Marjorie (00:05):

We all know that parenting is hard, so how do parents with disabilities do it? With creativity and because we know of the value of interdependence! Come hear about ways experts say we can best empower these families and let's all learn about how parenting can be done differently.

I'm your host Marjorie Aunos.

And today my guest is ... Beth Tarleton. Beth has done incredible work to support parents with an intellectual disability through empowering social workers and professionals who work with them. She values a collaborative approach and is convinced teamwork is how we can best support families.

We started our conversation with Beth talking about *a publication called* the Good Practice Guidance *that* she developed with some of her colleagues.

Enjoy! And don't forget, for more information about where to find the full recording and additional resources, check out the show notes!

Beth (01:15):

So this came out in August, 2006. it basically was a survey of all the different services around the country that were working with parents. And then we did follow up interviews to seek out the good practice and also went to visit some case study areas when we talked to the parents. So it was basically looking for what the issues are and got those written down clearly. But also the positive practice for me it's always about finding the positive practice and moving things forward. <affirmative>, we've got loads written about what's going wrong. We need a lot more about what's going right. So that was published as a report by the Berryman Foundation. It's still on our network webpage. It's quite old obviously now. But I think all the things in it are still completely relevant. Lots of issues and the positive practice remains the same because it's all about Understanding parents and their support needs and providing the right support to help them be the best parents they can.

Marjorie (02:22):

<affirmative>. Can you tell us a little bit more specifically what it said in terms of what was the situation in those services and what you saw that was positive?

Beth (<u>02:40)</u>:

I suppose in the services that were doing brilliant things, there was normally a worker who'd seen the situation for parents go wrong and normally had seen children removed when they thought they shouldn't have been if they'd been given better support. And that kind of motivated those workers to set up new services or parents' groups. And we found that all the time in the intervening years in the network that people are motivated by seeing something go wrong. And basically, in those areas they were just working in a person-centered way with parents and adapting things and making things easier and getting advocates involved. As far back as then there were a couple of areas that had a protocol and of Care pathway established. all the stuff we're still talking about now. Was kind of in that report and I don't, that sounds a bit, but it's kind of not much things are coming out with different versions of it. But the basics were sort of there.

And we talked about parenting with support as an idea, which hasn't taken off greatly, but I still talk about it every now and again. But it is the same as what they talk about in America as parental supports or Supported Parenting. Just the idea that parents can need support possibly ongoing long term to be the best parents they can and we ought to provide that. And all our childcare policy and everything says that we need provide support to vulnerable parents or parents who need support. So it just seemed to the right sort of words to use and slight, this may be quite a bit controversial but I'll say it anyway. In England we have the term Supported Parenting from the Booths. The brilliant Booths who set everything going in England.

But during my time in talking to people, drawing that, finding the right support and particularly when I was trying to disseminate it to children's social workers, they said, Oh, children's social workers said we don't go with Supportive Parenting because it only talks about the parents' needs, not the children's. And I got that from quite a few children's social workers and I'm sure that's not what the Booths meant at all, but it is what children's social workers had taken from the snippets they'd heard. Cause I'm sure the children's social workers probably hadn't read most of the Booth's stuff. They'd just had the highlights at conferences or somewhere and that was what they said. They said: We don't engage with Booth stuff. So we took a deep breath and decided to use a different term and called it Parenting with Support, which also put the parent first in the way that is liked by people with learning difficulties or learning disabilities in this country. So the person first, but it, it felt like a departure at the time from what the Booths had done before. And interestingly Scotland who we worked really closely with decided to stick with Supportive Parenting.

Marjorie (05:57):

Interesting.

Beth (<u>05:59)</u>:

And lots of their policy or their policy documents and their good practice guidance document is called Supportive Parenting. So we've got a thing, a little difference going on.

Marjorie (06:12):

But I think England and Scotland usually do have a little bit of a

Beth (<u>06:14)</u>:

Difference. They do have a little difference going on. Yeah.

Marjorie (<u>06:23):</u>

So you mentioned a couple of things here. First, the good practice guidance, which I would like for you to talk and expand on, but also what is Supportive parenting or what is parents with support? So if you could talk about the two and maybe they are linked together, which I believe they are, what that is and what it looks like concretely.

