



## Zack & June's Story

“Whilst I’m letting go of some of the day-to-day management, it’s not creating the opportunity for me to have a better relationship on a mother-son basis.”



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**Interviewer: Addison**

**Addison:** Do you want to start by telling me a bit about your journey?

**June:** Okay? Here, do you wanna say this?

**Zack:** When I left school I had my transitions meeting and did a path. I said, "One of my dreams was to live in my own flat." To help me write the person-centred plan, Mum thought it would be good if I had a Circle support. So, we set one up. We went met once a month. We looked at my future and the choices I had to make.

**June:** So, I'm gonna just say a little bit, is that okay?

**Zack:** Yeah.

**June:** So, Zack was one of the first children to be on a Direct Payment. When Direct Payments were set up in the county, we were one of the first families that had a Direct Payment. That was put in place because Zack went to an out of county school placement. When he did his transition meeting he said he didn't want to go to school any more, he wanted to come back and live closer to us. Then we did this transition meeting and did a path where he identified that he didn't actually want to live with us long term, he wanted to live in his own flat.

His goals were to live independently within five years and to be as independent as possible. We've typed all his goals up. "To have a budget, to have his own car, to not have epilepsy, to have fully trained staff, to have advocacy, to work in a record shop." Zack! You can tick that box now! "To have relationships with friends and family."

So, because Zack had been at a school fully funded, when he came home they gave us around 60 hours of Direct Payments to cover us working because at that point in time we were both working parents, working full time. So, there was Zack and this lady who was running Circles Network. She set up the support. She was promoting Circles through Circles Network and she facilitated it. You read this bit.

**Zack:** How did I go forwards? Mum heard about the new project called Self-Direct Support, which we joined. As part of this they showed me different housing types.

**June:** So, this was after the LDP came out, after the transition meeting. We talked to Zack about the different housing options available. Then we went to visit some, didn't we?

**Zack:** I wanted to live near my family. We found out that there would be some flats, so I put my name down for one.

**June:** We identified that this whole estate was being built and on there was some social housing, specifically housing for the LDP. Zack was the first one on the list. This was just a plot of land when he first saw it. People used to bring him up here to see what was local. He did various things. Zack, we're just gonna read a bit more.

**Zack:** Together the people in my Circle of Support helped me do the things I wanted to do.

**June:** Yeah, so we still have Circle meetings. We did another path for him, "Where he was going and what he'd achieved." So, every year we try to revisit his person-centred plan and then that feeds into his support plan. He's PCP's pictorial because there isn't a connection between how the council want the support plan. Person-centred plans were originally supposed to be able to be written in any way that somebody could present it, whether it was a video or whatever. It should be the document on record but unfortunately it starts another process.

It isn't the document on record that's held by Social Services because they have to then put it into their format and every few years their format changes. I think it's partly to do with government legislation but it's also to keep everybody on their toes because if a form's the same every year then it's so easy just to duplicate it. So anyway, what's this say?

**Zack:** They helped me think about the future. We had lots of fun and worked as a team. They help me build my own personal-centred plan and review it each year.

**June:** Well done. So, we need to think about what kind of team Zack had because he's got 24/7 package. Circle of Support helps Zack do this.

**Addison:** Is Circle of Supports funded through Direct Payments?

**June:** No, that's not funded at all but it is a very good way of collaborative working. It helps someone with a learning disability or anybody who's trying to make decisions on their own but might find it harder to do it on their own than with a group of people, to give them ideas and thought processes.

It did take a long time for Zack because it was a two-year process. I wasn't involved in it because up until he was 18 I was his mother. I was making some of those big decisions for him, partly on what I understood Zack's likes and dislikes were. Some of the things I was taking into account were risks and historic things that had happened. However, I'm not of Zack's generation, he has his own likes and dislikes, he's a different gender to me, you know, all those natural differences. I couldn't bring those to the table. So, when we set up the Circle I purposefully stayed back and I was just hostess making the tea

and coffee. However, if somebody wanted to know when he was next going to the hospital I could fill in those gaps of knowledge.

What they would do was try to tease out of Zack how he would like to live, what he thought was important, you know and so forth. They did a huge piece of work and then they would come back every month and double check what he'd said the previous time, because some of the meetings he would be very sleepy and not able to really participate. Then another time he'd be full on and another time he wouldn't even attend. So, it'd be very hard.

