

Our Time: Parents' Focus group – abridged transcript submitted as written evidence (PSC0057)

PARENT FOCUS GROUP 06.05.2021 ABRIDGED TRANSCRIPT

Participants: 9 parents (8 mothers and 1 father). The parents taking part were existing KidsTime Workshop members, and represented KidsTime Workshops in London and South West England; some were long-standing members (several years) and some had only recently joined their KidsTime Workshop.

Facilitator 1: In terms of the support you've had for you and your family, what has been working for you in this time, and what hasn't been working for you? So, in terms of support for you as a family living with mental illness, what's been working and what hasn't?

Parent 1: It was a very difficult time, since last year and this year, **because especially if you have a mental illness, it is stress[ful] to stay indoors and not see family, and not be able to go anywhere.** I was asking for support, you know, at KidsTime, in the Zooms, to do the things that make me feel better, things not to make me more depressed; make me to support me and my family; doing activities with the kids like drawing, talking to family on the phone, - I know we can't meet each other, but we can WhatsApp, video call, you know?

And if you have someone you trust, if you have stress or are struggling and want to talk to someone, you need to break out (open up), otherwise it makes it more difficult if you keep inside; that's what I was doing - talking to my older sister in [-], she understands, I know she's not going to tell other people. When I do the parents' group at KidsTime, every time I ask for support, because I don't just keep silent and make myself worse, **because if I'm well, then I can look after my family;** if I'm not well, or I'm not happy, then the family, all will be difficult.

I have small children; I want to look after them, I want to see them grow up, **I want to enjoy my life, not always stay depressed, thinking, worrying.** I do my college online, I do a lot of things, but it does help me not to be more difficult (depressed). Especially, I had a difficult time with my husband last year, - we had a break up - , so it was so hard for that, you know?, and it's not easy. I try my best not to be weak, not to think too much; I know he pushed me so much to be depressed, he tried a lot and he's still trying that. Especially today, I was very upset and someone called me from the court - **he tried to take my children from me and this makes things worse.**

My life is my children - I'm alive, because I love to see my children, I want to look after them. If it's not my children, then I'm nothing, you know? Before, he was doing the case for mediation, now there's a proper court he's taking. I was just worrying. You know, the **domestic violence** asked me if I want, I can make a case and application for a court order you know, he can't see the kids, he can't meet the children; I was feeling bad as a human being, you know, I don't want to do that, because the children, they love him, and from the beginning, they were

very close, they want to see him; And, after that, I let him see the children wherever he wanted to see the children. When I have an appointment, I ask him to look after the kids, he refuses, just when he wanted to take one child and he's got five children, he just wants the one child. And today, I decided I want to do that case, you know, to do the application, so I'm still trying my best, you know, not to make myself low, and my health is not good.

I just tried to be strong, make myself happy, mix with my friends when I drop my kids, doing something that makes me happy. I don't know if I say good things? I just want to say every parent, if anyone has a problem, don't make yourself down, just do something that makes you happy, because everybody just thinks of themselves; I have to think of myself first. **If I don't look after myself, nobody can look after me, the doctor can't help me until I help myself, the doctor just gives me medication, but that medication won't work, until I help myself come out of this stress, talking about my feelings, just someone you trust.** I try to talk to people I don't know, not the family - **I know that it will go everywhere when you talk to the family;** they're going to tell this and that, "*Oh she's crazy, depression, mental health...*", you know? *that's* why.

I had so many things that happened in my life from the beginning. I'm still being strong. Thank you so much for listening.

Facilitator 1: Thank you for sharing that with us. So it sounds like what's worked for you is, you've really reached out to people, you've tried to look after yourself and that's worked for you, and you talked about talking to the staff at KidsTime. You also talked about that you talk to your sister, that you get help, that you are talking about it, and you've said that's really important for you to talk about it and not just keep it in. Other people may want to come in here about what's been working for them in this time and what hasn't. What would good look like for you? What other services or support could help?

Parent 2: I also put phone calls and my daughter, obviously, whether it's playing with her or doing school activities with her, I love that. I'm the same, **I live for my child.** I put 'seeds', because I've started to learn how to do seeds and stuff, and I think it's so beautiful; I've been doing my own lemon pips and stuff like that. I don't have a garden, but I have a balcony, so I have strawberries, tomatoes, potatoes - I love doing that; and cooking, as well

And I also go to AA meetings, I've been going to them for eight years now, so I'm eight years in recovery, so AA is a big, big part of my life. I also say a prayer when I'm a bit stressed, I do do that.

