

Families sidelined by law on over-18s with learning disabilities

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Parents of children with autism and other learning disabilities want to use a test case to challenge a law that sidelines families when a child turns 18.

Rosa Monckton, whose daughter, Domenica, 23, has Down's syndrome, said that although the children might technically be young adults, they lack the mental capacity to make key decisions.

Monckton said she had heard from "hundreds" of distraught families who had been ignored as officials made "terrible decisions" for their children.

Under the Mental Capacity Act 2005, parents who want to be the decision maker for a young adult must ask the Court of Protection for "deputyship" – awarded only in very difficult cases.

Monckton and two others want the presumption to favour parents, or siblings if they die. "The 2005 act was designed to protect people heading off into Alzheimer's; nobody thought about its impact on people who never had capacity in the first place," she said.

Another parent, Caroline Hopton, is a single parent of two sons with autism. She is seeking deputyship over her younger son, 18, whose treatment in residential care "shook her to her core" and is being investigated by police.

The parents are being advised by Alex Rook, a partner at Irwin Mitchell. They are trying to raise £10,000, via the CrowdJustice website. By yesterday they had raised £6,030.

Rook said their case could be listed two months after the money is raised.

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