In Control had this pilot promoting Self-Directed Support and I was aware that, within the policy frameworks they were moving people from Direct Payments to Self-Directed Support.

The reason why I took up Direct Payments was that I wanted to know that the person I was leaving Zack at home with when I went back out to work was somebody who knew Zack well and we weren't subject to that ever being someone different. If I'd let Social Services put the package together, then we had a strong chance of someone just arriving at the door because they were filling in for someone sick or someone who'd not gone through any kind of training and did not know Zack. He has very complicated and life-threatening epilepsy. At 18 he'd been in hospital quite a few times prior to him coming back. He'd had intense support at his school with experienced staff that I knew well and knew Zack well. So, we were going from that very comfortable situation to potentially having strangers arriving at our door every morning. So, I took the Direct Payment initially for staffing only and it was very rigid but at least I knew that the person arriving was someone that I trusted. Then we'd go out to work and come back.

Self-Directed Support came along in its original infancy. At the beginning when it was unchecked, it was just about the philosophy. It was about giving somebody some money to have their life and make their choices whatever they were and be in control of their lives better. At the very beginning obviously it was very very different. As long as it wasn't illegal, what you were doing with the money, as long as you weren't gambling it, then it was fine. Effectively you were given a free reign, which was very different to the Direct Payments. That meant that I could maybe have some staffing but if we felt that as a family we wanted to do some of the shifts, I could use that money for something else that Zack benefitted from and was part of his support plan.

So, it was a pilot that was run by In Control and it was the Self-Directed Support pilot. We worked with other families through the process and with their help we looked at what was required to get Zack a personal budget so Zack could live independently and fulfil his dream of living on his own. And, he did fulfil that. It would have been earlier because the flat was supposed to be finished earlier than it was, so that was a bit difficult that bit.

Having the funding in place allowed Zack with my help to pay for the support staff necessary for this to happen and other services he needs. I had to write a person-centred plan, which we took from Zack's person-centred plan that

they did as part of the Circle, which was mainly pictorial. The plan shows what Zack wanted to do when he moved into his flat and how he would need to be supported to achieve this. Then I wrote the support plan in the seven sections it had in it and apply for the personal budget.

**Addison:** Did you get help with that?

**June:** Only through my networks of support really. However, it was early days and I sort of knew what I was doing. Also, because the pilot was around there were people I could ask. In Control were giving the support at that point. What didn't happen is that this is now a formulated process.

So, it was agreed that Zack would have 24/7 support. It was agreed that he qualified for that and he had an hourly rate already being given to him for the hours that he was getting. So, I just multiplied that by 365 days times 24 hours. I effectively told them how much budget I needed for 24/7 care. They'd laid down some kind of structure and I'm a finance manager, so it made sense to me. I had one budget for this many hours so I just multiplied it up.

However now you have to have your assessment and your RAS which is a Resource Allocation for Services. So, someone comes out and assesses your need and then do this RAS. Then they tell you to go away and make a plan of how you would spend the money, then you get it agreed by panel, then you personally organise your money, and then you organise the support, then you live the life and then you review it. And, this is the process. There's lots on the In Control website.

**Addison:** And how did you find the whole process generally and how did Zack find the whole process?

**June:** Well, what he says here is, "It took a long time." We all got very stressed and everyone was trying to help, I have to say. However, it was all about the panel delaying. There was a big delay because at the end of the In Control pilot, what County Council was supposed to do was to have sorted out all of their legal obligations, all their paperwork and then got a system in place to go forward. What happened was, they sort of tried that but realised there was a lot more to it because they had a Duty of Care. They suddenly put the brakes on when they realised they weren't actually as well prepared as they thought they were. So, it all stopped, we'd done it all and then it stopped.

Then I met somebody and I was just talking to them and they asked me how it was going and I explained. Fortunately they helped me talk to the right people and it was effectively decided that anything was happening already in the pipeline they should honour. Any new ones they could stop but they should honour anything already in the pipeline. So, it that took a little while!

**Addison:** So, what did you do in the meantime while you were waiting?

**June:** Well Zack was still living at home on his shorter budget, on his Direct Payment still. What we did was, we delayed recruitment. Zack did get sad

because we'd started every month to go out and purchase a fridge, save up again, go and purchase a bed, save up again go and purchase something else. So, we had a garage full of all his stuff but he couldn't use it. So, he did get sad and he didn't know if he could move 'cos there was all of this. It took a long time for the building to be finished and even longer for the paperwork to be done.

