



# Ben

*Years of being misunderstood led to one failed placement after another before Ben was eventually sectioned age 29 and spent 3 years in an ATU. His first supported living placement was too unstructured with serious repercussions for Ben's health and wellbeing. Under the Care Act 2014, Ben's family now manages his community care package. Their commitment, combined with new understanding of what approaches would be helpful following Ben's PDA diagnosis, has resulted in an amazing quality of life that no one would previously have thought possible. Ben's sister shares his story ...*

After years of struggling with being labelled as a naughty child and poor parenting being to blame, Ben was diagnosed with Asperger's aged 21.

Over the next eight years all local education, supported employment and day placements, along with all relevant learning disability and mental health respite, residential and support living settings in the vicinity, were tried and failed. Every placement was set up to fail because inappropriate strategies were being used that inflamed the situation, escalated Ben's anxiety and exacerbated his 'challenging behaviours'. His spikey profile meant that he seemed very capable on the surface, but he didn't have the skills to keep up with people's expectations.

Services showed him that he **didn't have a voice** despite telling him he did: he would sit at meetings pleading to leave and professionals wouldn't listen, forcing Ben to take the next course of action that life had taught him was effective. If you're physically violent your placement ends, you're immediately removed from the source of your anxiety and unhappiness to a police station, and then your family comes to rescue you as there are no other options that aren't 400 miles away in a secure facility.

Eventually the **placements dried up** along with social care and health's tolerance of a situation they couldn't comprehend, and Ben's family were told that one final placement was the last on offer and that they shouldn't 'save' him from this as it had to work. And so Ben was left in the police station the next time his plea for his placement to be changed was ignored and, with all other options exhausted, he had decided to hit out at a staff member. Ben was taken under Section 2 of the Mental Health Act to an in-patient ATU (Assessment and Treatment Unit). This is where he remained as a voluntary patient for the next three years as there were no other options available.

When he was being discharged from the ATU, a recently qualified psychologist who had worked at the Elizabeth Newson Centre in Nottingham, identified that Ben presented with a PDA profile of autism and recommended that a different approach was required. This made complete sense for Ben's family, who could now see why all the previous placements had failed because his needs hadn't been properly understood or supported.

Ben moved on to a supported living placement on a 1:1 staff support ratio. After a long stay in the ATU, Ben had become quite institutionalised and his daily life had been restricted and tightly controlled. So the abrupt change to a supported living ethos, which promotes user choice and freedom, proved unsuccessful as Ben didn't have the capacity to understand the implications of his decisions. This had serious implications for his health and wellbeing. With a daily diet of junk food and fizzy drinks, his weight ballooned and cholesterol levels soared; with the freedom to sleep whenever he liked, his sleeping patterns became very irregular which jeopardised his work placement; and when he repeatedly ordered his support staff out of the room, he was left alone with spiralling mental health difficulties. This pattern continued for a further three years, with staffing levels upped to 2:1, resulting in an unhappy, uncooperative and un-communicative Ben.

Things changed after the Care Act 2014 came into effect and meant that Ben's family could take over his care package, using a combination of social services direct payments and a personal healthcare budget. This was a massive commitment and challenge for the family, who had to be on-call constantly and manage ten staff members at any one time in order to maintain the 2:1 staffing ratio 24/7 (absences or staff shortages also meant the family needed to step in themselves on many an occasion).

However, Ben's quality of life improved dramatically, and local services have highly commended the successful formula his family has put in place. These are the key elements of that formula:

**Trust** - Ben must trust his staff team, the staff team must trust each other and the family must trust that the staff team will deliver the agreed support plan. Due to Ben's intelligence and ability to 'manipulate' situations to his own initial advantage but with probable negative long-term effects, trust in one another's judgement and instincts is essential. Equally important is an acceptance that not all eventualities can be foreseen, but that these occasions can be learned from and discussed with Ben before drawing a line in the sand.

