What is the impact of looking after a child with autism and/or learning disabilities who demonstrates violent or extreme behaviour?

A presentation of the views of six parents of children with autism, and a discussion about how services can better support them to manage extreme and violent behaviour at home

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"Your children are climbing on everything, touching things, licking things, putting their tongues in the key-hole, and it's all that stuff that I find quite endearing. You know, it's quirky and sweet, and I think they're the loveliest children in the world".

"I usually get between two and four hours sleep a night... for two years now … it can't last for ever. You just can't ... you're putting families in danger, I wouldn't hire a baby-sitter who had only got two hours' sleep for two years."

"trying to fight off a child that you love to bits, and ... then he can be his normal self, and it can be very difficult when you're physically hurt, bitten, scratched, and he has no understanding of that..."

"Things you do when you're a small person with autism are inexplicable...not being able to resist the impulse, you have absolutely no control... I'm there ... saying "why would you do that?! Why would you pour milk in the remote control? Why would you put silver polish in the fish?!" There are dozens of bizarre things everyday"

"You hear about these stories about people just getting in the car and just driving off the Forth Road Bridge, and I can honestly say I can completely understand it. I've honestly felt very close to that."

"...My daughter's obviously really angry at Kieran for attacking us... Kieran will attack her, so she's really physically frightened of him"

"That's where we are now... at the bottom of a big black hole, trying to hold on..."

"Throwing money at parents... I'm sure benefits, but I would give up all of that, I would much rather have a much longer term approach, because that child's needs change, so you might have one service for a month, then a couple of years later there's another issue that cropped up that he needs help with, and he's on the waiting list again"

"when people [like our social worker] really care about your children, they see the person, not the disability..."

"their behaviour was so altered by this one night away, that it was like they had been abused. That shook me probably more than anything, more than the diagnosis, the breakdown of my marriage, or anything like that. I think that was probably the worst point of my life, the day when I realised I was on my own..."

"getting people parachuted into a situation, when it's at crisis point is not helpful, you don't have any relationship with them, you can't connect with them"

"going for a knife out of the kitchen, and actually cutting himself, or head-banging, swearing."

"It's the unpredictability - for six months we've got vouchers, and you don't know if they'll renew them, and Kieran is picking up on your stress as well, worrying am I going to get them back again, and then you're having to go through it again, which is really disheartening, because you're having to go through the same story, the same situation, and it's awful for me to listen to what I'm telling people, for me to admit to what my son does, and for me to say that I don't cope, that's really really hard."

"I feel like a battery, and I'm not, I'm an individual, and I think the children are better off with me than with anyone else. I don't think anyone could love them like I do, it just seems really strange to wait til... to leave people until they're in crisis....Pushing the family to the point where either I end up in hospital, or mental ill, or just say I just can't cope any more. And then the stress that that would put on the kids... I can't even imagine, and then introducing strangers to look after them, in foster care whilst I get better, I think that is the most dangerous and ludicrous suggestion, and it would only cost more in the long run anyway..."

"I know him better than anyone else, and I've found it massively frustrating that people aren't listening"

" the result of the section 23 [social work assessment] was that I had too much respite, and I honestly feel it's the only time I've been depressed. A lot of people talk about depression, and they feel sad, but I wasn't feeling sad, it was genuinely hopeless, demoralised, it was really difficult to keep going. I try not to be very emotional, and keep it together, and I think that's my character as well, but I felt devastated... It was like I had completely given up, I felt absolutely spare..."

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