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Parents of vulnerable adults deserve a voice

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Appalling abuse of people in care shows how powerless their families are

Those of us with children who will never be capable of looking after themselves – and therefore will probably at some stage come under the care of the state – have had a week of horror. Last weekend it emerged that Walsall council had sought an injunction to silence the father of a profoundly autistic 17-year-old called Bethany, who had been kept for two years in a hospital “seclusion room” 10ft by 12ft.

Jeremy – we know only the father’s first name – said she “was falling apart in front of my eyes”. He claimed his only permitted communication with his daughter had been by kneeling down to talk through her tiny room’s metal hatch. Walsall insisted that its attempt to gag the father (who had been using social media to complain about her treatment) was not to shield itself from criticism, but to prevent the child from being identified. Whatever the reason, Mencap successfully took up the father’s case, which is why we know about it.

Then on Wednesday, *The Times* broke a scarcely credible story about the state’s treatment of another person described as “autistic and with severe learning difficulties” – in this case a 23-year-old, and therefore an adult. The unnamed Manchester woman, said to have an IQ of 52, was, according to *The Times*’s chief investigative reporter, Andrew Norfolk, “repeatedly exploited during a court-approved two-month trial period this summer in which random men were permitted to visit her Manchester care home between 10 am and 4pm each day”. In effect, the family says, this woman with profound lifelong learning difficulties was being pimped.

This was not some self-conscious act of wickedness on the authorities’ part: they genuinely believed they were acting for the best, amazing though that may seem. The woman had in her childhood repeatedly left home, to be subjected, according to the court report, to rapes and “sexual violations” by men, “particularly Asian men”, in whom she had developed an obsessive interest. “Socially inappropriate behaviour was seen every time she was with men.”

As an adult, but still in the care of the authorities, she continued to show this behaviour. And so, with the full consent of a court, it was decided to allow a steady stream of men (many of whom she didn’t know) to visit her, on the grounds that this might – in the opinion of a psychologist – help her “learn

from her mistakes”. I wonder what part of “severe lifelong learning disabilities” that psychologist, and that court, didn’t understand.

The system, at least, corrected its own conduct. A second expert, Dr Christopher Ince, a psychiatrist specialising in autism, offered the advice that should never have been necessary: that the court-approved plan was “inherently dangerous”. The woman was unable to assess any risks posed by these men. There was no evidence that she would be able to “learn from her mistakes”.

Her aunt, with whom the woman had lived until taken into care as a teenager, told *The Times* she felt “betrayed and so, so angry ... what they allowed to take place this summer made me feel sick ... it’s heartbreaking and disgusting.”

This is only an extreme and grotesque example of a wider problem, which concerns all parents of those without what the courts call “capacity”: that when the state takes charge, little or no respect is paid to the insights of those who know the individual best: the family. Instead, potentially life-altering decisions are taken by an ever-changing flow of social workers, sometimes without their even having met the person whose care is being decided.

So a group of three concerned mothers, including my wife (we have a 23-year-old daughter with Down’s syndrome), is bringing a court case to change the way the law is administered. There is provision under the Mental Capacity Act for a “welfare deputy” to be appointed; such a person is appointed to make significant decisions involving the person under the court’s protection. But the code of practice that the local authorities use to interpret the act states that only in the “most difficult cases” will a deputy be appointed.

In the words of the three mothers’ crowdfunding appeal (which rapidly raised

sufficient funds to contest the case): “We will argue that, rather than appointing a deputy in only the most difficult cases, the court should adopt a test that flows directly from the Mental Capacity Act and generally assume that it is in the dependent’s best interests to appoint a deputy from among his or her close family.”

The mothers’ case is being prepared by Alex Rook of Irwin Mitchell, a remarkable solicitor whose legal practice is dedicated to the protection of those with severe learning difficulties. Overcoming all hurdles to date, his efforts have ensured the case will be heard by Mr Justice Hayden, the vice-president of the Court of Protection, in a month’s time.

I’m not qualified to assess the legal arguments. But even if I were not the husband of one of the parties to the case, and, of course, the father of a woman for whom it is potentially vital, I would be persuaded by the moral clarity of their claim: “Our children, now young adults, have learning disabilities and lack the mental capacity to make important life decisions for themselves. We love our children and need to continue to take care of them and make decisions about their welfare. We find it unbelievable that now they have become adults we have lost that right.”

This is not a blanket criticism of those who care for these adults “without capacity”, who require special skills and temperament. As Caroline Hopton, who has two sons with autism (and is one of the three mothers bringing the case), said to me: “There are some truly fantastic support workers.” But she continued: “They are about one in every 20, and they move on. The rest are not fantastic.”

In the local-authority care home where one of her sons was placed “there were many [staff] who lacked the ability and caring nature to assist vulnerable people. Over an extended period of time I raised my concern, but to no avail. A series of dreadful events ensued, including maltreatment of my son, attacks on him and serious unexplained bruising, which culminated in a police investigation.”

Giving mothers such as Caroline a legal right to be the decision maker about significant changes in their children’s care cannot altogether prevent such abuse. But it will give those parents an authority within the system that they currently lack. Who better to understand what a vulnerable and possibly wordless person might need or be thinking? Not the state alone, which as Nietzsche pointed out, can be “the coldest of all cold monsters”.
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