**Communication** – Years of being misunderstood and ignored led Ben to conclude that challenging behaviour is the most effective communication tool as it produces instant results. It took his family a long time to build up his trust and help him to see that verbal communication is just as effective and far less damaging for all concerned. Everyone involved has taken great delight in seeing these skills develop again in Ben and to see the communication blossoming between him and his team. Likewise his team has become adept at picking up any slight increase in Ben's anxiety and working to reduce the stressors.

**Structure** – Ben craves background structure to enable him to feel secure. Menus, staff rotas and schedules are meticulously planned and adhered to, as deviations cause Ben to have a steep rise in anxiety. However, in the event of increased anxiety

from other sources, it is essential to be able negotiate these structures to give Ben some control.

**Limited choices** – Ben needs limited choices, handpicked by people who know him very well, with in-built flexibility for adjustment based on his anxiety levels. For instance, on a pub night he has two options on his planner: a quiet, low arousal, low demand pub and a loud, all singing, all dancing alternative. In this way, Ben has the required structure of a defined pub night but he can choose which pub to go to, based on his sensory needs, anxiety levels and ability to cope with demands on the day, or always has the option to stay in if he prefers. His level of engagement on pub night will also vary: sometimes he doesn't feel able to order his own drinks and needs both staff members to sit with him in a familiar local pub; on other occasions he might go out with just one member of staff, order his own drink and sit away from the staff member listening to a live band.

Ben has been assessed as having **fluctuating capacity under the Mental Capacity Act**. Working closely with health and social care, his family has been able to agree **deprivation of liberties (DOLS) through the Court of Protection** which are both in Ben's best interests and provide protection for staff. Sometimes Ben's anxiety levels result in cognitive impairment such that, even with specialist adaptations in place, he is unable to make informed safe choices and so the staff team must make them for him. However, the team and family doesn't take an overly risk adverse approach and sometimes support Ben in making 'unwise but safe' decisions when he has the capacity.

**Negotiation** – Ben has very enhanced negotiating skills and being able to 'barter' provides him with some control which in turn reduces his anxieties. His team has had to develop complex skills in relinquishing some control without losing total control. For example, his staff might write a list of household chores rather than verbally instructing him. This depersonalises the demand and provides a visual reminder, whilst giving him the control and flexibility to get the jobs done in whatever order and timescale he likes.

**Novelty and surprise** – Expectation demands leading up to outings or holidays tend to significantly increase anxiety, whereas Ben usually responds very positively to surprise treats or trips. Using this strategy, the team has supported Ben to achieve things that he would never have thought possible.

**Low demand times** – Ben isn't a morning person, so mornings tend to be kept as demand-free as possible. One staff member works with him using physical/visual prompts for the things that are part of his routine, for example his tablets are left at his bedside, his bowl is left next to the cereal packet etc.

**Transitions** - Ben struggles with transitions at the start or end of an activity and can become very anxious during the lead-up to an activity - even his favourite activity sometimes proves too much and this can often trigger a panic attack. His team discusses the transition phase and Ben's anxieties with him and provides relaxing, calming sensory input to support Ben in regulating his body and mood.

**Humour** – Humour can alleviate the vast majority of stressful situations for Ben. The ability to laugh and not take life too seriously is a must have for his staff team 😊

Ben's family estimate that the [cost of his care package is around one third of the cost of an ATU placement](#). Thanks to his family's commitment in managing his community care package, combined with implementing helpful approaches which meet his PDA needs, Ben now has an [amazing quality of life](#).

He lives in his own home in a village close to his extended family who he visits at least weekly. He is supported by a team of staff he helped to select. He works five days a week, enabled by a specialist support worker whose background is in the same trade. With his team's support, Ben does his own weekly food shop, visits his local pub once a week and watches live pub bands at the weekend. He goes to the gym and swims twice a week and enjoys local walks, heritage and wildlife. During summer months, Ben spends his spare time swimming at local beaches and escaping on surprise short breaks with his staff team.