

David's Ordinary Life



"David is just a person like anyone else. If you take out the Down's Syndrome, then he is no different to anyone else."

Elizabeth, David's sister

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My Life

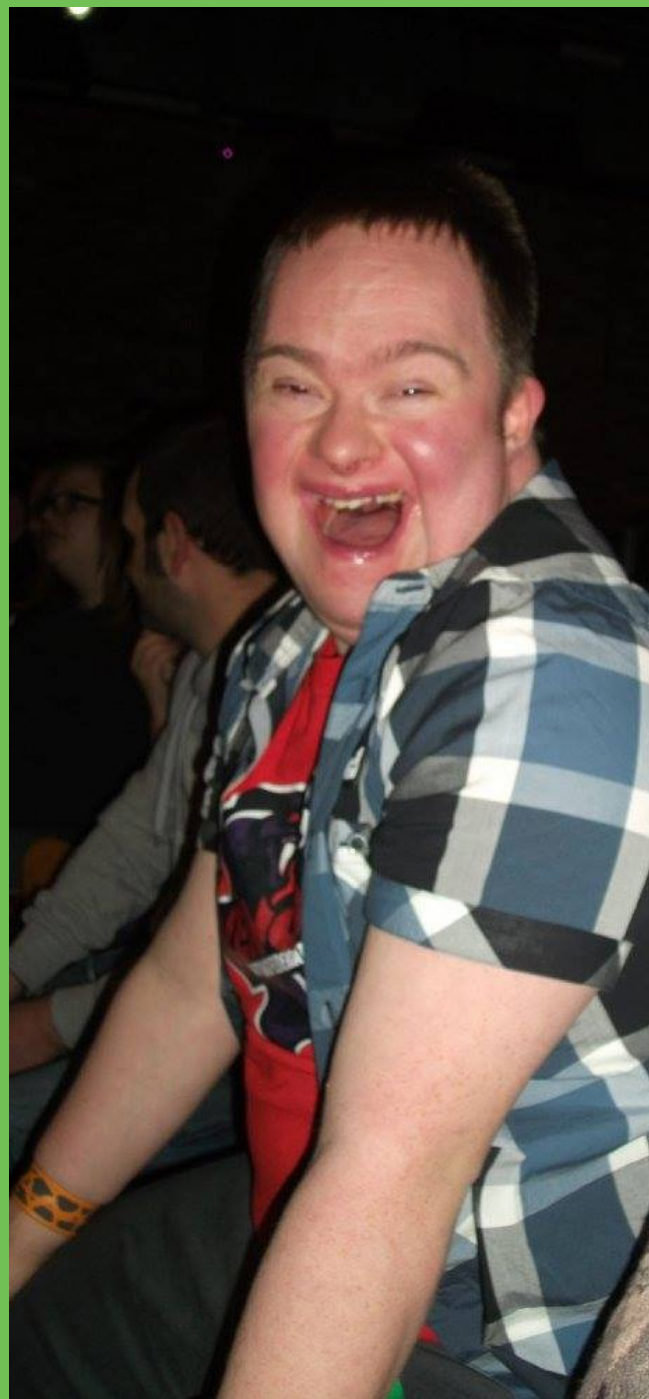
My name is David. For the last 6 years I have been living in my own home and loving it. This book tells you about my life, my strong sense of independence and some of the challenges I face and how I overcome them.

A bit about me as a person

I am my own man! I know what I like and what I don't like, and I am confident communicating in this to other people. I am very much a people person. I am friendly, outgoing, fun-loving, and have a wicked sense of humour. I definitely have a cheeky streak! If there is something I should not do, I will do it and then smile to myself or have a chuckle. I can't resist!

"David is a pleasure to work with. He's very mischievous; he doesn't miss a trick. He really keeps me on my toes and entertains us all."

