

This is a pre-print extract from Chapter Three of the book ***Supporting Positive Behaviour in Intellectual Disabilities & Autism: Practical Strategies for Working with Challenging Behaviour***

3. Working Together or Pulling Apart?

Coming together to openly discuss issues is an opportunity to share experiences, perspectives and solutions. No single person or group holds all knowledge.

Challenging behaviour is difficult to deal with when you are alone: this is everything to do with the uncertainty such behaviour causes. The two following 'letters' illustrate the common frustrations that over the years I've heard expressed by professionals and parents. The only way forward is to work together.

About Professionals: A Letter to Families

Dear Family,

I have no magic wand. I'm a limited resource in high demand. Like undertakers or midwives I will never be out of a job. My time is of the essence. My employers measure my effectiveness in terms of the number of people I advise whereas families measure me by the quality of the advice I give and my availability. I'm doomed to disappoint someone.

The first thing to go when I unpacked my training and began work in the real world was my capacity to spend time. I had to ration myself. All too often my job doesn't allow me to do what I once thought the job would be. I thought I'd have more autonomy to use my skills. (It feels wholly ironic to call ourselves a service at times, because we're increasingly expected to serve the interests of our own organisation.)

What you often want is my presence – in person or via a phone. You understandably want to feel supported, perhaps even not wholly alone. But I can't fix everything. I know it frustrates you when I fall into professional-speak, or say '*I know how you feel*' even though I probably have no experience equal to your own, but that's how I'm trained, even though I suspect such trite phrases actually show a lack empathy. You've noticed I stopped talking of *cases* or *subjects*. That's an improvement.

There's an aspect of the professional's life that rightly dominates: accountability. I have to record everything in triplicate. There's a culture of fear that easily grows along with paperwork: if something goes wrong and my name is the last recorded point of contact, what I did and who I am will be questioned. I could be hung out to dry. Thank goodness we professionals rarely are held to account.

We have no magic solution. This is why often my colleagues and I prefer to be distant and indifferent, because we'd rather be a little impersonal than devastated. I can't fix disability and I can't mend broken hearts or marriages. (Though I can make a referral.)

I'm sorry if it feels to you that I expect crumbs from the captain's table to suffice. It makes me feel crumbly, too. I can seek to mend the barriers to good person-centred work by challenging how we organise things, but you know what hierarchies are like. (They make us all stupid.) I can work to give you what you need rather than simply manage your expectations. I can be honest and try to not speak in a strange language at you. Finally, I can learn to pass on to you freely what my training and experience, my clinical intuition, have taught me, because you need these ideas each day.

When you ask me what you should be doing, perhaps out of self-doubt or fear, perhaps out of respect for my reputation, my job role or my qualification, I have learned to say, *“I’m sorry, I haven’t a clue. I don’t know the person. Not yet. But together we might come up with some ideas.”*

About Families: A Letter to Professionals

Dear Professional

We know you’re busy so will keep this letter short and sweet, a little like your attention. Thanks for asking how we’re doing. That stopped us in our tracks. We’re so caught up in doing everyday things well - it feels we have to be better than any other family, just to pass muster - that when you asked us, we laughed. We hope you were not offended. Such questions are rare – time is an endangered species in your world – and it surprised us to hear someone in your position ask how we are doing as a couple and as a family.

Have you seen the signs at the train station that warn commuters to ‘mind the gap’? We’ve joked about putting that sign on our front door. This family is moving at colossal speed and each appointment with professionals feels like a sudden stop to let a passenger join us for a moment. Mind the gap. Off we go.

We're very grateful for our child; we get tired and irritable: we become frustrated trying to get people to keep their promises and make human decisions, and we're sorry if you seem to get it in the ear. We've been waiting for the things you said we should experience - trauma and the 'bereavement of disability', but eleven years in and we're tired and (sometimes) a little beaten but we are not out and certainly do not regret the gift that is our fierce and beautiful daughter. I know she's difficult not to hear but she's easy to ignore.

What we want – as a family – is us: warts and all, challenging behaviour and disability. We'd like more time for us to be together, but who wouldn't? What we want *from you* is for you to be able to stand by us. We want you to be able to listen and pull us up short or give us advice when we need it. We want neither rocket science answers nor vagueness, neither critiques nor hints of wrongdoing. Talk to us normally. Be honest. No side-stepping, no avoidance. We want practical help when we need it: perhaps another pair of hands, a holiday, time for the other kids. We want to be able to speak to a competent someone when we need practical advice, or when we want to celebrate successes, or share our fears, or say *this is a bit shit right now*.

We sense the potential for us to fall into isolation. The very people whose job it is to make life easier often make it harder because of the way they work. Sometimes it feels the education system is designed to frustrate *everybody*. I'm sure you meet utterly horrible people. And some of them are in families and some are in professions.⁷ This is too important to make much of personal affronts. Get over yourself and get off our case, get on our side.

The last time we met you had a student with you. We were asked if there was anything we would like to tell him. Tell him we'll welcome him based on his value to us as a family not because of his qualification. Respect has to be earned with each visit and with every letter. Respect is not awarded in perpetuity along with his doctorate. When he finishes his studies tell him that he will be a centaur: a half human and half professional creature that parents and people with intellectual disabilities will rely on. Tell him to remember that ultimately it is we – our daughter and her parents – who pay his ridiculous salary.

Tell him that numbers are important but it is stories people learn from. Loving someone whose behaviour challenges is hard but also joyful: what he does can make or break us. Tell him he will be privileged to hear our stories. A child with a disability

⁷ The proportion of awful parents matches the proportion of awful professionals (Clements, 2013).

is a child with a future, and a family with a child with disabilities is always a family: we will never stop being our daughter's parents. Love does not disappear come diagnosis.

Tell him that what he counts may not count with us. What matters to families may not matter to his bosses when they measure his impact. This *will* lead to differences of opinions. He needs to learn not to take offence: he represents a sometimes heartless system. He needs to take it on the chin. He needs to 'mind the gap'. Tell him to remember that it takes families a lot to ask for help, but it takes very little for him to screw trust up.

Tell him that despite the promises of inclusive education and community care, discovering a person-centred professional who knows their stuff still counts as a remarkable event. Tell him the small things that matter for children and adults with disabilities are only small to him; to us they make a significant difference. Tell him we are the experts: he is just someone who knows stuff. He doesn't know us.

Tell him to come to our house at 9pm when things are not going well. Tell him to visit us at 4.30am when our daughter is up with the larks and laughing at the pillows tumbling over our heads. Tell him to sit with her when she is screaming and frightened by a world she does not understand, and the cruelty she experiences

everyday from people who should know better. Tell him life is not just or fair, and tell him not to add to the injustice. And if he can bring us a cup of coffee on his way up, he will be most welcome.

Tell him to remember our daughter has a name; she is fully qualified as a human and she is very much loved. And she loves us fiercely.

Key Points From *Working Together of Pulling Apart*

- Challenging behaviour is often difficult for one person to understand
- Sharing our knowledge with others requires us to trust them
- Not only must we feel we are taken seriously, we must take others seriously
- Solutions are often negotiated from different perspectives
- A busy professional can often come across as not listening
- A busy family can often be perceived as challenging, when all they really want is good support