**Addison:** Was there quite a lot of back and forth between you and the panel?

**June:** Yeah. There were times when no-one knew what was happening. So, it was a bit of, "Oh, it's housing, oh it's the disability organisation, oh it's the budget." Zack did begin to feel that it was never gonna happen.

By this time I had employed a team and I put the team together because we got the budget but the flat wasn't finished. So, then they started working with Zack at home. It was difficult because having a group of people living with us as a family rather than Zack, delivering one-to-one support to him but being in our personal space too. 24/7, it was not comfortable, even though all the people I employed are really nice people and I'm really good friends with quite a few of them. It was just a bit awkward, you know? If I got up in the middle of the night with my hair sticking up and sort of looking like a bit of a disaster, needing a glass of water, it wasn't just me and Zack. We, as a family, spent an awful long time supporting Zack at night ourselves. Having someone else there, it doesn't mean we could switch off. So, it was not like we slept through when he was having a seizure. Then we would end up going in and helping because until we knew he was okay we couldn't rest either. It was quite unusual to say the least. But, in hindsight I think it was actually a very good way of transferring all our knowledge to those people who then moved here.

So, after a long journey, much work by the family, local authorities, support workers, Zack's fulfilled his dream of living independently with support in his own flat and we're all very happy. Zack says, "I'm very happy to have my own flat. It looks really nice."

**Addison:** And this is moving from Direct Payments to Self-Directed Support, right?

**June:** Going from school, to a sort of part package on Direct Payments, to going to Self-Directed Support has meant he can live here independently on one-to-one support. He's had the opportunity to do voluntary work, he's had the opportunity to achieve goals at college. He worked for a little while as step-in librarian but now they've got automated system so that doesn't happen anymore. He's forged a relationship with a chap who's happy for him to go in and do woodwork and use his woodwork workshop. So, when Zack moved in I had someone make the desk, the table and the bookcase, all with rounded edges. Can you see it's all rounded?

**Addison:** Yes, I can.

**June:** And bevelled, trying to stop there being any sharp corners. But, Zack made that table to match. It took a year and it was a lot of hard work and I think people might have helped a lot but that's him doing that. He's made signs, like presents for his nanna. He's recycled a bed into a bench. And, in his home he cooks.

Self-Directed Support hasn't given him his transport 'cos we've done that through Motability. So, instead of getting all of his DLA we use the mobility element for the car. We did that because our home is far away and they don't have a bus service there. Zack is asleep today and because of this if a taxi had arrived now they would just go, they wouldn't wait for him to wake up. Whereas I can make a decision to let him sleep now because he won't go anywhere now but in an hour's time if we wanted to, for example, the pub. He might still be able to do that because there's some flexibility in the time for that.

He's been on holiday and the Self-Directed Support has allowed us to be flexible around that. So, for instance he wanted to go on a cruise, so he went on a cruise. Two people went with him. By me doing some shifts before and after for nothing, I then had some spare money to pay two people to do a whole week together, so that's two-to-one. Normally he only gets one-to-one. That's the flexibility that we can have.

**Addison:** That is very good because speaking to a few people with Direct Payments it seems a lot more rigid.

**June:** Yeah, I couldn't do that with Direct Payments because I'd only get the payment. I'd have to go back and explain, whereas I don't have to explain this because its money still being paid for staffing and because it's fulfilling his support plan. He gets to do lots of activities. He gets out and about with his family, he has new experiences and he get to go down the pub.

We've had a family wedding and one of the support workers came with us. They were able to facilitate him attending and gave us the opportunity as a family to attend. If Zack was sleepy like now, then the support worker would be with him and we wouldn't be restricted from participating in the family wedding. When my niece got married it would have been awful if all four of us couldn't go because Zack couldn't go.

So, it's really helped. I think from Zack's point of view his independence has really been expanded on. When he was living at home, it's very hard when you're living as a group of four people not do everything as a collective. The person who's strongest does things for Zack. Although he'd occasionally put the dishwasher on or put things in the washing machine and he had his chores to do in the house, it wasn't his responsibility. He didn't have ownership of that.