The (KidsTime Workshop) Zoom meetings for me, personally, I'm one of those people, I can't handle social media - I can't be in groups on Facebook and things like that, I'm already fighting to be positive, and I feel that it brings me down a bit, so I don't do that. The Zoom, for me, I wasn't that much into it, **but it was nice to know that it's there if I needed it.** Obviously, **I like going to KidsTime in**

person, I love it, because I panic and I get a rush all through my body, and it's nice to just sit there and talk with people in real life, the same for AA - you can't beat a real life meeting. And then, I do talk to my family and stuff, but the other lady just said it as well, **speaking to the right person is a big thing, because you can speak to your family, but sometimes their advice is not the right advice, or sometimes we need somebody that looks at it in a different angle,** so, once again, I'm quite lucky because I have AA, so I think that's it for me. Is that ok?

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Facilitator 1: That's great, that's really helpful. Would anyone else like to share what support they've had and what hasn't been good perhaps?

Parent 3: I'd like to share my experience. So, for me, **when lockdown first started, the routine that I was used to was messed up, so that was a bit overwhelming for me,** because having the children around the whole time when the schools were off, **I love my children, but then it was a bit much for me;** in the sense that my youngest one, she's just four years old and she's super clingy, even now, she's super clingy, she constantly wants physical touch to make her happy, - she finds comfort in physical touch -, so she'll come and stick to me and all that, and **I found that very overwhelming,** for me.

And what helped was, because I had a **Family Support Worker** at that time, she helped get the kids back to school and nursery, so **that was a great, great, great help to me.** And then also the **KidsTime activities,** it kept my older one busy, because it was **something for him to look forward to, and it's somewhere where, other than us, he had some interaction with children and others around his age, so that helped him as well as me, honestly, because, even when we have the grown ups KidsTime, that's a place where you can talk. I have friends, but I cannot open up about my problems to them,** because I don't know if it's the same with everybody, but, **for me, I prefer to put a different suit on when I go to see or speak to my friends, and I have a different suit on at home;** and I don't know if it's the same for everyone, but **I cannot speak about my problems to everybody,** so that helped me as well.

Also, initially, during the first lockdown, **I had talking therapy and it was through the phone initially because of lockdown, and that was a big help for me too,** because I too had issues, I *still* have issues, with my husband, because he leaves most of the kids responsibilities to me, and while I'm happy doing it to a certain extent, **I also get overwhelmed very easily;** there are times when **I feel suffocated and I desperately need a break,** and he doesn't understand that bit, so **when I get overwhelmed, I know that it affects both of my children as well, so that was really bad during the lockdown, because they were around me a lot.**

About the texts and calls, yes, that does help, but texts and calls can also get a bit overwhelming for me. I tend not to reply back on time to any text, and this is not just from anyone trying to help me, even my friends, and I don't know why, it's

been years, and I've had several complaints from my friends as well, especially that, why do I not reply back on time? It's not because I'm rude or anything, it's just when I see a text, I don't know why, I just feel overwhelmed, and put it on the backburner - I say I will reply later, or I that I will send a text in the evening, and I just stare at the text and I could reply, but I don't though, I don't manage to at that time - a lot of people misunderstand me because of that, but sometimes texts can be overwhelming, even calls.

Facilitator 1: Thank you. It's good to hear that you got support from your Family Support Worker and talking therapy. It would be interesting to know if other people have had support from other organisations during this time that's been helpful.

Parent 4: I have. **I have a Community Psychiatric Nurse (CPN) which is a psychiatric nurse who started to look after me during the first lockdown, and he's literally been amazing to me;** he's given me loads of other support as well, so, for example, when I get really sad, I binge eat and I've gained a lot of weight, so he's referred me to the Eating Disorders Service to get support with that, and he's given me lots of **coping mechanisms of how to deal with my anxiety**, making lists and how to approach situations where I'm not having a good time, and also reassuring me that when things are a bit rubbish, and I'm feeling down, that that is alright, that it is ok to feel like that, that's completely normal.

Facilitator 1: Thank you. Has anyone else had any support, or would've liked support?

