

Difference.

Humans don't like it much, we judge it, we mock it, we reprimand it but more usefully we accept it, we are curious about it, we value it. We are all different, they say, but how much difference can we individually tolerate?

And what if, when you have a child, they seem different? Perhaps they don't settle very easily, and they seem over sensitive to sounds and light? They need to be rocked all the time. In fact, during that first year, they don't sleep much, and you don't sleep much. They don't even want to play those baby games you dreamt of doing when you were pregnant, and your mum told you that you absolutely loved playing when you were small. Your child doesn't like being touched or held very much either. They don't seem very happy, and you don't feel very happy. Exhausted, you start to wonder what you are doing wrong. All your friends with their new babies are not finding it so hard, in fact they are having a ball. You remember the time you had a glass of prosecco when you were pregnant. Perhaps it was that that's affecting your baby. Then you remember the birth and the days of labor and the pain and the emergency C-section at the end. You couldn't even do that right. What good are you ever going to be at this mum thing. You feel like the worst mum in the world; in shameful silence you try to keep going.

Your mum says you need to have more of a routine for the baby. Your dad tells you; you need more boundaries; your partner tries to reassure you and your friends say your baby will settle in time. Your health visitor does a 15-month check. Their assessment shows your baby isn't developing as they should be. In fact, they are not developing in any areas. They initiate referrals for your child to Speech and Language therapy, Physiotherapy, Occupational Therapy and the Neuro development team. It feels like your child is broken so you tell them you have been feeling quite low and can't parent your baby. So, they then refer you to the parenting team and your GP. They also tell you about the variety of support groups you can access.

Six months later, after fifty or more visits to various professionals and support groups, nothing has changed except instead now your child is throwing themselves on the floor, lashing out at anyone who comes near and only wants to play with water and watch Peppa Pig. They still can't walk, they haven't said a word, they won't sit at the table and eat. The GP has put you on antidepressants. The support groups just showed you how different your child is and worried you about how they may end up. Alone, scared, isolated and

tired beyond tired you keep trying to do your best to help your child. You try to implement some of the hundreds of ideas you've been given but it's pointless, overwhelming and disappointing. You worry again about your child and their development and what will become of them. What if they always throw themselves on the floor and lash out? What if they never sleep? What if they never walk or talk? What if you can never toilet train them? What if no one ever understands them? What happens when society disowns them and you?

All these questions and worries and anxieties are held not just by mums but by dads as well and by many, many families of children with developing learning disability daily all over the world. It is not unusual for them to be referred to a plethora of places that have been designed to help; and for them to have several appointments a week to attend to get their child fixed. Yet each mum, dad and family feel alone. The blame, the shame, the sadness, the being told what to do just increases and entrenches the difficulties. If this continues, this is one of the many children we will see ending up in a care home where parents can't visit because they are living in a different county and even worse in forensic services.

It doesn't have to be this way!

What if instead you had people to talk to, people who understood what you were experiencing? Who validated your experiences and made things feel less different? What if you could speak to others who had found it even harder than you but had found a way to cope, manage and understand their child? And what if, when your child was found to have globally delayed development, the first concerns from the professional system were to support you, to understand your child better and to nurture your relationship with your child?

This is what holistic, community driven, preventative care really looks like. A new approach that takes the pressure off professionals' waiting lists, nurtures attachments, reduces stress, anxiety and shame for parents. It also reduces system overload and wasted resources are prevented. Currently those unhelpful patterns organised by Professionals, Managers, Service leaders all think they are helping. But these children have a multifaceted condition; they are not broken. They need more chapters in that parenting manual than other more typically developing children because they have a unique way of learning and processing and understanding the world around them. They each need integrated seamless support that considers the whole child and does not divide a child into small parts to be fixed.

In Cardiff and the Vale NHS, I lead a small team who are creating a shift in the landscape of support for these children and families. We are called Llygad (Early Years Experience Team). We meet families at the start of their journey. We have a team ethos which puts kindness, connection, active listening, difference to be celebrated, curiosity and humanity at the heart of what we do. We seek to understand the child within their context, embed parental expertise into what we do, and we work holistically. We have also obtained some short-term funding to embed E-PATs (Early Positive Approaches to Support) within the early years systems so that families having these experiences have a place to go, to be seen, heard and validated. E-PATs is a co-produced supportive group experience, co-facilitated by a professional and parent carer to help families make sense of the ways in which their child is learning and developing. It offers ideas of things they can do differently that really make a difference. Central to it is the fact that no one judges them or tells them what to do because both the parent carer and professional understand that each child is unique and living in a unique family context. It is only through many connectives, listening to curious conversations that the uniqueness can be understood, and ways forward can be found. The parents find their village in E-PATs and difference becomes more normal. To date we have run about 12 of these groups and are developing and creating an army of E-PATs pioneers, who are more empowered, more connected, less isolated and not self-blaming or despairing. They have found a different path and are forging a way forward together. And it isn't just parent carers who gain from this work, Professionals do too. They begin to see different perspectives, they see the child within context, and they learn from the lived experiences. They understand the uniqueness of these children and their learning styles.

But this is just the start. There is a battle now for more funding to embed and grow the work we do, so we can reach all the families that need us. We need a pathway of care created for this population, with a recognition of the expertise needed to ensure the families and children's stories are listened to, their needs met, and they feel supported. There is an urgent need for other services to stop responding in the ways they currently do because they are doing more harm than good. Siloed working isn't useful; we need to make connections, listening and not knowing, a part of the professional remit; alongside the intervention targets and episodes of care. We want holistic, community driven, preventative care to be embedded across the whole of Wales and beyond. There is an urgency to stop the numbers of children ending up in residential care or forensic care each year. This new approach cannot wait.

My voice; Llygad's voice and the voices of the parent carers need to be urgently heard. This is what keeps me awake at night and what I have been trying to change for over 7 years. Within my organization my voice hasn't been heard, just like the voice of these families and children. We are invisible to the system. Much like these families I wanted to give up and felt helpless and despairing. I have written a business case to the Regional Partnership Board which just came back covered with red pen; much like a failed essay, saying we are already doing enough for these families. There was no interest or curiosity as to my perspective or why I was seeing it differently to them. I was also involved in a LIPS Project (Leading Improvement in Patient Safety) but the model of connective, supportive multi-disciplinary working we created, using parent voices, was dismissed as being too difficult due to different waiting times for the different services and it being difficult to log on the electronic system!

But this has not stopped us. Working on the ground, seeing the same issues and problems unfolding day after day, seeing what does make a difference has given us courage to keep going and made us resolute in creating system wide change. We have so much passion, desire, hope, belief and excitement that things really can be so different. We are currently wasting so many resources but there are some very simple changes that can make a huge difference.

Difference means things need to be done differently right from the start. We need to understand the child's interests, motivations and support them to make choices and be able to have influence in the world around them. This is child centered care. We need integrated care plans, developed together, unique to each child and family. We need to listen to support parent carers and create pathways of care led by those with lived experience. We need to value what those who have been through it know and believe that they can show us a way.

This army will keep marching! And as a Leader I will help bring about this essential change. We need to make a difference to a population that is different.

My final ask today is that next time YOU meet a difference, please Do something that makes a difference!