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Social care has affected us positively and at other times frustrated our family. My son Jonathan is 22 and has a rare, life limiting and life threatening genetic condition called Lowe Syndrome which affects boys. There are only two families in Scotland that we know of with sons with Lowe.

The condition affects the eyes, brain and kidneys. Jonathan has multiple and profound learning disabilities, physical disability, is a part time wheelchair user, registered blind, has epilepsy, is doubly incontinent and has a lifelong kidney disorder called Fanconi syndrome, or renal tubular acidosis. He cannot read, write, count or speak. Developmentally he's like a toddler, but with big gaps in his skills. He requires 24/7 supervision and help with self care, eating, drinking, medication, playing, getting around, keeping safe, finances etc. When he turned 16, my husband and I got lifelong Legal Guardianship for both welfare and finances. We also have two daughters,

both carriers for the syndrome, one is 15 and one is 23. Jonathan, also known as the Bold Joff, is an absolute legend. I'm so proud of him.

When he was born we were living in Lossiemouth and services were good, we had plenty of therapists, he got a place at a pre-school developmental playgroup, we had occasional respite and were beginning to access residential respite through Aberlour Children's Trust.

However we moved to Fife when Jonathan was four, as we had no confidence in the proposed education services he was offered. This took us from an area we loved very much to one with no friends and family was at least an hour away, and cost us £30,000 in lost sale from our house, selling our car and renting privately until our house sold.

There have been two main hurdles with social care; getting into social care services in the first place and transition to adult services.

When our youngest was born, my husband was under threat of redundancy, so I approached social services to ask what options were available to help us if we couldn't pay our mortgage and were made homeless. They were spectacularly unhelpful but offered to put us on the list for respite care, meanwhile we were getting four hours a month respite from Crossroads Dunfermline.

The waiting period was incredibly stressful. We were allocated a social worker who we felt was mentally writing us off, telling us how lucky we were, and talking about other clients who had it so much worse than us. I would have withdrawn at that point but with two kids under 8, one profoundly disabled, and a baby, I was desperate for a break. Help from family was intermittent and dwindling as Jonathan got bigger and heavier to carry out moving and positioning. He developed epilepsy during that time. It was a really rotten and anxious period of our lives. At one point, my husband was threatening to go and live with his folks to push

us up the waiting list. We didn't feel listened to at all and had no idea how our case was being presented to the panel. We've normalised what it is to live with Lowe Syndrome, but what does the average social worker or funder understand what that feels like?

We finally got a place in Aberlour Children's Trust in Glenrothes but it took 22 months from referral to get in. Once in, we loved the service, one weekend in six during school terms and one week a year in the holidays. We continued with four hours a month from Crossroads too.

The next hurdle was transition into adult services. We wanted a day service and to continue with short break respite. The social worker had no experience of getting a family through transition which didn't give us confidence as we needed guidance and support. We were offered four services to look at but two weren't suitable for Jonathan.

We chose Leonard Cheshire in Rosyth, he's been there for four years now, and it's going really well. The funding wasn't released by the council until his last week of school, so that was incredibly worrying to have found a good place but not know if we could have the funding.

We were also funded to have short break respite, after a further five months. Jonathan gets 21 days a year residential respite, and like the day service, they don't follow school terms, so having year round services is very helpful. He usually gets the breaks in chunks of 2, 3 or 4 nights, most often midweek, whereas the children's service was always weekends. You can request specific dates and they try their best to accommodate that request.

The overarching concern is that councils are so stretched and getting worse that any of these services can be cut or withdrawn according to budgets or changing criteria. This is a perpetual worry now, at least with children's services, education service is mandated but nothing in adult services is set in stone. One thing I do feel has been helpful is having the Legal Guardianship, as I feel that it signals a legal incapacity that parents themselves don't have the weight to convey on their own.

Another element is the arrival of Self-directed Support. I totally buy into the principle of SDS and the many different ways of delivering it. I heard of many great examples of how people used personal budgets to live good lives. When Jonathan was leaving school, Fife Council had a pilot for SDS for children leaving school, but I was so overwhelmed by all the changes ahead I didn't press to get onto the pilot, which was deeply ironic and frustrating.

Now I think about SDS occasionally as it's now law, but fear asking for it in case it's used as a way to cut Jonathan's budget within commissioned services, which we are very happy with. I was given an example of, say, asking for a few days less a month either day service or short break respite, and using that money to help us get to the Lowe Syndrome International conferences in the USA. In principle that would be great but I fear they can turn round and say, well if you can manage with less of these services, we'll take them off you - without the extra budget being used for SDS reasons.

We talk very occasionally about the future, I've heard a few success stories of adults living independently with 24/7 carers. It worries us that one day we might be too frail or not here to care for him, and we try not to make our girls feel like Jonathan's carers. However, even if we went for independent living today, I fear it would take over a decade to get into place, leaving us still doing crisis management in the interim. And the system isn't robust enough to entrust Jonathan to it at the minute, if ever.