Parent 5: Well, I've been supported. Firstly, **the lockdown was terrible in our house, because, for one, with my depression, it's like related with health and death - they're my two triggers, and so to have a pandemic come, it just floored me completely**, and I couldn't just help myself, **I felt useless, I couldn't help my kids**, because I couldn't tell them how it was going to go and when it was going to end, or anything; so, **I just felt really helpless, and I found it really difficult to go out at all, I just became really isolated**, and unfortunately, the reason what it ended up, you know, I'm glad I've joined this (KidsTime Workshop), but it was over **my son who just completely went off the rails, and so we had to get outside help**.

The first people we got to help us was the **Family Support Team in [-]**, and **we got a key worker who's great, I'm so happy that I've got her there, because she's helped me with so many things regarding the kids;** and things I knew needed to happen, but I wasn't able to get the things into motion myself, because **I was so unmotivated and so down, and it was so good to have her there;** and she actually referred us to this service (the KidsTime Workshops), so it's just been really good in that sense, because, **before that, I just felt like I**

couldn't really talk about it, because I just thought everyone is in a similar boat and everyone else has got their problems as well, so it's kind of hard. **So, it was just good to get on this and to see some happy faces, and positivity, because it has been a really bad time**, it has really sucked this pandemic, and it's still not over, but now I can sort of get my head around it, because **at least I know there's somebody I can talk to about it**.

And the same with family and friends, it's the same, you only tell them so much. My family, anyway, they're not really here, my sister's in [-], and how much can you put onto people, you know? Everybody's got their own issues, so at least here, **it's good and I just feel more supported than when this all started and I just felt totally lost altogether, I was completely lost, but now, at least, I've got some back-up**; and with the kids as well, **it's been good for my daughter, it's brought her out of her shell a bit more, helping her to talk to different people**, and yeah, that's the positive side I've seen. My only negative is that I haven't been able to join you in the life situation yet, I haven't had that experience, which I look forward to, because I would prefer that face to face and seeing the people rather than Zooming, but we'll get there.

Facilitator 1: It's lovely to hear that KidsTime has been such a support, but this isn't just to gather information about KidsTime as a resource, it's any resources, any other support, from any other organisations or individuals that you would have liked?

Facilitator 2: It sounds like your Family Support Worker was really helpful, and it was a really important moment when things started to change and start to be a little bit easier. I don't know if you can put your finger on what it was that he or she was doing that made the difference, because support can come in lots of different forms; sometimes it's about having someone to talk to, who listens, who isn't in your family, but were there any practical things that you got from your Family Support Worker, or if you could say the best thing that they did was...have you had any thoughts about what that was?

Parent 5: **She made me feel really comfortable**, and any problem I had with the kids, she will be there, she would be the one to get on the phone, **just get things going and moving**; and **because of her position, people listen to her**, like, I could be struggling with the school to get them to do whatever, get the child tested or assessed, or anything, **I'm hitting my head on a brick wall**; but now I've got [-], that's her name, **she is fighting the fight, and they listen to her, and it's really good, I've got someone in my corner**, and people listen to her, so that's the support she's given me, and I really appreciate it, because **sometimes it's too much of a drain for me to have to keep going on and on and on at people, and they're not listening**, so that's where she's really helped me; and I know that she chases all these people down, she gives me updates on what's happening and I really appreciate it.

Facilitator 2: Thanks, that's really helpful. So it sounds like it's about having someone in your corner, and who's able to do those exhausting phone calls, but also being heard and actually feeling like people are listening to what you're worried about, and trying to get some practical help for the things that matter?

(To the rest of the group)

What was the support that you really needed?

Parent 3: For me, whenever I had a **breakdown**, and there was a time when the talking therapy ended, and she would listen to me, she would hear me out; there was also a time when she mediated between me and my husband, - it was over our child playing playstation, it was not age appropriate for my child, and there was a huge argument over that and she mediated for us -, so that as well was helpful for me, **because, normally, my husband is really stubborn - he listens to everybody, but me, so I'm always wrong**, so that helped in a way that, with someone else in the room, he's willing to listen to me as well when someone else is present. And also, we are **struggling financially**, and she helped look for activities which were free for my children, and let's say she comes across vouchers she could get for me, for the kids; and she also referred me to the Asian Women's Resource Centre which was also helpful for me, **so she constantly looked into avenues where I could get help for the situation that I was in at that point**. So, having her around me was very helpful. **Unfortunately, she had to close my case now, so I...., really, really, it was very helpful, and I do feel the difference of not having her on my case.**

Facilitator 1: Thank you, that's so helpful. Would it have been your ideal that she carried on providing that support for you?