He has ownership of his flat, he has ownership of those jobs and when needed people support him to do it or he does the majority of it on his own. I think there are lots of things that he does now that he wouldn't have done at

home. The other day he came over and after he'd taken all the plates away he got a dishcloth and wiped the table down. Well, he never did that home because I would always do that as part of my routine. However, because it's part of his routine now he does it.

Those are learnt behaviours. That's the way Zack can learn even though his intellectual ability's not going to increase a great deal and he's not academically going to increase. Learnt responses and regular routine he's expanded on. Now I can't guarantee that he'll do it every time! He can't, because he's got a short-term memory problem but sometimes those things become embedded, don't they? Those habits that you don't have to necessarily have good short-term memory to remember that after you put your plate away you wipe the table as well because you've done it so many times. Now it's just part of his routine and he's doing it half-subconsciously. Those are the things he's built on, which I think if he still lived at home or in a group setting he would not have had any chance to do that.

Zack doesn't live well with other people in the way that he takes up a lot of space when he has seizures and that impacts on people. He also he doesn't understand body language or personal space. He's very person-centred to himself, so he doesn't take into account other people's feelings or empathise. He has safety social skills and conceptual values, like time, money and stuff like that. That's all the kind of stuff he has a learning disability around or difficulties with. Then of course his epilepsy can really impact on somebody else's living in his space.

His bedroom's only got a bed in and a few cushions to make it the safest space for him. We do encourage him to go and sleep there when he's sleepy 'cos otherwise it can be dangerous. He potentially has nocturnal seizures, so potentially he could have a seizure while we're sitting here and there's a lot of stuff he could come into contact with whilst he's having a seizure in this room.

So, one of the negative sides of all of this is that there isn't a great deal of help or there wasn't, about what is the best way to set up a team of support and all the legal stuff.

Zack has a communication book which has an entry for each shift. On there there's a tick lists about the things that have to be done like medication, what he's eaten and so forth. That's so he doesn't get repetitive meals, 'cos if you asked Zack what he wanted for tea he'd probably say burger and chips ten times out of twelve. It also states how his mood's been, what seizures he's had and how much he's slept. That's quite hard as a family to have somebody that you love so closely monitored and to be part of that monitoring. However, when I'm over here I have to do that otherwise I cause a gap in the information but on the good side everybody's well informed.

So, this is Zack's person-centred plan. This is where he talks about his story. You know, who he is, how he communicates, what's really important to him, who is really important to him, what he likes doing, what he doesn't like doing, what he's done, what he's good at, how his support needs to be, how he

needs to make decisions and then hopes for the future and what he doesn't want to happen to him. We looked at various years as a way of mapping stuff. There's lots of tools out there to use, so we try and use a different one each time. He does that with his friends in his Circle of Support.

So, his support plan, which the council require and has got to be read by new people, is much more wordy. These are the headings you see, "Who am I? What's really important to me? What I don't like? Things I enjoy. My goals. How I achieve my goals. Risks. How I use my money. How I manage my support." Then outcomes, "How my goals have been measured." They have to be, improve health, wellbeing - this is Social Services - quality of life, making positive contribution, exercising choice and control, freedom from discrimination and harassment, economy wellbeing, dignity and respect.

Here we've got, "Continue wherever possible to assist in all my household support such as cleaning, blah blah blah. I do most tasks with minimum supported guidance although I do need gentle reminders throughout the week to keep on task and keep myself and others safe." So, effectively he's learnt some skills and more recently all he's doing is maintaining those skills but if he suddenly went into a group setting where he didn't have to do those skills, then he'd actually decline in those skills.

It written, "To continue with the help of my team to reinforce the concept of value of money. I'm now being more flexible and negotiate the amount I might need to save if I have something particular I need." So, that's an outcome. "My routine at night with regards to getting ready for bed continues to work smoothly. I do need guided support occasionally to keep this routine but mostly I've done this with minimal support." So, he's more in control of that than he was when he was at home and he's sort of maintaining that and that's increased his independence.

