do in a neonatal intensive care unit, there's a big disconnect between the reality of where deaths were happening and the evidence base that people had.

DD: How did you change these opinions? You know, you've got the numbers, now, and you're developing your team, but how did you make that next step of changing opinions, changing policies?

JL: Yes, you know I think you can't do that alone, it's all about building a network and a narrative. And that narrative has to connect to things people are committed to. So, how did we get newborn health and newborn deaths onto the agenda, and we failed with still births, which is the same number and should matter just as much, it matters just as much to families. The reason, totally, is because there was the Millennium Development Goal target for child survival, on the front page of the Lancet neonatal series of 2005 was, "Newborn survival key to the millennium development goal". So, that was our first figure in the first paper, was about the percentage of under-five mortality that was neonatal and the much slower progress in neonatal. So, if neonatal stayed as it was, it would be the entire target, you can't meet this target which everybody, actually, knew and was committed to in those days.

And so, you know, because of it being a national government priority, so it's not about us convincing people, you have to find what people already care about, and then you have to build a narrative, not just from the numbers, because that doesn't count, it also has to be the human side, and then what you do. So, I think the shift was linking it to the Millennium Development Goals, that meant that governments cared, the global community had to care, it was still very disconnected within the UN. So, it's only really within the last five years, really, that UNICEF has taken such a fantastic leadership role for newborn health, and they're the main implementor, for supporting implementation across many countries.

So, the other thing is bringing in the parent voice and deliberately did that with high-income families from the US, so that was with the report called Born too Soon, which really focussed on pre-term birth. And pre-term birth is an in-your-face problem, particularly in the US where the rates are very high. So, that combination of having country governments and lower,

middle-income countries, powerful parents in rich countries, professionals and then the UN has really shifted the needle for newborn health. We managed to get a sustainable development goal target which specifies newborn health. In September this year we had an event where we have the Director General of the WHO and the Executive Director of UNICEF jointly announcing coverage targets and I had the privilege of doing the talk about what those coverage targets were. But that's, you know, what do we do in the next five years to get to where we need to for mortality targets in ten years. And we could never have dreamt of that, even two or three years ago.

DD: Can you tell me about how you convince people about the importance of the work you are doing when, maybe, it isn't something that crosses their agenda?

JL: I think it's very important for people not to feel hit over the head with something. So, I actually have also learned from watching people in how not to convince. So, you can be very passionate about something, and you can think that by being rational and passionate you will change people's opinion, but actually, that rarely works.

DD: No, it doesn't at all.

JL: So, a lot of it is understanding what their hook is, what to hang the narrative on, what matters. And it will be different for different audiences. So, you don't come with the same narrative to everybody. And to really change things, you need both the right facts that affect somebody's head, but you definitely need to connect, also, to their heart and how they feel about it. And then you need what can be done and the belief that it can be done. So, for example, going to a country in Africa and saying that their neighbour, Malawi, is going twice as fast on reducing newborn deaths as they are, and here's the things they're doing, is much more convincing than talking about something that is happening on the other side of the world, and being practical about that.

And then the voices of other people. So, one of the things that we looked at in the last Lancet, the Every Newborn series, and that was a shift. That's a funny shift too because in 2005 newborn was not a noun, it was a deliberate creation of newborn being a noun in the Lancet and so newborn was an adjective, it wasn't allowed to be used as a noun, and that's why the first series was called The Neonatal Survival Series, we weren't allowed to use, even though a lot of people think of it as The Newborn Survival Series, that was a later construct. It was a

deliberate construct, nobody says, “my neonate,” it’s, “my newborn.” So, the change in the narrative, including changing an adjective to a noun because it’s a human face of it. And similar with stillbirths, and the tractability so the first stillbirth series was called The Stillbirth Series, the next one was called Ending Preventable Stillbirths, that was the whole top line because the perception is that stillbirths are not preventable.

And then learning to lead with your message, so as technical people we usually start with the evidence and end with the message, show success is always important, and not superficial success. So, calling things easy to do, low-cost interventions, I don’t say that. But you can show people in countries that have done it, I think those are more committing to people.

And then the voice. So, often it shouldn’t be us, the professionals or the academics. Whether it’s a parent, a politician, a health care professional, so you know, what’s the voice that has credibility in that context. Yes, I mean my life has been spent particularly on standing up for women, and for their babies, so the women who this happens to, whose babies die, either as a stillbirth, or a newborn birth or a pre-term baby, or a sick baby, most of those women, whether that’s in high income or in low and middle-income countries, sometimes the women who don’t have voices. But also, this condition which particularly affects women, we need more women who are part of the solution, you know, in healthcare, now, there are more medics, nurses, the majority are women. But the scientists and the epidemiologists and the data people aren’t always. I feel very passionately that in a condition that particularly affects women it’s very important that women are part of leading the solution, leading the science, taking that forward. And particularly the women from the highest burden section should play a role. That’s a very deep privilege, for me, to be able to help raise up women leadership and particularly women leadership in their own middle-income countries. But that is something that funders, or whatever, think happens in a couple of years, it takes five, ten years. And so, walking that walk with people is just critical.