Lynne, one of David's staff team



Living in my own home

I have now been living in my own home for 6 years. In the first year, it took me a while to understand that this was my own home, as I had lived in residential homes before. I did not have as much choice and control in residential homes, as I do now.



"David is a lot happier now he lives in his own home. He does more with his life and he's got a lot more choice. I get to see my brother a lot more because he's got his own home and we are a lot closer because we spend time together. I remember when he was in the residential home he was angry. He's not angry anymore, just mischievous and always planning something."

Elizabeth, David's sister

"David has more freedom to do what he wants because it's his own home. In the residential homes he lived in, it was very controlled. It is much better for him and for his family having his own home."

Helen, David's mom

Staff support me to live independently in my own home. I am supported to do my house work. I don't like doing housework, it's boring but I know I have to do it. I clean really thoroughly once I get started but still don't like the actual word 'cleaning'.

I am supported to cook all of my own meals, except for when mom cooks a Sunday roast.



"David loves a cup of gravy with his Sunday roast, whether we are at home or in a restaurant."

Helen, David's mom

Making my own choices in my own home

I like to make my own choices and I'm in control of my life each day. I know what I like and what I don't like. I take risks in my life and I like to learn and try new things.

Until I lived in my own home, some things were 'kept away' from me. Staff in the residential home said they had to lock things away from me. At Christmas I always used to post the Christmas decorations. This means I took them off the tree and posted them down the back of the radiator or other places. Now I am in my own home, this doesn't happen. My tree stays up for the whole of Christmas from 1st December to Boxing day. This is a real achievement for me.

Sometimes I will still 'post' things as it can be a lot of fun, but not as often as I used to. I might put things down the radiator or out of the window. Sometimes it's also fun to throw things over the fence and see what staff do.



"David still posts things as he finds it really amusing. He's got a really mischievous streak. Sometimes he will plan all day how he's going to trick a staff member as he knows it will get a rise out of them. When David was in the residential home he was posting things because he was angry and sad, now he posts things in a cheeky way to get a reaction out of staff. He will look at you, and the look on his face says 'look what I got away with!' This really keeps staff on their toes. If David has fun in this way it also stops things escalating.

In his own home, it is safe for David to express himself and some of the things he does like posting items and being mischievous are ways David communicates. It's when he is not mischievous that I start to worry. Being mischievous is not just fun to David, it's a coping mechanism. He does not like being bored and likes to make his own fun."

Helen, David's mom





Whenever people come to my house, at some point I will either be rolling up paper to make straws or taking apart a foam baton. I like to hold them and listen to the sound of them and I like the feel of them. A large box of straws is always sitting on the living room floor and if any of my visitors want to take a straw, they will not be allowed. I'm very strict about this.

I have a double bed now and lots of pillows. That's important to me because in residential homes I lived in, I had to sleep in single beds. For a while I was sleeping on a mattress on the floor because I didn't feel safe sleeping in a bed and wouldn't get in it. No one tried to find out why, they just took the bed frame away. Now I love my bed! One time, I took the pillow apart and made it snow feathers. It was great fun! But the staff did not like this and I got told off. I ended up not having any pillows so now having a big bed and lots of pillows is very important to me. Occasionally I still make it snow, but my staff understand it is an obsession and when I do it they just replace my pillow and I promise not to do it again (until next time). Staff now let me know it's not a good thing to do but they don't tell me off like I'm a 'naughty boy'.

The life and soul of the party!

I am really sociable and love to party with friends. I enjoy the dancing, the music, a soft drink and the food! Sharing food with friends is one of my favourite things. Party songs are my real favourites; I do a mean Gangnam Style, YMCA and Star Trekking! I'm out three nights of the week partying. I love live music and theatre, as well as wrestling shows. Most weekends I go to shows.

"When David is being supported to cook, he even dances in the kitchen."

Helen, David's mom



My voice

My staff team are trained by my mom, so they know me really well. She trains them so they have an understanding of autism and how it affects me individually. She also trains them in the ways I communicate. There are lots of ways I communicate with people around me.