Parent 3: Yes that's correct, because I do feel like, at the moment, for many reasons, there's a lot of stuff that's ongoing, but then, **because of her seniors, she had to close the case, because she was on it for a while, but she is still in touch with me**, and has asked me to update her if the situation changes or anything, and she's **helped provide letters of reference for certain things that I needed**. She was looking for a course for me, as well, because I was looking into brushing up my skills, so she helped with that as well.

Facilitator 2: When people are making decisions about services and how organisations should be run, or what organisations should do, or what questions we need to find out more information about to make decisions about what support is available to people, and how long it's available to people, - those kinds of people -, **what do you need them to know, so that they can make decisions that would be right for your family?**

Are there things that you think, *'Whenever I see someone at the clinic, they just don't understand what my life is like, they don't understand this or that', or, 'I really want them to know...'; 'These are the things I worry most about...'*, or, *'This is the thing that's just the hardest for me as a parent when I go and see the doctor, or when I see my CPN...'*

Are there things that you think people don't know about your lives that would make a difference in terms of how support was organised?

Parent 2: Basically, **I don't really have any of that support**, I don't know if it's my borough. Unfortunately, I don't have any of that support, I would *love* to have some support around, basically **travelling, as well, I find very hard, education** - getting back into education, I left school with no GCSEs, now I don't have anyone to help me with that; **I had a problem with my child at school**, I was trying to explain that **I'm a single parent, my partner died when I was pregnant, so in the lockdown, my dog also died**, I've had him for 16 years, so I was trying to say to the school, is it ok if you just speak to her, help her, help her clear her chest a bit, and **I didn't find the school helpful, I found them a bit judgemental of me**. It's like, **when I come to KidsTime, I can say I'm a recovering alcoholic and I say it proudly, I can say I suffer from anxiety and I suffer from post-traumatic stress, and I panic and things like that**; I could say all that with the last headteacher, not all of it, but most of it...

Parent 6: So, **I've got quite a few diagnoses**, and I've got **borderline personality disorder**, and when I said about that and how I can get support etc, **my CPN suggested calling in complex PTSD which I think it's pretty much the new name for EUPD (Emotionally Unstable Personality Disorder), because they said you find more avenues open if you use that term, rather than the EUPD term**. But I find that **you either get lots and lots and lots of support, and then, it's a bit like you're over supported, and then as soon as they realise you've probably got to the best place you've got, everything withdraws, and then when you need that support again, you have to start from step one**, re-referring yourself, assessments.

Here we have a team called [-] Options, and then anyone can refer anyone to that, you can self refer to that as well, or you have the Mental Health Teams in each little area. **My GP told me I wasn't ill enough to be with the Mental Health Team, so I self-referred to Options, and then Options then denied me and said I was too ill for Options and I should be under the Mental Health Team**; so with this to-ing and fro-ing, **I asked my GP for a little bit of help, it was the winter of 2018, and I finally got my first consultant appointment in February 2020, because they were just arguing - I was too ill for one, but not ill enough for the other**. So, I waited nearly two years for that help, and then, of course, the whole world shut down in March because of Covid, so **help's been a little bit sporadic to say the least**.

Facilitator 1: So it sounds like what you want people to know is that help needs to come quicker?

Parent 6: Yeah. I really don't understand, like you've got the Options way, or you've got the mental health way - **why they can't do some joined up thinking?** I don't know why they have to argue? **They're there for one primary reason - mental health, surely they could come together and offer more services, rather than fighting over who they want to help.**

Facilitator 2: Sounds like it's about **making sure people don't fall in between the gaps in services?** The question is around how do we have something that's joined up, and how to help when things get hard again, rather than going right back to the beginning again and having to go through all of the stages.

Parent 6: Before I left the hospital, they did a section 17 meeting, and they laid out all the services that had to help me by law. I got discharged in February, and by the middle of March, all the section 17 people said, "*Well we've done what we can do*", and **I was completely discharged from all mental health services, I had nothing left.** And then, I had to start right from the bottom, when my mood..., I mean, **by nothing, they took my meds off me, they took therapy, they took everything off, and I was just standing in my lounge going, "Oh my God, I've had six months on a ward"**, yeah, it was **very, very overwhelming.**

Parent 7: The lockdown for me changed my life as well, because everything I was doing, like my work, they closed the shop, I wasn't doing the gym, the gym closed and everything, but the girls and I tried to do gymnastics in the house together, we'd bake things, they even learned how to sew with the machine. **But I do have support, a lady called [-] who calls me every Friday; she talks to me, I can talk to her about my problems, because there's a day I'm down, days I'm up, and she helps me a lot.** But I think **KidsTime has been helping a lot as well, because it was in KidsTime where I could open myself, to talk about my problems, because where I come from, I'm not allowed to talk about it,** so I think I had a lot of support from KidsTime.

