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Our experience of managing a direct payment

I'm really sorry I can't be with you today, I was so looking forward to catching up with the many colleagues and dear friends who I know are there and meeting new people. As well as the fact that I'd bought a new frock!

Christopher is now 38 years old, he was diagnosed as autistic when he was just three years old, at that point they did not know the extent of his intellectual disability, but to us he was a tornado, a bundle of energy with a beautiful mop of blonde hair, who could keep going until the battery ran out, hopefully before ours did!

We were sent to Birmingham Children's Hospital to see a Consultant Psychiatrist and I asked him, what the future held for Christopher as he grew up and he said 'Bring him to me at 17 and I'll tell you what he'll be like at 18. My first reaction was 'thanks for nothing' then I realized that it was probably the best advice I was ever given, Firstly it was an honest appraisal of the knowledge base at the time, but more importantly he was saying don't over expect and don't limit him. From that day forward we tried to keep his voice in our heads. As it turned out Christopher's learning disability was significant. It was at times both exhausting and exhilarating, sometimes lonely as the gap widened between him and his peers and the invitations to parties started to dwindle. For his 5th birthday we hired a soft playroom and invited all his classmates from his special school as well as children of friends and family. I was going around videoing the merriment when I realised Christopher and his dad were not to be seen, I found them in the ball pool, Christopher was lying in his dads arms with his coat over his head, it was then I realized that this was not what Christopher wanted but was my idea of what he should have for his birthday. It was a steep learning curve but very quickly we became aware that we had to follow his lead and value what pleased him rather than what we thought we should give him. His sixth birthday was spent on a deserted beach eating his picnic as we were dive bombed by the local gull population, which Christopher found hilariously funny.

From then on it was expected that other folk fit into Christopher 's (and by default) our world, which was in fact quite liberating, His school career started with an exclusion from his special school, naively I didn't think that was possible but clearly they could not meet his needs, we looked around for somewhere that would suit our boy and found a local authority school for children aged three to nineteen with what at the time was moderate and severe learning disability, unusually it has an autism unit, our problem was it was in another county who said sorry we have enough kids of our own we can't accept him but the head was an amazing man who said he was sure he could accommodate our beautiful boy, so we sold out house drew a circle around the location of the school and bought a house in a village just outside of the town, after some negation with a pretty annoyed LA Christopher got back into school after a long nine month. They were true to their word and between them and us we managed to keep him In school till he was 18, it was at this time that we realized he could not tolerate people in his space unless they were invited in by him.

So what next? Serendipity intervened as a new life skills college for Autistic young people was opened 40 minutes away and Christopher became their first student, and had his own house, we had input into the training of his support team and I was lucky enough to have fabulous colleagues who gave their time for free to upskill the team, he came home at the weekend and all seemed well, but inevitably things didn't stay that way, it was sold to a hedge fund and 'fillings voids' became the aim. More students arrived and it was decided to move Christopher into a flat with his own bedsitting room and bathroom but communal spaces for sitting and eating, instinctively I knew that his would not work and Christoper became withdrawn and retreated to his bathroom with a towel over his head, he began to lose interest in food and his tics became more pronounced, we tried to work with the college but we knew it was a lost cause, in May of 2010 his dad's 60th birthday we took Christopher to our friend's holiday home on the coast and we sat on the beach with him the inevitable towel on his head and his chest was covered in nicks where had been digging his nails in and his dad said 'we cant take him back can we'? I was so relieved, he said he'd retire and take the job of being at home with Christopher. We nurtured him back to health, at times following him round, spoon feeding him just to get the calories into him. His dad took him for a picnic everyday and walked in the fresh air we removed any pressure from him and gave him his longed for structure and routine.

We realized that congregate living was not for our boy, he needed to be in his own home with a team around him. I said the only way we could guarantee this would not happen again was to ask for a direct payment and arrange the care ourselves. For the second time serendipity intervened and our local authority was one of the pilot authorities making direct payments and had some very keen individuals within social services wanting it to work. It was unusual for a direct payment be given for such a large package but they felt that we were capable of running such a high cost budget and agreed to fund him one to one 24 hours a day as long as we agreed to run the service and act as emergency back up in times of staff holidays, sickness and the inevitable crisis etc, I don't think at that time we appreciated the enormity of the commitment, but we were just relieved that we got the funding. Our next hurdle was find him a suitable home and yes you've guessed it our old friend Serendipity intervened for a third time and I saw that for the first time in 15 years they were building social housing in the form of a pair of semi detached bungalows specifically for people with disabilities in our village in fact just a few hundred yards from our house. Amazingly he was allocated one of them. Now the hard work began, recruiting staff was the first job, we didn't have to advertise as four of his support staff from the college asked to come and work with him. The administration was down to me with a payroll service provided by a charity set up by the local authority. Again my lovely colleagues were on hand to help with training etc. and we slowly transitioned Christopher into his new home. He christened it 'The Shed' as on his first visit he ran through the bungalow into the garden and shut himself in the garden shed. It is still referred to as the shed which does take some explaining to those who really do think he lives in a small wooden structure! I would like to say this was a happy ever after story but the reality is that Christopher still experienced anxiety, sensory overload and bouts of self-injury but we are able to manage it in a sensitive person centred way by working to the SPELL principles of providing structure and predictability, engendering a positive attitude and empathy within the staff team, using the low arousal approach at all times and linking him with his community. We keep it simple – we rent a pool he can splash about in a couple of times a week, we have many walks where he can go on a hike after his picnic. The staff team is stable with the longest serving members having known him for nearly twenty years and eight years respectively with the two newest recruits having been with him for 4 years.

But I don't want you to think it's all rainbows and unicorns Getting him into his own home was just the beginning, this is not without its challenges, managing staff, dealing with finances and services can be daunting. Christopher has many challenges and the winter months when he dips considerably can be exhausting for all, this is when the enormity of the responsibility we have taken on hits home. This is when we make sure we support the staff so they can give their best to Christopher. We don't allow double shifts, as we don't want burned out staff, we don't need to employ agency staff as that would be disastrous for Christopher, So for his dad and I we have had to adjust our lives to accommodate him. But we feel that if we did not do this Christopher would be in danger of ending up in a service that purported to be 'Autism specialist' which in my experience is often akin to the emperor's new clothes. passed from hedge fund to hedge fund with a change of name and when it all inevitably went wrong, he would end up languishing in an ATU where we are sure his life would be miserable. We cannot contemplate that and so we do what we do, we have a good life with great family and friends, entertain a lot at home and quaffing the odd glass of wine , and I am in a great position of being able to still work in a job I am passionate about.

So what next? as we get older we have become more aware that we are not going to be around forever and it is this thought that hits me in those middle of the night moments and fills me with dread, but I have come to the conclusion that there is no resolution to this, we are inevitably going to die and so I need to make sure that we pass the baton on to the next generation and that means nurturing relationships with younger members of the family. All the practical bases are covered, we have a discretionary trust set up with two of his cousins, both very capable young women as trustees, they know what it is we want for our boy. I have to be hopeful that the life he has now can be maintained but I cannot guarantee it, and so remains my biggest fear, that our son will end his days without anyone linking him to his past and understanding where he came from and how much he was loved. Successfully addressing this fear is still work in progress.

Linda Woodcock

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