Beth (06:45):

Oh well the Good Practice Guidance was written in 2007 in England and it was written by an activist called Jenny, a disabled activist called Jenny Mo, who was employed by the government at the time and who we knew quite well and the Good Practice Guidance used lots of themes from finding the right support in it and caught quite and quite a lot of the examples, Good Practice Guidance got put into the Good Practice Guidance. So it is there but it's not, it's guidance but not a statute level. So it's the sort of guidance that should be used but nobody can tell you off if you don't use it. And so the government wrote this but it didn't really disseminate it in any great way. They didn't say to Children's Services, you must use this guidance, it's the way it is now. They just sort of put it out there and left it to us to disseminate.

But since then we've, We the working together with Parents Network, and the dean who is our policy officer, new Dean Tilbury, has updated the policy sections of the guidance a couple of times because every few years it gets date. So she keeps updating the Policy Guidance. And so we had the latest one

last year. So the content's exactly the same, just different links and different policy references. And Nadine worked really hard to engage with the Family Court and the president of the family division and she got the president of the family division to endorse a good practice guidance ooh, three or four years ago. And so judges and lawyers and PE are aware of the Good Practice Guidance and it gets talked about in court. So even though the government hasn't backed it, the family court is backing it. And so it gets talked about in court because judges have been awaited aware of it.

So that's quite a good thing. But this is probably a diversion for this podcast. But the Family Court has come back with another way of trying to stop parents getting the support by talking about something called Substituted Parenting. So if parents are given a lot of support, then they're arguing that parents won't be parenting the support work will, so they should still take the children away. So that's the current battle. So we've moved on from court judges being aware of it, well mostly to the counterbalance from within the court that if parents get too much support that's bad. Which is a very odd logic, but it's the logic that's being argued back.

Marjorie (09:37):

And I think it's interesting that you mentioned, cuz I think it's pretty much everywhere in all the countries that we know anyways, where there's this constant sort of back and forth in terms of what should we do and how it's seen or perceived in terms of support for parents with intellectual disability. And one thing that I think is often forgotten is that when children are young, you know, there might be a need for intensive support, but as they grow older that support is not necessarily needed at the same extent it's a different kind of support. So it's not like we're supporting but nothing happens. It's just that the children are growing older and the needs are different. And so we need to adapt and adjust the support that we offer.

Beth (<u>10:29)</u>:

Basically that is what Parenting with Support said. I think it's said about creating a work, empowering parents to speak up for themselves, empowering local services that they could so that they could work with anybody so that they had local services, knew how to work with parents, would learn difficulties and providing parents with tailored support. So that's kind of what it was. And that would take into account that children grow up and have different needs and need. I dunno, parents need help with understanding the internet and internet safety when they get older rather than baby gates. 'Right". Yeah. And I think the idea was also that the support could be ongoing or as required.

Marjorie (<u>11:12)</u>:

Yes, yes. I think it's fascinating. It's definitely something that's very common to all of our countries.

So there was a third document that you submitted for this talk that's called Crossing No Men's Land. First of all, I'm really interested in knowing why this title cuz it's so compelling. And then what's the paper about?

Beth (<u>11:36)</u>:

Okay, well this paper was an evaluation of a specialist support service in an area of England near London called Medway. And it was a service, it was set up by a wonderful woman called Rosie who was a background, who had a background in working with people with learning difficulties and being a health visitor. I dunno how she managed to get that background, but she did. And she set up the specialist service and she had support workers who worked with parents in a really intense way and they wanted an evaluation just to see about its usefulness basically and whether the local authority should keep on paying for this quite expensive service.

The project was started by Colleague Porter and it was basically an evaluation. So we did some focus groups with parents, we did interviews and focus group with staff who worked on the service and other staff who were engaged with the service. And we got an expert social work researcher in to do case file

analysis and to evaluate the impact of the services on the outcomes for children. And there was also a cost benefit element. So tried to look at all of it and basically it was fascinating in lots of ways. But one of the key things that I remember is that even though we had two fewer focus groups with parents and that was for parents who who'd kept their children and another focus group for parents who have still have their children removed from their care even though they have support from the service. And those parents still thought the service was brilliant even though they'd had their children removed because they understood what was going on, what the issues were and why the children had been removed. And they also said really difficult things about how they'd been suicidal and what bridge they were gonna jump off, but how the severe services had supported them through that and helped them to come out the other side. So it was just really powerful. I remember Sue and I in a focus group was like: wow. And they came along even though their children had been removed to tell us how good this service was.