**Addison:** Okay. And, who's there to help him with this?

**June:** Well, this is me working with the team to put together a list.

**Addison:** So, this is Social Services and everybody else?

**June:** Social Services want this information, so you have to provide this. When I'm due a review, when Zack's due a review and I know the date, I go back to the team and say, "Look we need to look at some outcomes." So, that's the previous year and there are some new ones on here. "This year, with help I've been looking for some work related to replacing my previous job. I love voluntary work when the opportunities arises and I'm able to attend. This might be something like working at a friend's farm with animals or helping with their new building project. There might be a possibility of an opportunity to help behind a bar. Also, with recent set-up of a music studio at my family home I can continue to develop my DJ skills." So, that was a goal for this year coming. "I will also investigate working at the radio." Well, actually we've got him working voluntary at a record shop, an independent record shop. This was us negotiating or forming a relationship with a shop-keeper. We've

actually got a good outcome for that, 'cos he's got the voluntary work and he's working in a field that he enjoys doing.

"We're going to investigate football opportunities with a view to joining a group and meeting potential friends plus regular exercise." Well, that one hasn't come. There are still opportunities but Zack seems to not be able to get to these events. So, it's not that we're not carrying one on but that's one to keep plugging away at. Regular exercise is always good for him physically and if he's better physically then he's more likely to have a better outcome for his seizures and just generally, everybody's better off, aren't they?

"Working towards developing more positive independent choices in my home using Assistive Technology prompts." That was something we were going to look at but that again has failed 'cos it doesn't work for him. He doesn't interact with the technology very well because he just doesn't understand it. It can be talking to him and he completely ignores it, so we've got to find other ways. However, we've tried something and it doesn't work. So, we've got, "Yes this needs to be carried on but this one's a no."

**Addison:** That's good, so trial and error.

**June:** Yeah. The council want to see measurable outcomes. So, they don't want to see a package that's being misused, not effective. They want to see the benefits from it and you have to come up with that. So, it's quite a lot of work. I mean these are all care plans; this is how to work with Zack and various bits and pieces. This is quite hard for a family to do and I think it is quite often off putting. So, this is In Control's plan. If you go on the In Control website, you might be able to get the latest bits and pieces.

**Addison:** That's quite a good place to go for advice and support is it?

**June:** Yeah.

**Addison:** 'Cos, that's, that's a big thing. Often a lot of people have asked me, where they go to for advice, where they go to for support because a lot of people don't know.

**June:** But, you have to be happy to go online and look at these things. You have to have the time and the cognitive ability. I mean, whilst this is easy read, I was physically given this. To get to that, I bet you have to try and get it on the website and then you'd have to navigate the website quite well to find the easy read version. If you were Zack that might be beyond your means to do that.

The other thing is that we realised very soon that we had to have care plans. We had to say, "Well this is what works well around all these different areas of his life." So, there's epilepsy, medication, body and happiness, communication, start of the day, end of the day, food and mealtimes, relaxing at home, housework, community activities, travelling, holidays, finance,

relationships, behaviour and so forth. There are the health and safety policies because I'm an employer and risk assessments.

Nobody gives you any kind of paperwork or even any kind of templates, except for now Skills for Care. And I'm not sure about Penderels because Penderels and I haven't worked together. I don't need their help doing payroll because that's what I do in my professional capacity. I don't actually have any relationship with them. I do all my own recruitment within my networks. We've just done a recruitment drive and got three people starting the next few weeks. So, I've not found them useful but then I haven't sought their help either so I can't really comment too much, except I've not heard very good things about them over the years, in my network. They might be getting better. But no, there doesn't seem to be any support. So, a lot of families struggle and I know this because I do peer support for other families.

Fortunately, I got the template for how we do our care plans from the lady who did our Circle of Support meetings because she happened to do that kind of work somewhere else. However, if you didn't know the right people or if you didn't have any opportunity or time or gumption to do it, you wouldn't do it. You have to be very proactive to make this work.

What I'm trying to do now is make sure that the people on Zack's team take some of this activity that I do because in the long term, as I get older I'm not going to be able to maintain this level of management and support for the team. If they all do a little bit of it then it's not reliant on one person and if it's reliant on me for too long then there's no resilience in the team if something happened to me. So, I'm trying to now withdraw myself but again, I've made that choice and I've been the one to orchestrate the process and the steps. Nobody, no social worker has come and said to me, "You know you've been doing this for such a long time now and you don't want to be doing this forever." I always felt I should say to Social Services, "This is not fair to assume that the family will always do this." I didn't want them to think that one day they might not be asked to pick up a bit more of the management of Zack's care. I think they're under-resourced. I think that Zack hasn't had a review for two years now.