Facilitator 1: And who is [-]? Which service is she from?

Parent 7: I don't know. **My psychiatrist referred her to me,** I thought she was a therapist, that sort of thing. **She calls me every Friday at 2pm, and she speaks with me for an hour** which has been really helpful. Some people don't have any help, but **I can say that I have a lot of help, which I appreciate.**

Parent 8: Yeah, **I'm finding it really hard to get any help, actually. We did have a support worker at the beginning of the first lockdown, and she quickly dropped the case,** I mean, she was saying that it sounded like a lot of people were needing help, and **she felt that we were at the stage where we didn't need any more help, and we do.** I mean, it's just me and **my daughter who has autism, and we're completely isolated. During the first lockdown, we were just at home, with no one to talk to at all; I was able to get a few telephone therapy sessions, other than that, we had some support from KidsTime, I haven't been able to get any help. My GP did refer me to mental health services, but they rejected my case,** so I'm just kind of stuck in a position where I don't know what to do really, because I either have to go back to my GP, and I don't know, **I'm just stuck with no support whatsoever.**

Facilitator 1: What support would you like?

Parent 8: Well, I do feel I need help for my mental health; **I've had issues for years, and I've always been able to get some sort of support, in fact, these people would not leave me alone, because my situation was quite serious, and now, I guess with the things as they are, I don't know what sort of situation, what circumstances you have to be in before they will help you.** I think it's really bad, **I feel let down,** really, with what's happening at the moment.

Facilitator 1: I'm sorry to hear that, I don't think you're alone in that feeling. Do you think that's a result of the pandemic?

Parent 8: It seems to be that, yeah. **It seems you must be in a really serious situation before they can help you, and I feel like I'm teetering on the edge;** and, obviously, **I don't want to go over, because it's just me and my daughter, and I don't want to be in a situation where I have to go into hospital or whatever, but I can't get any help from anywhere, that's my situation at the moment, no one's helping me.** I suppose it will get to a point where whatever happens happens, because I'm actually trying to contact my GP again, because **my local Mental Health did not accept my case, and said my situation was that I've got housing issues, so that's what my problem is, so they didn't want to take my case on.** So I've been trying to call my GP and the line is constantly engaged; they give you this time slot to call and, obviously, everyone is calling at the same time, so it's just madness at the moment, it's ridiculous, it really is. So yeah, just for people out there, **for people to understand, there's people with long term mental health issues that they are letting down,** basically. **I don't know what sort of state you've got to be in before they accept you.**

Facilitator 1: Thank you for sharing. I really hope that you get some support of any kind.

Facilitator 3: So far, we've spoken about GPs and mental health support for parents. What's been people's experience of family services or social services, support for your family as a whole?

Parent 4: I've had a few interactions with social services. The first one was when my daughter was a baby, and I had really **severe postnatal depression**, and **I actually wanted to take my own life**, and **I had a social worker visit our house, who literally just said, "I don't see any problem here"**, and off they went and didn't offer me any more support. Luckily, I had a **really good Health Visitor**, who put me in touch with other places to go; I had **CAMHS involved as well for a little bit, because they did parent and baby postnatal depression workshops** at the time, so I was involved in that.

And then, **my husband, he's got mental health problems as well**, and he ended up having a bit of a **drink problem**, and in the October half-term, it was quite bad to the point where I had to phone an ambulance, because I'd been out with my daughter and he promised me he was going to be alright; I came back, he had the boys and he was drunk, and I had to call an ambulance, because he was that bad, and the ambulance crew had to do a **safeguarding referral**, understandably, and we were contacted by social services then, and literally, **she just took my word for it on the phone; she didn't come and visit, she was just like "Yeah, alright fine, I totally buy what you're saying"**, and that was that, and I've heard nothing since.

Facilitator 1: What did you want her to do?