So it just show and it was because in relationships they had with the professionals there and how they'd cared for them and how they'd explained and how they knew what was going on even though it wasn't the best outcome for them. And it was all about the individual relationship with those workers and how they'd engaged with them and advocated for them and explained everything to them even though it didn't work out in the end.

Marjorie (14:33):

That is pretty powerful. And I remember reading the article and I remember you presenting, you know, and you talking about it right now is just even more powerful in recounting sort of the despair that these parents face. And sometimes, we well actually often we don't even talk about this and I know soon I'll be talking to Rachel Mayes who talked about the grief and loss of parents when they lost custody of their children and how that piece is often not talked about and services are not offered. So we remove children but we don't help and support the parents in understanding why. But also in rebuilding I guess their lives without their children in their care. And that's not, I think great practice.

Beth (<u>15:31)</u>:

One of the mums involved with this service was on her seventh pregnancy and she'd had all of them removed, but she said it was the first time she understood what the problems were, a seventh pregnancy and he just, and we did follow up a year a while afterwards and she did have the seventh baby removed but she tried, she'd moved away from the area she was in. She engaged with anger management services and all the rest of it. But it was felt that she was so depe, she really enjoyed the pregnancy bit and the attention from services and when it came to having actually having a baby then that didn't go so well. But she felt she knew. And that always sticks in my head that there were seven babies who had to be moved and adoption doesn't always work out, is good for some people, doesn't work out the best for others. And this and the amount of time and money spent on that mum when if somebody had explained it after the first one it could have been also different. And with the right support she might have managed to look after the first one but by the time she got to seven, so yeah, it was, Oh yeah, I just will never forget her.

Marjorie (<u>16:52)</u>:

Yeah,

Beth (<u>16:53)</u>:

Never forget her. It's just like it's what a waste it took to the seventh baby of the system going round the same loop of we removed the baby but we don't intervene and teach the mum or work with the mum or anything. So it all just keeps happening again.

Marjorie (<u>17:09</u>):

Yeah. Do you think that's why you continued in this field? Cuz it's a pretty hard field to work in at times.

So do you think those stories, cuz you seem very inhabited by those stories when

Beth (<u>17:24)</u>:

Yeah, I think it was just when I started on it, just having children myself cause I've done, I suppose I hadn't even thought then, that somebody can come along and tell you it's all, you're doing it completely wrong and can remove your children and that sounds really naive but most people don't live with that fear do they? That everyday fear. Whereas these mums and dads just do. And they get scared to tell anyone they've got any problems because they think it get used against them and all.

Yeah. So yeah. The other thing about this service to try and remember to tell you is the case file analysis indicated that with support, ongoing support from the services, the outcomes for the children were far better than the children that had been removed. And yeah, so it was the first evidence I think of the impact of support and how it can be good and how it can work.

Marjorie (18:25):

And can you describe a bit what they were offering as a support? What did it look like?

Beth (<u>18:33)</u>:

It looked like a support worker who got to know the parent really well and tackled the issues, the faces they were facing with them and were really blunt with the parents about what they needed to sort out and said thing, I think said things along the lines of you need to sort your house out and get the dog out the kitchen and clean up or your house will be unsafe for children or you need to get the dog in the garden. But actually then rolled up their sleeves and did it with them and showed them how to do whatever was needed in the house. The parents said they were really blunt and rude, well not rude, but really direct about what was happening and really direct about the concerns about their children. So the parents knew but they also knew they had the support of the workers to sort it out.

Marjorie (19:25):

Right. So it's interesting because you're coming out to me anyways, is this sort of a mix or a right balance in one worker of someone who is very caring or believing in the strength or the capacity of the parent, yet is keeping them accountable and saying these are the things you need to work on and until you've worked on those elements, your children won't be safe in your care. And so, But in the same time what I'm hearing is that it's not also someone who stays behind a desk or just gives a couple of phone calls. It's actually somebody who's going to show them and not assume that because they've said clean the kitchen, that the parents understood what clean the kitchen is. Because there's a lot of values also in terms of those elements, right?