**Addison:** I thought they were meant to be done annually?

**June:** Yeah but we're now on two years. So, I think they're so under-resourced and because we're not asking for more help and we're just getting on with it, they have so many people above us asking for help, that they haven't got to us yet. I'm sure they will do however.

**Addison:** Do you feel that you're able to go to them and ask for help?

**June:** I have the capacity to email them and say, "This has come up, what can we do about it?" And, I could ask them to come and do a review but if nothing's changed there's no point? There's no point in putting me through all of this.

Initially when we started the Self-Directed Support the social worker got in contact and came and visited after three months and then after six months and then a year. They were regular in the first year. The last one that they did two years ago, after the economic austerity came in. I felt that they weren't just coming to review, they were coming to re-assess. We were all being re-assessed to make sure that nothing had changed because they were trying to save money.

In some respects, it's better that we just sit and let it tick over. That is fine but you know, it does worry me a bit how long will that go on for. It would better for someone to just say, "We know everything's fine with you, get in contact with us if you need us. Unless you make us aware of it, we're not going to worry you or we'll say we're coming to see you in three years' time." That's what we like, when you have a medical condition they sometimes say, "We need to see you every six months," and then after they've done that a few times they say "Right, well we'll review it in a year." Then they say, "Oh, we'll review it in three years." So, then you know that you would just get on with life.

However, I don't know when they're going to come. I can imagine them just saying, "Oh I've got a cancellation, I'll pop in and see Zack tomorrow." That kind of appointment won't be enough preparation. In the back of my head I'm worried that might happen. So, every three months I review Zack's paperwork and update it because I don't want to be put in a position where I'm up to midnight the night before trying to pull everything together but not doing a good job. They say no news is good news but you don't know what's ever round the corner.

There are lots of other things. Part of Zack's budget came from ILF, Independent Living Fund but that stopped. Originally there was a fund set up 20 years ago for people by the government. It was a central funding to help people be more independent. This was before Self-Directed Support, before Direct Payments and before the whole personalisation agenda came into being. It was at the very infancy of those processes, Valuing People and stuff. When Zack first got his package part of his funding came from ILF the County Council were able to say, "You applied for this much money so we say that this is how much money you need each week but you can get X amount of it from this central thing and we'll pay you the difference. Okay?" So, that's what they did.

However, in 2015 the government turned around to this Independent Living Fund and said, "We no longer need to do this because each local authority is supplying funding for independent living through Self-Directed Support. Therefore, we're gonna disband this and send the money off to the local authorities." But, some local authorities didn't ring-fence the money so it literally went in the top and then got spread out. They said that if you still qualified, which Zack did, the local authority would pick up the budget and pay whatever it was, as well as whatever else they were paying. However, we weren't guaranteed that and potentially it didn't sound like we could get it.

Especially because at that point the funding had started to become difficult, 'cos of austerity. However, they did fund it, Zack did get it.

Then there's his team. All the ones that qualify to have pensions paid for the automatic enrolment but no-one's come and talked to me about increasing budget. I've got a 1% increase on my salary bill going out now and we've had no increase in all the years Zack's had a personal budget. I've had to pay people pay rises, so there's less and less. So, Zack gets X pounds per hour plus an on cost and I'm just grateful that there's not so much sickness.

I do some shifts, like today I'm covering. What is happening now is all the funding is needed to cover all the legal costs as part of payroll. Whereas, before I could do something like let him go off for four days two-to-one because I had the surplus when I put in the hours for nothing. Now, I put in the hours in for nothing just to make it so people can be paid.

People who have been with a team for a while I have to give them some wage increase to stay, otherwise I'm looking for additional people. Someone new will be shadowing for up to two months before I let them work one-to-one with Zack. So, that's doubling up. If you're doing three people once a year that's six months' worth of doubling up shifts and that comes at a cost.

I might have to call a meeting 'cos I might be running out of money now I'm having to pay out pensions too. Fortunately, because I've done pensions for organisations before, I've done the same for Zack's team. I've already worked with the pensions company so I do know the system. However, if I didn't know payroll and pensions as well as I do then that would be another thing. It's another worry, where the money's gonna come from? Some authorities have said that they would just pay another 1% to all of their Direct Payment and Self-Directed Support people but Cambridgeshire haven't made any statement. That might be one of the reasons why I call a meeting with the social worker sooner than she might have called it with me. Maybe she's being quiet because she knows I'm gonna be asking for more money at last, for the first time since we started to cover those extra costs.