Parent 4: **It would have been nice for her to give us another phone call a few weeks later to check in how things are, you know?** I just felt like she took my word for it and that was that. **I felt a bit disappointed, really, because, at the time, my husband was quite poorly, and I was also quite poorly, and I felt like we were just left.** I said, "*He's doing this, he's doing that, I'm doing this*", and she was like, "*Ok, fine*", and kind of let us on our way, where a few weeks down the line, **we had kind of got like a bit worse, so I would have appreciated, "How are things? What can I do for you?"**, and we could have got some extra support.

Facilitator 1: So maybe to just have a little bit more care, give you a follow up phone call, check-in, see how things were going?

Facilitator 4: You said that she just took your word for it on the phone - would things have been different if she'd come to visit, do you think? Would you have preferred that?

Parent 4: I don't know, I think I would have freaked out to be honest [laughs]. The whole process when my husband was poorly, and when I was poorly, I feel like, me, **I have got a lot more support - all I've got to do is go to my doctor and go, "I'm not feeling great at the moment, my moods are all over the place"**, bearing in mind I have got history, so that's probably why, **they put loads of stuff in place for me, straight away; whereas my husband, he's been to the doctors, he's been to people, and he's said, "I'm not feeling great", and they kind of just leave him to do it on his own;** I mean, he's here with me, **he hasn't had the support that he's needed from the services, it's always been about, "Let's support Mum", it's never been about supporting him.** Am I saying that right?

Parent 9 (Father): Yeah, I've just learnt you have to deal with it yourself if you want something done, if you want to get yourself better, you've just got to want to do it, and you've got to do it yourself

Parent 4: But he's had to do that himself, it's because he hasn't had help to get there, so it's **been longer and harder for him**, whereas if he'd had the help, he probably would've... Parent 9 (Father): I just feel with the kind of issues that I've had, **the finger gets pointed at you and you get accused of not being well or, you've got a problem, and you're always going to have a problem, and you get this label, and it doesn't really help.** For my situation, you've got to find what works for you, really, and there's so many different types of help out there for people with problems and addictions, and go-to's for trying to help their mental health etc, it's very much got to be tailored to you really, I think.

Facilitator 1: Thank you, that's so insightful and so helpful. There's something there about not being judgemental, and not wanting people to judge you - that being the opposite of help and support.

Parent 3: I wanted to speak about mental health support, as well. So, **once the support stops**, and your condition gets worse, like, for example, **a few days ago, I was literally feeling suicidal and I didn't know who to call**, because, you know, they do give you numbers for crisis and you can call them, especially if it's out of hours, but, you see, when you call these people, **they do not know your history and sometimes you don't want to go through it.** I've recently recovered from TB meningitis and, even though I'm out of the hospital at the moment, they have given me a number where I can directly call the TB nurses, and as soon as I call them and I tell them I'm having this issue, I, straight away, within an hour, go to the hospital, get my bloods done; they know my history, I don't have to explain anything.
I just wish there was something like that for mental health services as well, when you're feeling really low and you're at a breaking point, and

you don't want to have to go through several barriers you have to normally go through to get the help you need, so I wish there was something like that in mental health as well. **Once they discharge you back to your GP, it's so difficult to get back onto...and, you know, mental health isn't something that, you know, click and it's gone**, you know, therapy's over and she's all good and she's all fine, **it takes years, especially if it's something that's been affecting you since your childhood, so it takes time and different therapies to get better**. I feel it's almost like, **"The therapy sessions are over, just prescribe some meds and she's going to be fine"**, and that is something I wish would change in the mental health services.

Facilitator 2: Thank you so much for sharing your experiences, and I'm really sorry to hear that many of them have been so frustrating, and not managing to get help that you've needed.

To slightly change the question a little bit, are there things you think we should be looking into more, to try and understand more about? I'm a psychologist by background, but I'm also a researcher now, and in research, it's about trying to ask questions, what do we need to understand better? What do we need to know more about? **I was wondering if you had questions about things that you would like us to be looking into more, to try and understand more about, either how services could be improved, or about whether you had thoughts about questions that you would like science to try and help us answer, to investigate a bit more?**

Parent 6: My husband is a registrar in the A&E department, and sometimes he teaches junior doctors about mental health; **by his own admission, they don't learn a lot about mental health in their training** - they train for five years, and I think he said he had about one week's worth of training when it came to mental health. So, I always offer to speak to the juniors about how a person with mental health feels they get treated when they come into the department, so they're at crisis point, or they've self-harmed...You can be taught how to stitch up a wound, but you can't be taught what people are thinking, no one knows. The word 'crisis' is a big umbrella, **someone's crisis is not the same as another person's crisis**, so I always offer and they always say **no they can't, they don't want people in the department that are not medically trained to be teaching. To me, it's not teaching, it's making them understand.**