Beth (20:20):

Yeah, <laugh>. Oh yeah,

But just the other thing to say was that these workers were, they were respected by children's services and the other services as well. They knew that if there was a big issue that needed reporting they would report it. So wasn't the myth of because parents are supporting the adults, workers are supporting the adult, they didn't care about the children. The other workers from other services were clear that they knew that if there was an issue they would report it. And so some of the month closed cases earlier than they would have because they knew that the service was holding that balance of supporting the parents but for the best outcomes of the children. 'Yes'. So that's what you need. Cause it's always still about the outcomes for the children and what's best for the children, but it's about supporting parents

Marjorie (21:11):

I think that's also very striking or definitely an element that comes out in everything that you've done in

terms of your work, the element of collaboration and the element of working with child care workers. So do you wanna talk a little bit about that? I know you didn't submit a particular document about it, but I know that this is often where our discussions go when you and I talk about like we need to support workers and we need to make sure that we collaborate. It's not one against the other basically. So do you want to talk about that.

Beth (<u>21:49)</u>:

what I've come to learn is that there isn't much training around working with parents with learner difficulties, particularly for children social workers, they don't get an input and they end up working with these parents when there's a big crisis going on. Somebody is very generally concerned about the welfare of children and so they're sort of stuck without support, without an understanding of how to work with these parents. And it's all very difficult and I think you need to just have compassion for workers who end up in this situation without the right training and support. So it's just really important that we get the services together like adult services and learning difficulty services together to support children's services and work out a plan between them. And it's about sharing the skills and knowledge that professionals need and making children's services workers aware that they can do different types of ongoing support to make sure that issues don't increase and whenever possible to keep the child at home.

So you need to give people the knowledge and skills to be able to do that and connect them up with other services and with community resources or help them find family members to help out so that parents have got the best shot. Saying all the time these services aren't working right and feel people feel criticized doesn't help you share positive practice. So I try and avoid that. I try and say look, this is the way we can do it. And so lots of the recent projects have been trying to find positive practice and sharing it and that's what the working together with Parents Network is about sharing. People can ask questions and somebody else will come in and give an answer or when we used to have events it all used to be about positive ways of doing it and services talking about how they did it. So yeah, it's just sharing the positive really.

Marjorie (23:48):

Do you wanna talk a little bit about the network and how that came about and what it is?

Beth (<u>23:54)</u>:

Oh the network came out at the first study we did Finding the Right Support and the Bearman Foundation kind of looked at us with the findings and said well we need to do something to help the field. And they said we're gonna set up a network. So they put out a tender for an organization to run a network and we tended for that. And we set up the working together with Parents Network and originally it was a partnership between England, Scotland, and Wales and an organization in Leads called Change, which is led by disabled people and has done lots of campaigning around parents support needs. And so that was 2006, 2007. So now we've got a network of about 900 people on the mailing list, 900 and something and we share positive practice.

There's a website. before the pandemic we did regular events sharing positive practice around the country. At the moment we sort of run out of funding so it is really just the email network.

Nadine Tilbury does lots of policy work. So that's her main focus at the moment is to try and keep people being aware of the good practice guidance and challenging things like the substituted parenting thing. So she's actually running a project about substituted parenting at the moment to work out where this term's come from, how it's been used in court and to try and get some guidance written about it. This term has arrived and nobody knows where it's come from or what legal basis it is, it's just being used. So her main focus at the moment is trying to tackle that through a research project.

You are talking about funding. And funding is definitely something that we all struggle with I guess. And it's a bit sad to me that I hear when I hear those beautiful projects, the Together Working Together network that due to lack of funding may sort of lose like its steam a little bit. And in Australia it was Healthy Start that lost the funding and that stopped when it was clearly best practice and seen and perceived as the best practice by researchers throughout the World. We were all looking at them, we were all sort of using their resources and then it lost the funding. And so it's a bit sad that we know what is needed for services to work better, more efficiently, to be more supportive for families, yet we're not investing in that money.