**Addison:** How easy do you think it will be to get?

**June:** I don't know and I think what I need to need to run it for a few months. I want to run it for six months and then I've got a clear idea of the costs. What works best for Zack is to have part-time people because it's so intense. When you work with somebody five days a week it can be really, really intense. Especially on a one-to-one basis, where you've got to be with them all the time, that's your job. It's not like you can go off and have a cup of tea or take yourself off for a walk and get some fresh air. You can't do that with Zack, you have to be with him. So, eight hours a day, five days a week is going to drive both him and that person nuts.

So, everybody works part-time, which gives me a bit of flexibility for cover. However, because some people only work once a week or once a month or whatever they've chosen to do, that means they fall outside the pension

earnings. I've just got to work out how much it impacts. So, it's another thing to add to the long list of things to organise. Whilst I'm letting go of some of the day-to-day management, it's not creating the opportunity for me to have a better relationship with Zack on a mother-son basis. I'm just doing other jobs like thinking about the pensions.

**Addison:** It's not really helping you to back off a bit, which is what you said you wanted to do.

**June:** No, not yet anyway. Hopefully they don't throw anything else at us now like they've done with automatic enrolment. I think that's the last hurdle. I do believe that every now and again, every few years they have a bit of a shake-up. So, when the next the next election comes along I'm sure there'll be some changes. You can never sit and think, I've got this system in place and that's how it's gonna run smoothly for a little while. The little while is little. I think you have to review it regularly and have to accept there's always a possibility of change, for the good or the bad.

I mean, I've just put some Assistive Technology in for Zack and that has thrown us a bit as well. We are actually just trialling it, both from Zack's perspective but as a general sort of trial of this piece of equipment to see whether it's suitable for other people. I can appreciate Assistive Technology might support someone else to have less one-to-one support but as we can't predict Zack's seizures I can't go away and leave him.

**Addison:** Yeah. So, one of my questions which you've sort of already answered, was about challenges and how you overcame them?

**June:** Basically on our own. Ha-ha! I would say that one of the things is that when we first were on started this journey, it was a much more optimistic journey than it is now. I don't believe for one minute that Zack would be in this flat with the opportunities he's got if he started this journey now. I just think austerity's put too much of a restriction on what you can and can't do with Self-Directed Support and the Resource Allocation System, which is the RAS. Eligibility and the amount of money available for a package is so limited.

So, I don't believe for a minute that Zack is not entitled to have, through Duty of Care, one-to-one support 24/7 but what that package would be looking like and what would be... Because we were on that pilot and because it was so open at the time and there was no austerity you could have your dream. That's what they were encouraging. Now, there's a much more conservative view on that. I think what opportunities are out there are very limited. To some degree that's why we haven't given our presentation because I can't really tell people how it is for Zack because I'd be worried that they will be trying to achieve something that's not achievable now. So, that is really sad for others, 'cos there's lots of people out there who're in just as much need as Zack.

**Addison:** Yeah, very much. I know it is becoming increasingly difficult.

**June:** But, one of the reasons we did this, was to go out there and get people to embrace this, because I think it's the best thing and it's worked brilliantly for Zack. The personalisation agenda was the right way to go and Self-Directed Support is the right way to deliver that. However, some of Self-Directed Support legislation, local changes to what's now acceptable and what's not acceptable, it's got narrower and narrower.

You know, they always say this one gym membership was acceptable at the beginning. Now people are saying, "Well you could just go for a walk and it wouldn't cost you anything." That kind of extreme. I can see the reason why because I'm a financial person and so it makes sense to try and save money where you can. Ultimately though if I asked Zack to go for a walk that might be quite hard unless we've got something to achieve by that walk. Walking to the pub might be different to saying, "Let's just go for a walk."

Actually getting him in a gym, with his group of friends, doing an activity with a disabled group where he's making it a social event is much more beneficial to his wellbeing from lots of aspects. It brings him into a group setting with his friends and social life. It's doing something that people find quite tedious, going to the gym but because you're a collective you don't realise what you're doing really. And, if his wellbeing has improved, whether it's in a social context or the health benefits from doing some exercise every week, that's going to improve his seizures and it's going to improve his personal outcomes all the time if he's not having the seizures.