



Transcript:

[Music]

Gill: You alright, Han? Hello. Are you going to get up? Put this on. Come on. Hanna's twenty-two and she has Angelman's Syndrome and lives at home with us. Morning, you. About 80% of people with Angelman's Syndrome have epilepsy. Unfortunately, Hannah is one of those and she ends up in hospital, erm, nearly every time that she has a fit. She's got partial sight, so we do have to be careful about trips and falls on things. There's no sense of danger, so she'll climb out of a window no matter where it is.

Gill: (getting Hannah a drink) Good girl. Careful with it.

Gill: We live at the moment on a boarding kennels and cattery. It's twelve acres of land so a chaotic household with lots going on, which fits into Hannah very well, because she's hyperactive as well, so it's a nice, freedom place for her to be. I now work from home so I can care for Hannah at the same time. Erm, Dad's around, and also her sister. When Hannah was eighteen she finished at her special needs school and at that point in time, we were very concerned. We did look into an awful lot of things, including residential care, because we found it very difficult to recruit carers for Hannah. And although we tried it, it was ... we couldn't have carers within the home, erm, Hannah just wanted us all the time.

Gill: Do you want jam in it, Hannah? (taps Hannah's arm) Do you want some jam on it? (points to mouth) Please?

Hannah: Points to mouth.

Gill: Yeah, okay. Chrissi's getting it.

Gill: When we then found out about the personal budget and how that would work, it just seemed so suitable for her.

Hannah's Dad: (waving) Bye-bye.

Hannah: (waving)

Gill: That's right. Be careful on the roads. Chrissi's Hannah's elder sister and she's very involved with Hannah's care. And we couldn't really cope without her, to be honest.

Chrissi: (looking at dog logbook)

Gill: We can move the lab outside.

Chrissi: Move the lab.

Gill: But if we move the lab, then Rodney needs to go next to Wodan, because else they'll gob off at one another.

Gill: When she was not on the personal budget, we were unable to pay Chrissi. So we've got round that. The personal budget is agreed, due to extenuating circumstances, that we are able to give Christina a wage.

Nicola: One of the challenges with individual budgets is the different funding streams that you use, erm, you could use a disabled facilities grant or an independent living fund. Erm, and they all have a different impact on the funding and how you can use it, and so it's not as straightforward as, as we'd hoped it had been. And our vision for the pilot was to be able to use as many funding streams as possible. What we've done now when we've set up self directed support, Essex County Council, is to use, er, really just Essex County Council funding because we're still quite a long way away really from getting it all, er, fully integrated.

Chrissi: Personal budget's meant that I can help mum out, do, running her business and looking after Hannah. It's a business we've always wanted to do, and me and mum work a lot with the dogs and the kennels and the cats. Being here and being able to look after Hannah in our own home means a lot to everyone.

Gill: Chrissi coming home and helping has been a Godsend really.

Gill: Are you off? Yes, that's you in the mirror. Who is it, Han?

Hannah: (laughing)

Chrissi: To be able to choose what Hannah would like to do in her personal budget was quite difficult, because Hannah's got no speech. We got a written account from everyone, which was quite a moving experience in itself, to get something written by each member of the family and people that were close to Hannah as to what she would want from this personal budget.

Chrissi: (Chrissi and Hannah going out of the house) This way, Hannah. Come on. That's a good girl. Hand.

Gill: One of the strange things we did with the personal budget money was that we've actually bought a Mongolian yurt.

Chrissi: (to Hannah) Hold my hand because it's really slidey. (entering yurt) Come on.

Gill: Chrissi and Hannah go up there quite often, and it's a nice meeting space that they're away from the home but they can have all their friends round and have a good chat. They've got the telly in there and everything, and they just have a really good time.

Chrissi: (taking Hannah's boots off) What do you want to do?

Hannah: (laughing and saying own name)

Chrissi: Good girl. Yeah?

Chrissi: It's incredibly warm, considering it's a tent. I can have Hannah up here instead of her wanting mum all the time. So I can have her up and she can stay over, and she's not going to go and pester mum. It gives me somewhere to hide from Hannah when you're being horrible, doesn't it?

Hannah: (smiling and laughing)

Chrissi: You. Yeah. But yeah, most of the time we just come up and watch sort of DVDs and if she hasn't got anywhere to go with her carers it's quite a nice space for them to come with her. (putting Hannah's boots on) Right. Come here, Hannah, it's wet.

Gill: If I had to sum up what personal budget's done for us, it's, it's united us. It's kept us together as a family. Erm, we were at the point of Hannah

going into residential care, not because we wanted it to happen but because it was the only way we were going to be able to function as a family. Being able to allow Hannah to develop as a person, go out on her own and have her own life has given me my life back.

Gill: (sitting with Hannah and Chrissi round table) Hannah, look, Chrissi wants to take you away with Joe again. Have a look. Yeah, we can look together.

Chrissi: There's the list of what we can do. There we go.

Gill: This is where you're going to stay. Look. That's nice, isn't it. (looking at brochure) And you'll have your own bed. And you'll be back on the Monday?

Chrissi: Yeah. I don't know what time though.

Gill: And you're not going to break her, this time are you? (laughing) I'm worried about like last time, I was worried about her going away without me. But you'll be alright with her?

Chrissi: We've done it twice and she's come back in one piece. I think she'll be alright.

Gill: And don't take her go-karting.

Chrissi: Why?

Gill: Because that would be scary. (laughing)

Chrissi: She'd be fine. Me and mum do disagree quite a lot on the sort of things to do with Hannah. And mum does worry a lot, especially when we take her away for weekends and when we go out. But I've sort of found the best way to do that is just not tell mum until we've done it. And then say "oh, we took Hannah and we pushed her down the flume today and she had a great time".

Gill: What's happening today is Hannah's going off to Butlins with her sister and her friend, which is very exciting, isn't it, Han? Yeah. The main difference with Hannah now that she's got the personal budget is that she can actually go out, be independent to us, start getting used to being away

from mum and, erm, you know, sort of me doing everything with her, and also, going out with people of her own age and being able to choose the type of respite that she can do.

Chrissi: (shutting car boot) Is it all in there, Hannah?

Gill: She's checking your packing.

Chrissi: Right. In you go. Mind your head. Crunch.

Gill: Have a good time. Phone me when you get there.

Chrissi: Hannah, say 'bye.

Gill: No. She says I'm just going on my holiday. Have a good time. 'Bye Han.

Gill: The main thing I think in the future is continuing for Hannah to develop as who she is. I think she's always going to want to be around the family and the animals and that. It's, it's what she clings to, so ... and just continuing with the support that we've got really, and hoping that it stays in place.

Chrissi: (in car) Han, hello.

Chrissi: (on beach) Follow Jo, Han. (Hannah sits in wheelchair)

Jo: I'm not pushing you in it on here. (wheelchair sinks into shingle) Oh look, it's sunk. (laughter) Hannah has decided that is enough walking. But we won't get anywhere.

[End of Recording]