DD: Can you tell me a little about these large trials that you’re doing in health systems development?

JL: Yes, so on that kind of journey you start as a clinician, you look after the baby in front of you. Then you think public health and numbers, then you think breaking your numbers into cause of death and then what you realise is you need to give people solutions that work, and they need to work in the highest burden places, you have to be ambitious to do things, not just in

the easy places. So, the Gates Foundation, who really were the main funders for nearly everything for newborn health in the first ten years of it, you know, now USA and now other donors, but governments are really funding this. So, while I was based in South Africa, so from 2005 we had the privilege of working with eight different country governments and teams to run very large community-based trials for what could be done at home with community health workers, for maternal and newborn. You cannot do the two separately, they link together and they have to be looked after together.

And, you know, it is in particularly in hard-to-reach contexts and humanitarian contexts where most births are still at home, that is critical, and important but your impact is capped, you can't get above about, you know, a reduction of about a third of neonatal deaths. So, to do what we need to do, which is reduce neonatal deaths by about 90%, you have to do things in hospitals. And the other thing that has changed in the last ten years is this unimagined shift of births into hospitals. Now, more than 80% of the world's births are in hospitals.

And countries and families' aspirations is to do, you know, not to continue to do sub-optimal things at home but to do better things in hospitals, that's what middle-income countries want, that's what families want. So, to do that we have to work out how to safely and effectively provide more complex newborn care in lower-resourced settings and how to do that within the next five years means we can't just have people doing random things all over the place, we need to think of a package, think of all the different parts. You know devices alone are rubbish, we need people, we need devices, we need more space, we need water, we need electricity, we need the right data to do it safely.

So, yes, that's just such an excitement at the moment, to have the privilege of working with more African countries and 16 organisations, mostly in Africa and the NEST360 consortium. So, yes, it's kind of fun to come back from doing numbers and lots of kind of, it just feels very practical and very exciting and a bunch of people who are implementing and doing things, despite 2020 and Covid.

DD: Fantastic. So, alongside this kind of stellar academic career and all these achievements you've had, you've also had major personal traumas in the last few years, the very sad passing of your husband, Steve. I didn't know him well, at all, but I remember going to these Wellcome Trust conferences and I would just see him talking about HIV and TB and the thing that came across was just his passion, that's the thing I remember of his talks. And I know

it must be hard for you to talk about this, but can you tell us a little bit about how you found out his diagnosis and that kind of final journey you both took together?

JL: Yes, thanks. I think it's important we talk about these things, western society likes to pretend people don't die. Well, we're all born and we will all die, we bring nothing into the world and we'll take nothing out of it.

Yes, with Steve, I guess not everybody has that privilege, after we started going out, we'd only been going out for nine weeks when he proposed, we were just such kindred spirits. And we both made each other braver, maybe stupider, would have been difficult to go to Ghana if we hadn't both made each other braver. Yes. And we did six intercontinental moves, often with, you know, in the middle of delivering babies. Yes, what a journey.

And Steve was doing a TB, HIV research trial in South Africa and Malawi and he went for a trip and he had a headache for three or four days, landed back, I'd been off in Sweden getting some prize thing, landed back and found him, you know, hadn't even gone up the stairs, he'd been back for a day and he was lying on the sofa just looking terrible and I thought, *oh, no*. Yes, so, my best friend from medical school, who also worked on HIV stuff had just died of a brain tumour just a few months before, I guess I didn't think of that straight away.

He had a CT scan and had a tumour the size of a cricket ball, which the doctor kindly showed us the scan. She refused to do a scan and then she did the scan and she broke the news by bringing us out and showing us the scan and said, "Here's your scan." And Steve's first line was, "I told you I had a headache." So, yes, so glioblastoma, you know I think we both knew that it would be a matter of time, it would be how long, and he was just remarkable. I mean he still insisted on going to work, made it almost two years, he insisted on going to work until just a few months before, yes. And it was very tough on our kids, they both reacted very differently, but they've done so well, I'm so proud of both of them.

DD: I appreciate you talking about these kinds of difficult issues, as well as all of the stuff that's gone well.

JL: I had the privilege of having almost thirty years of a partnership that was extraordinary and I wouldn't be the person I am now if it hadn't been for Steve. I'm deeply grateful for that and,

of course, it's a massive gap that he isn't here. But, on the other hand, if I'd never had that, would have been worse.

DD: Joy, it's been a pleasure to speak to you today, in the field of global health and child health and maternal health, you're obviously one of the leaders, your contributions are so much more than just academic and you're improving lives, saving lives and also for the people working in this field, so thank you very much for joining me today.

JL: Really my privilege, thank you.

DD: Thank you to my guest, Joy Lawn, the episode was produced by Priscila Sato and myself, artwork by Bet Stinchcombe and our theme song is Paper Stars by Liam Aiden this is a Global Health Lives podcast, thank you for listening.