

Point of view: parent

The difficult parent

Judith Hooper looks behind the label at the reality of parenting a child with SEN

I am sitting in a meeting. Around the table is a team of fellow professionals: physios, speech therapists, OTs and psychologists. They have been talking about a parent of a young woman with learning disabilities. The parent has just been described as “difficult”, “over-attached”, “unable to let go” and “interfering”. I hear these words and I take no action.

Two decades on, I am sitting in a workshop. Around the table are fellow parents of children with additional needs. No longer part of the professional team, I am now a member of the parental team. Several of these parents have described themselves, confidently, as “difficult parents”. And this sets me thinking – if we peel off the label, who might the person behind it actually be? Who is the “difficult parent” of a child with additional needs?

1. A parent who is fully in touch with the weight of their responsibility towards their child.
2. A parent who knows that they are, and probably always will be, their child’s advocate and ambassador in the world.
3. A parent who wakes up in the middle of the night thinking: *What will happen to my child when I’m dead? Will they be safe and happy? Will someone abuse or take advantage of them? What will happen if they can’t look after themselves?*
4. A parent who may well, like myself and my husband, have been told that their child’s

prognosis will depend on how committed they are as parents, and how determined they are to practise therapeutic recommendations and provide the requisite support.

5. A parent who had not necessarily expected to be leading this life. They may have assumed, like most parents, that they would be taking their child to scouts, football practice, ballet or playdates with friends. In reality, they are taking them to appointments with neurologists, paediatricians, OTs and physios; they are preparing them for operations and MRI scans.

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Most people want to be liked. But the difficult parent is willing to take the risk of not being liked because their child needs them to, however uncomfortable that makes them feel. If they make a suggestion, check something out or follow something up, they are not trying to undermine professionals. They are trying to ensure their child gets what they need. Sometimes they notice things that other people don’t.

Most of us hate having to intervene at any level. The worry about how to approach a professional may keep us

awake at night. We do not raise issues lightly and there is no handbook. We have to learn from our mistakes. This sometimes upsets professionals and makes them dislike us. A parent may have experienced painful encounters with professionals – medical or educational or from social services – in the past, and may be carrying the memory of these nightmare encounters like a tortoise carries its shell. Nine years ago, I was told by a medical professional that I had been irresponsible because I had temporarily accepted the assurances of another medical professional that our daughter was fine. That accusation changed me. It forces me now to listen more acutely to my instincts. This sometimes makes me very annoying.

In theory, a professional can shut the door at the end of the day and get on with their life. A parent of a child with additional needs can’t do that. They are on call 24 hours a day for the rest of their lives.

A difficult parent may be grieving the life they expected their child, and their family, to lead. A difficult parent may not have slept much in many years. A difficult parent may be determined that their child will live the richest, fullest possible life and be encouraged to show the world who they really are.

If that’s the sort of parent I have to be, then so be it. Had I known this two decades ago, I would have stood up in that meeting and defended that “difficult parent”. Now, I understand. **SEN**