L’s Story So Far…….

December 2021

L is the eldest of three children and was diagnosed with High Functioning Autism (a label we no longer use in the autism world for good reason) at the age of 7. He was later also diagnosed with ADHD and severe Dyslexia.

L attended Greenbank School, a LA special school, and left with no formal qualifications. He then attended Reaseheath College which wasn’t without its issues, and finally enrolled on a Supported Internship with Total People involving a work placement at a social enterprise in Winsford. This was a really successful year for L. Having lost a lot of confidence at Reaseheath, he really found his feet and gained in knowledge and independence. He ended with Entry Level 3 qualifications in Maths and English. The social enterprise confirmed that they were happy for L to stay on with them, BUT they rightly pointed out the level of supervision L needed. L volunteering there was not without cost to them, and I understood that. Between myself, the social enterprise staff, Total People and L’s Social Worker we made a case for his continued placement to be funded. I made the case that the alternative was day services, at a higher cost. The ‘paid placement’ was agreed.

Three years later and L still ‘works’ 3 days a week at the social enterprise. He has moved from initially working in the kitchen, to working in the warehouse. The team are the nearest thing he has to friends, and are a valuable constant in his life. He continues to learn and has trained in lifting and handling, so at busy times he can help with loading and unloading the vans. He has learned how to ‘banter’ with the other lads in the warehouse, and is a valued member of the team. However, to be clear - he still needs a lot of supervision, and in particular often needs a lot of pastoral support to maintain his mental health and wellbeing. Some people would undoubtedly say (and some have) that after 3 years, shouldn’t he be getting paid? I would say absolutely not. The staff invest a lot of time and effort in L, at a cost to them, and I would argue strongly that they deserve the modest payment they receive to support him.

Once L was settled in his volunteering role we started to investigate supported living with his Social Worker. L had always maintained that he didn’t want to share a house, he wanted his own place. This would have been unusual previously, and seen as an expensive option. By the time he got to 22, he was still saying the same thing, so that was what we asked for. We were shocked when only 6 weeks later, a new build facility in Winsford was suggested. This would be a flat of his own in a block of 12, with assessed 1-1 support and an office which would be manned 24 hours a day, 7 days a week. We went to visit. L went from being scared at the prospect of leaving home, to excited. The care provider visited and assessed his needs, the package of care was agreed and he was offered a place. He needed to furnish the flat himself , and arrange his own utilities - fortunately Mum had anticipated this and had slowly saved a small nest egg, so he was able to choose furnishings, curtains, curtain poles, blinds and bedding of his choice. He then spent 6 months planning routines, practising cooking, and checking costs, spending many many hours pouring over minute details (as autistic adults do) with his Dad. Covid hit, but the move went ahead - not ideal but he got on with it.

After he moved in, there were a few initial wobbles and then he settled into a routine. Care staff helped with cleaning, laundry, cooking, food planning, shopping, finding a gym and martial arts classes (very important to L) and supported visits to Opticians, Doctor and Dentist. All seemed well, so Mum and Dad, seeing him safe and happy, finally felt able to put their house on the market and complete a much wanted move a little further south. This meant that they were now 50 minutes away rather than 10 minutes.

Then the pressure started - Care staff didn’t turn up if they were short staffed (clearly because L was seen as fairly capable compared to others in the setting). They started to pressurise L to do his weekly food shopping alone (and the term pressurise is used with no apology, that was exactly what happened). L made many distressed phone calls home. They then also asked for him to keep his own bank card (they had previously held it and supervised him using it), L started to seriously wobble. Staff at the social enterprise expressed concern to Mum. Mum and Dad had to ‘talk him down’ from major meltdowns regularly, twice they had to drive over when he threatened to harm himself, and staff couldn’t be reached. Then L reluctantly revealed to his Dad that he’d been to the Doctors and was taking medication - he didn’t know what it was. Mum was able to eventually coax out of him that he had been diagnosed with acute anxiety, and a photo confirmed that he had been prescribed Sertraline.

Over the first 6 months L also ran up debt of £900 with his electricity provider. Mum and Dad couldn’t understand how he was using so much, and asked the care staff to help - they didn’t. They then asked the housing provider to look into it. After 6 months of stalling and excuses, they gave up and investigated themselves. It is possible that the heating and water systems were not timed properly, and certainly correcting the timers helped, but both timers were incredibly complicated - it took Mum and Dad hours to work them out. It begged the question, who would have sorted that if Mum and Dad hadn’t intervened? Mum paid off £600 of the bill, but L still pays £189 per month for electricity in a 1 bedroomed flat. His care staff and housing provider remain uninterested.