My little boy is an absolute mischief and when he was three years old, he managed to open a bottle of Calpol and drink half the bottle, so I took him up to A&E, to the department where my husband works, but he was in another part of the country at the time, and **because on my record, it shows that I had mental health problems, they wouldn't talk to me**, they had to ring up my husband who was in another part of the country working to relay the plan of what to do with my son. **I just don't like when people go up there and they see that thing - 'past medical history', 'mental health problem' -, nine times out of 10 they'll**

probably have an alert attached to them, and then, it doesn't matter what you've gone in for, they only focus on, "*Oh she's got mental health problems, it doesn't matter that she's broken her leg, she can't have morphine, because if she's got mental health problems, she'll be morphine seeking*".

You just know as soon as you walk into a department and you say, "*I've got depression, anxiety...*", their whole demeanor changes, and it's like, oh, you've been out of your comfort zone, imagine how I'm feeling right now. But then, **they won't take the help that me and other people with mental health problems are trying to give them, so they don't have to make people feel that way.**

Facilitator 2: So it sounds like it's something around how we can educate healthcare professionals about what it really feels like to have a mental health problem and particularly how it feels you get treated differently because of those alerts on your notes...what it feels like going into a service asking for help with that history.

Parent 6: **I truly think if they just heard from service users what it's like, that would be much more beneficial than reading a paragraph in a book or a PowerPoint presentation, because we're speaking from genuine experience.**

Parent 2: I wanted to say as well that I wasn't brought up like this, but **I was always told not to speak about how I feel** and everything, and **I feel that we should start children at the youngest age possible to be learning about their emotions and confidence**, but I feel schools could do a bit more with that, you know, with the PSHE and stuff.

Parent 3: I would like to agree with the previous lady before [-]. So, I had a very similar experience when I went to A&E with a kidney stone, but at that time, it was not known there was a stone passing by, and because they couldn't see anything, the nurse was like, "*Oh, I'm not saying that you're imagining it, but maybe you are?*". So it's like, **because of my mental health history, they did not believe I actually had that pain**, and then everyone was worried that I would be addicted to opium, - I've never been addicted to anything in my life, and I am very, very wary of medication, like my mum died of organ failure because of taking several meds, so I'm very cautious about putting any medication into my body -, but then **the way that I was made to feel was that probably I was imagining it**. The problem with me is that if you tell me enough times that I'm imagining it, I'll believe you. So then I was questioning myself as well. Later on, it was found that it was a kidney stone. Similarly, when I went in with my meningitis issue, until they did the lumbar puncture and they confirmed that it was meningitis, everyone thought like, "*Oh she's probably imagining the pain*", so that's another thing I wanted to input.

Facilitator 1: So it's that whole thing about the stereotypes and the stigma and the assumptions, because we have a mental health history, that you wouldn't be believed, that your report is not valid.

Parent 6: I was taken into hospital last November with gallstones. I was in the hospital for a week. Because of Covid, they were not allowing outside medications to be brought into the wards, so when I was in A&E, I said, "*Look, you need to get my medication*", because mental health medication has got the worst withdrawal symptoms ever, that is never fun. So, by day three, there were still no meds, so that's three days of no mental health medication; by day four, I said, "*Look, please let me bring them in from home*", and they just outright refused; I may have got a bit angry, but **I was off my meds, I was feeling absolutely disgusting, my head was all over the place** and dealing with gallbladder problems as well. **So instead of the nurse understanding what I was saying and trying to find these meds, she made me have a psych review, because she thought I was in crisis, because I raised my voice a little bit.** So the Psych Liaison Team came down to the ward and said, "*Look, what's wrong? Why have you been disrupting the ward?*", and all this. I said, "**Look, I haven't taken my meds for nearly a week now**, I've got restless legs from the [-]". I said my head feels like it's going through electric shocks ten million times a day, and I said I've asked every single day for them to bring my medication in, and the F2 who's the psych liaison person just said, "*Oh ok*", and then he walked away, so he didn't even get my medication sorted. So by day eight, when I came home, I had to start it all up again, but they see that thing at the top of your letter, they see 'borderline personality disorder', or anything else, and anything written under that is completely irrelevant because they've already got that image in their head of what people with borderline personality disorder may or may not present as.