It's fascinating again how it works. If we go in terms of looking towards the future, what do you think is needed or where should the field go or where would your research go for the future?

Beth (<u>26:38)</u>

So research wise, we're doing the study on substituted parenting because I think that's really unclear and a big risk to families and part of the project is trying to explain, trying to explain this term to parents and getting their response to it. It's not a positive response to the term substitute parenting, but also trying to work out how we can explain that term properly to parents so they can be aware of it. And when they're engaging with support workers making help being helped to keep control of the support, so they're seen as parenting. So I think that's really important that there is a risk that somebody's gonna say: you've got too much support, you're not doing it yourself. Parents have to know the risk and then have strategies to avoid that. So we're doing some focus groups with parents and gonna make a video for parents about this risk with a brilliant, brilliant theater company called Mind the Gap that has already done quite a few plays about parents with learning difficulties.

So that's, that's a big thing. And the other project we're doing is looking at how adults and learning disability services actually engage with parents with learning difficulties because you'd think it was obvious that learning disability services would get engaged with them, but lots of the parents haven't got a diagnosed learning disability, they've got a milder impairment or what we might call a learning difficulty. So they often don't get support from learning disability services. And so they should be able to access support from the generic adult services under the Care Act. But nobody has any clue if adult services or learning disability services could engage with parents earlier, then they'd have the ON might have ongoing support and then it might mean that there isn't a big crisis and they don't have to be involved with children's services or if families are involved with children's services, there could be far more positive engagement with the adult services.

Social workers are the people that get involved with them and they shouldn't and it shouldn't have to be like that. So we're trying to work out how adults and learning disability services could, hopefully that would give advice to services on how they can engage with parents and how the other services can be more supportive.

I think we've needed to know what's been going wrong, but I think we've know now we've been hearing similar things about what's been going wrong for a very long time. I think we need to move forward and work out the best models of providing that ongoing support we need. Positive support was related to the attitudes the workers had, which is obvious really. About the meanings they held about parents with learning difficulties. And so it's trying to help change people's meanings and understandings and say, look, if you understand that a parent can work well with support and they love their kids, they just don't understand some things or some things need to be compensated for, as our Swedish colleague say, which is brilliant. Then if you've got that attitude, then you can most likely make it work. If you've got a negative attitude, then it's not gonna work. You're gonna look for the negative things like that parents say that are looked for all the time. So I think it's about research that enables people to grow and move forward and understand that these parents can be good parents and I've got the right t be a good parent and have the right to support, just to move it onto a more positive place and to argue that the Human Rights Act or whatever laws in whatever country supports that.

Marjorie (30:32):

So my last one question, if you could talk to childcare workers right now, what is the one thing you would like to tell them?

Beth (<u>30:43)</u>:

I think the first thing would be it's not your fault you're stuck in a dodgy system that doesn't allow you to often work in a positive way, as positive way as you'd like to. All the social workers I've met, generally they, they're sort of stuck. They've got so many weeks to do an assessment and they have to prove that parents have changed or whatever. The system's not set up for them to do positive work in. So I'd say it's not your fault, thank you for trying. This is how you could do it. Talk to children. So talk to adult services, make sure you've got parents have got an advocate, get your legal department to look at the rules because you can have longer for assessments and things because parents are classified as disabled.

I think it's about recognizing that children's social workers are sort of stuck in our crisis intervention short term system and so often they feel like they can't do much. But how to get past that and how to work with the other services and how to learn how work with parents, as long as they've got a positive attitude, then that's all you can ask for.

Marjorie (<u>31:53)</u>:

Yeah, I love your answer because when you're definitely, you know, used the word compassion earlier and I think that's what we need more and more. Unfortunately, our systems are breaking down on certain levels and it is hard, very hard for workers to work within that system and within those rules that are given. The right support is sometimes as easy as sort of asking for help from a different agency or from a different sort of worker to be able to support, you know, on different levels.

And for that, I thank you because I think it's, you just gave a little bit of a light at the end of the tunnel by showing how simple sometimes support and collaboration can happen. So I thank you for that and I thank you for talking with me today.

Beth (32:47): Thank you.

New Speaker (32:49):

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