The pressure continued, his level of care was steadily reduced, and eventually he was told that he was too ‘capable’ to stay, and would need to move into social housing. L’s anxiety spiked again and his medication was increased.

This is where we are today. L is only stable because he is medicated. He loves his flat, which he spent considerable money furnishing, only to be told he has to leave. He values his ‘independence’, but how independent is he really? Let’s have a look…..

- The ‘progression model’ has been applied aggressively to the point where it has damaged his mental health. He has been pushed to do things independently that he is neither practically or emotionally ready to do.

- How capable is he really? He has rote learned how to do various aspects of managing his flat and life - but if one minor thing changes, he can’t deal with it. Like most people with autism, he is only able to complete tasks if absolutely everything goes to plan.

- The care provider has ‘bigged up’ L’s ability so much, that L is now convinced that having care is a bad thing. No matter how much he may need it.

- L is fairly articulate, which gives an impression of ability. Those who know him well, and understand autism, know that it is a dangerous facade - masking anxiety and extreme vulnerability.

- L would never have managed the heating issue alone, and would have no idea of mounting debt. He has no idea what utilities are, or how they’re paid.

- L has no idea what his income is, or what budget he has for anything.

- L now shops alone. He enjoys cooking, and is obsessed with healthy eating, but as his literacy is so poor, following a recipe and making a shopping list takes hours. It regularly involves phone calls to Mum and Dad to decipher words he can’t read, or doesn’t understand. BUT apparently he needs no support for shopping/cooking! Since this support was removed his food bill has increased dramatically, as he has no idea of relative value. He will buy the first thing he recognises, often choosing the most expensive option, or an overly large size. A recent recipe which required 200g of flour, resulted in him buying 1.5kg of premium quality flour.

- Since moving into the supported setting L has never spent time with a friend. There has been no attempt to socialise the residents. He has never been taken out to a cinema, the pub, bowling, or his favourite Jodrell Bank.

- L’s is obsessed with health, healthy eating and fitness. Whilst the staff initially helped him to engage with the local gym and martial arts centre, nobody has ever discussed budgets with him. Gym membership, Martial Arts classes, fresh healthy food, sports massages (he can struggle with back and leg pain) and sports equipment, accompanied by his eye watering electricity bill, mean he is only just keeping his head above water financially. Without Mum’s constant monitoring he would be in significant debt.

- L can’t buy clothes or household goods unsupported.

- L can’t deal with any change in routine, and any domestic failure eg: no water, or heating failure leads to instant and extreme panic.

- L is desperate for friends, and would do anything to get them. This leaves him extremely vulnerable. Despite the concept of cuckooing being explained to him, along with the risks of lending money - there is no doubt he would easily be persuaded to do either, and then hide it from Mum and Dad.

- L is able to make a Doctor’s appointment, and has learned how to order a repeat prescription. He does not understand how different medication may interact, and if distressed or confused for any reason, may take medication twice or not at all. He is no longer supervised taking his medication.

- If L attends the Doctor for a new reason or illness, he will not understand what he is being told, and will need support over a period of time to process and understand it. He does not always know what to do if he is ill. It was noticeable when Mum last visited that he has accumulated a large amount of paracetamol in his cupboard.

- L does nor generalise learning, so if he moves house, he will need to re-learn all the skills he has gained in a new environment.

- Potential social housing options are often in areas which are challenging, and L would soon be picked out as vulnerable and easy to target for abuse.

- Despite his care plan saying family will give no support, they are fielding daily phone calls, often numerous times a day, and having to drive to support him. Yet he is considered to be independent?

- When something goes wrong, he needs practical support at that moment - not a phone line. When distressed, he can’t communicate his needs clearly or process and follow instructions. He may only need small amounts of dedicated 1-1 support, but he does regularly need support ‘on-call’.

What should we consider and what options should we be developing for people like L?

- Recognise that ‘higher functioning’ autistic adults often present a facade of capability. This often results in them ending up in debt, being subject to abuse, or compromising their tenancies. Their needs are under-estimated.

- Pressure to live unsupported is overwhelming many young adults and leading to mental health issues.

- There needs to be a ‘step-down’ option from supported living, which provides a lower level of 1-1 care, but has a 24/7 on-call option - from a person, not a phone line.

- Protected communities of lower level care settings need to be developed. Similar to retirement village settings, a community perhaps gated, which gives adults their own front door and independence, but reduces vulnerability.

- The importance of supportive, understanding work placements cannot be underestimated. But we shouldn’t be expecting often small companies to be providing ‘free day services’, at a cost to themselves!

- Supported living can work well, but not when the support is reduced/removed - the support is what facilitates the independence in the first place. We shouldn’t be surprised when people end up in crisis when support is removed. This is no different than removing a wheelchair from someone because they can now get around independently!