



Our son was born 30 years ago and had the devastating diagnosis of severe autism and learning disabilities at the age of two. This was followed by epilepsy, complex sensory sensitivities, self injurious behaviour and a helping of ADHD. Life has been a challenge for him and also his family.

Given his wide-ranging needs we naively thought that guidance and support would be a given but as with most individuals and their families in our situation, cruel reality stepped in. I will not go into all the battles endured to get services that our son was entitled to, just that the many experiences along the way gave us the wisdom to know that ultimately, professionals are just passing through, we would in all likelihood, be living our son's life with him 24/7 and 365 days a year, every year.

I purport to be an expert of nothing, certainly not autism, but I am the nearest to being an expert on our son who finds communication extremely difficult, choices stressful and daily life a challenge.

We did the courses, his father retrained as a teacher specialising in Special Educational Needs and we have a library exceeding 300 books on autism and related disabilities. You could say we have dedicated our lives to supporting our youngest son.

So it is galling to be lectured by "professionals" who have never met our son, telling him what his best life could be. Frankly we have had a lifetime of being lectured to by people who clearly have limited awareness of what our son is like and what he would want.

From the off we supported our son to be "included". He went to a "special" playgroup, he went to a local nursery. He went to a primary school with a specialist autism class attached (one of the first in the country). What became abundantly clear as time went on, was that E didn't want to be "included" in the way, others felt he should. As an experienced teacher observed "he does have the right to not be included".

And this is precisely the life he has led. It is the nearest he gets to clearly expressing his choice. He went to a specialist autism-specific secondary school where he absolutely blossomed and was, as the deputy headteacher said "The square peg in the square hole".

He did so well that he went to a non-autism specialist college, where he did not so well but we were trying to give him the experiences that those without his level of need enjoyed. We had clung to the notion of being like everyone else, despite it being patently obvious that our son really wasn't like your average 20 year old.

Every parent in our situation will know that ever present dread of what happens when X leaves Y, what happens next, where will they go, where might they be happy, settled and content? For someone like E this is all that matters as when he is unhappy his distress is overwhelming, for him and anyone witnessing it. We have to make sure we get it right, because his only means of expressing when it goes wrong is devastating. He cannot communicate how he might be badly treated, bored, isolated and frustrated. He will bottle up and endure the misery for it to all explode. We live with the shadow that if it goes wrong, E will potentially find himself in the criminal justice system, mental health services including an Assessment and Treatment Unit. None of which he needs or deserves.

So every move has been carefully plotted taking along people who know E best and have had a positive effect in his life. That should be all it takes but unfortunately, other people know best and this is not all about money but instead a dogmatic, unyielding viewpoint that can be catastrophic for the most vulnerable. Those that aren't interested in having their own front door, living in an ordinary street, going shopping locally, getting the bus to college or a day centre, or (as was said to us) choosing their own utility supplier!

We had in mind E spending most of his adult life in some sort of intentional community in a rural setting. We knew he thrived in open, quiet spaces where he released everything going on in his head. He needs space as he has complex sensory issues that means he paces, jumps, flaps and makes lots of noise but of course is totally intolerant of anyone else doing exactly the same thing.

In around 2000 a report was published citing that Intentional communities could be very positive for people like E and we thought that there might be hope in finding somewhere like that for him. Gradually these fell out of favour with the powers that be and the focus was supported living in the community. The ever benign community where people obviously very different are welcomed with open arms, where abuse and exploitation never happens and individuals can live the life they want. Except that many don't. I couldn't think of anything worse than to be living in an average house with people you have never chosen to live with, who may frighten you, where you are reliant on staff availability and access to a car to get you out of the house and where lounging at home is the norm as allegedly you are making the choice to be there with the telly on.

Residential care is in crisis but don't let's kid ourselves that thousands of people in supported living in the community aren't leading chronically impoverished lives too.

Bad care happens everywhere as does good and for families like us, we play the odds as to trying to find what would suit E given that there will always need to be compromise. This is the reality.

Our son was living pretty happily in a large residential setting surrounded by beautiful, expansive grounds, a godsend during the pandemic and where none of the 14 residents caught Covid due to the dedication of front line staff. The compromise was the poor state of the buildings, forever being promised for redevelopment by the national charity that "puts individuals at the centre of all they do". Except they didn't, the investment never came while the reserves swelled and closure was inevitable because this was an "outmoded model of care" – whatever that means. This despite the home being judged by the CQC as providing good quality care, support with a positive culture. It took the CQC until 2020 to realise these requirements should be the arbiter of care rather than the size, location and number of people living there. But the damage had already been done. The CQC had been denying choice by back door means, homes could only be registered if they fulfilled their recommendations specifically concerning size and location.

At his previous home in the country, E could be moved to another bedroom where he could indulge his routines without interfering with others but he was not isolated. He still had housemates, some he liked and others less so, but space made that easier to manage, the house was that big. The idea that large houses will be built or maintained for people like E who need that level of space is against all recent care recommendations.

Rural settings are not recommended either as they are isolated. Our son's rural setting that suited him has closed, no doubt the land is worth a lot but he won't be benefitting from it. The irony is that we left the city to live nearer to him at his care home. We chose to do so because we wanted peace and calm, rather like him but we could make that choice. Our son, however, is denied this.

So he has come home to live with his parents as there were no other alternatives. The peaceful retirement has gone and we have our son here supported by a team of Personal Assistants, carefully recruited by us. They are striving hard to ensure he is "included" on his terms. It is demanding and stressful with a lot of commitment from everyone and it is not a solution for

everybody nor can it be long term. The clock is ticking for my husband and I and what will happen when we are not there?

In conclusion, I am not against supported living and it works brilliantly for some people with the right alchemy of staff, commitment, location, type of house and housemates. But we have been around in the care game long enough to see the pitfalls for individuals like our son. A regular tweeter, Autism Care and Share, documents the life of his adult son and it is a lovely positive thread. R lives at home with his family and his dad posts about his days. But he stated the caveat "We do what's right for R, not anyone else". We take a similar view. E is not a conventional person, why would he choose to live a conventional life?

Another recent media piece, "We are England – Farming on the spectrum" BBC 1 told the story of life on Pennyhooks farm in rural Oxfordshire. They plan to provide live-in accommodation and we wondered how the CQC charged with registering services will approach this setting. It is rural, isolated and certainly not in the community. Yet the reaction to the programme and particularly the individuals involved was overwhelmingly positive. For families like us, it offers hope that a more enlightened future may dawn, where choice is meaningful, where variety is the spice of life and lives can be well-led in all sorts of places.