I liken it to, because my daughter is autistic, she doesn't flap, that's not her thing, but it doesn't make her less autistic, like everything's got different levels of what it is, so just because I don't act like another person with personality disorder, doesn't mean I'm any less personality disorder, but I wasn't there for that, there's a mental health hospital that's across the road that's there for that, I was here for my stomach.

Facilitator 2: Thank you to all of you for sharing your experiences, especially the difficult ones. It's really helpful to know about those, so we can think about how we can try and get it right both for you and for other people coming through in the future. Are there questions that people have got, things that they would like to ask or other things they would like decision-makers about services and organisations - want them to know, or if you think your children have got questions?

Parent 1: **I have seven children, you know.** My older son, when he was young in school, **he had so much bullying at school, and he never gets support** with what he wants; and at that time, **I wasn't that long in this country, and I don't know where shall I ask for support for my son**, and I was five years, I don't know, and they were just sending wherever they want to send; and, because of that, **everything my son involved with the people, you know, gangs**, every time with the police; then, something happened, and **they came to our home and I requested support and that involved social services**; then, **they were looking for my youngest children, they didn't give support to the one that's**

got a problem, and they involved the youngest I have. They contacted the school, but, luckily, the school, they know me for a long time, they supporting me.

I get everywhere support - **I have my care coordinator supporting me**, I have **psychiatric doctor, GPs**, I get everywhere support, but, you know, sometimes **I feel like my son, if he got the support before today, he would be good a person.** He was trying to be a police officer, you know, he did the training, one year was left to complete his course, and **he make me feel like he was a very good boy, quiet, he never talked.** Every time he get bullied in the school, so I just talked to my other children, I said to them, "*Whatever is happening to him?*", because, at the time it happened, I couldn't get the support.

So, I want to try to get support for my other children; so like, last year, **they was coming to KidTime, and they were enjoying doing drama,** and, especially, last year, we had **problems with my husband in the house shouting in front of the kids and swearing,** you know, that's not good, it doesn't help the kids; because, **I understand how I am suffering now, I don't want my children to be depressed** and they need to study, they have to focus on education. I ask for support with everything, you know, every time I get small, small support, **sometimes it's very important for us and for my children as well.** And I say to them (my children), wherever you feel anything, you should talk, and **the school, they have mental health (support) for the children as well,** secondary school, primary school - all the school now, they have the support there, and **my son has special needs as well and he gets support as well.**

But sometimes I've seen them quiet, you know? **He (my son) can't express himself to say what he wants and he doesn't get upset. (The other children), they come home, fight each other; these days, I've seen they get so much stress from each other, they argue all the time, I have to stop them, sometimes I get difficulty.** But I try to make them calm down, and I've asked the school as well, because they get this stress, and I speak to my GP, **I've asked for talking therapy for myself, one-to-one**

Sometimes, because of the mental health problem I have, before, when I go to the doctor, I have stomach pain, when I complain, they say, "**It's because of your mental health problem, you feel like you have that pain, but it's not real**". I say, "**I understand I have a mental health problem, but I'm telling you I have pain**". **Don't be like that because I have a mental health problem, because I'm stressed, I'm depressed, it's not like that.** I have a stomach problem - gallbladder they took out in 2010, but by mistake, - I didn't have the gallbladder problem, I had a stomach problem, and, after that, they gave me more problems. In 2015, my liver - I had a stone, so they had to remove that one as well.

It's just keeping going, keeping happy. Last month, my son broke his arm and, today, I went to the hospital and they removed the wire - three wires in the hand! **So much pain, I can't see my son having that pain, I wish I can the take the pain with me. Yeah, it's not easy the life, you know, but we have to just push ourselves. Sometimes, people, when lots of these things**

happen, they do suicide - I used to think that a long time ago, to end my life, because it's not good, I'm not enjoying my life, but, after that, I've seen my little children, you know, I want to be with them, I want to be alive, I want to enjoy the life, enjoy the world to be with them, I don't want to end my life, that's not a solution - it doesn't help.

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Facilitator 1 reading other contributions from parents in the chat:

It would be great if mental health services could be there for our children. They may not have supported you as well as they should have done over the time, but what you would like to see in place is joined up services, with longevity of care, supporting you throughout not just in the moments when they feel it might be..

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(Other parents) She'd like it if the school social workers would believe the parents. Doesn't everybody know that the children behave for everybody else except for their parents?!

Wrap up, thank you and close.

6 May 2021