Here are some of the ways:

- *I use words.*
- *Sometimes I speak about myself in the third person.*
- *I have visual planners that use photos attached to Velcro strips. On the planner are photographs of things I do, or people visiting or staff on shift attached to the Velcro strips. When something is happening, I take the photo off the Velcro strip and post it in a clear envelope. This helps me understand what is happening and when it is happening. It also makes me happy because I get to post things.*
- *I have a choice board which also uses photos and Velcro strips. It is on a door in my living room. I choose from the board what I want to do next.*
- *I use banks of photographs to help me to make choices. Most of the photos used are of me doing something and need to be very specific.*
- *I sometimes listen to a social story or read a social story using widget. I find this helpful to learn about new things.*

My family

My family are very important to me and I love to spend time with them. Elizabeth has a snake, a hedgehog, a hamster and two claw frogs. When I go to my family home Elizabeth gets the animals out with me. Mum is scared of the snakes which is very funny.



'I like my relationship with David now. It's chill! In the past it was difficult to see David in the residential home. Now I can see him when I like and do things as his sister because it's his own home. We can jump on the bed and its not a health and safety issue. I don't have to make an appointment to see my brother now like I used to do when he was in residential care.'

Elizabeth, David's sister



'Elizabeth does not have to fit in with the staff rota. David now has a proper family life; we no longer have to rota family life!'

Helen, David's mom



Having a full life

I am very sociable and know lots of people. Some people I know because they have known my family for years, others I have met through different clubs. Other people I know through going out and about to places like the barbers or the pub. I have two friends, Helen and Judy, that I normally see at drama and dance classes. They came to visit me at home in June, but they haven't been around since because of the Covid-19 lockdown.

Some of the things I like doing in my week are with other people with learning disabilities, and some of the things I enjoy are things anyone in the community can go to.



"If you walk down the street with David, everyone knows him and speaks. David goes to lots of places such as wrestling, the cinema, theatre, bowling, the seaside, the gym, the pub, the zoo or animal farm, Laser Quest and a great many more! We have a family friend who plays the villain in lots of local shows. David meets him in character after the shows. David really likes the baddies, people like Bill Sykes in Oliver."

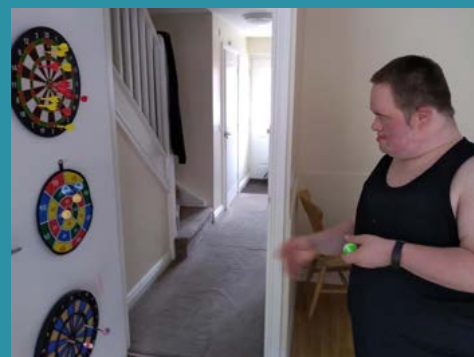
Helen, David's mom

David's life during lockdown

When COVID-19 hit, Helen knew that he had to be shielded because of various health difficulties he's had throughout his life, and so lock-down for David started early on 16th March 2020.

David's learning disability means he has struggled to understand some of what's going on during the lockdown and the reasons for it. David sees his staff come and go every day and finds it difficult to comprehend why he can't go out. David also relies on visual prompts to aid communication, so struggles to understand that shops and pubs are closed if he can't actually see that they are closed.

Helen manages the staff team that supports David to live an independent life in his own home. She has, through a blend of creativity, common sense and an unwavering commitment to David's human rights, reimagined David's day so he can live his best life possible under very restrictive conditions. As David can easily get bored, Helen has bought him a range of 38 activities that can be done within the home, including magnetic and sticky darts, dance mat, a remote control car, a new webcam so he can talk with his friends online, a foot spa and a Slush Puppie maker. David also likes to be creative; his long-term favourite thing is to roll pieces of paper up and make them into batons. More recently David has taken a liking to foam batons, which he dismantles, removing their flashing lights. Both of these are calming to David.



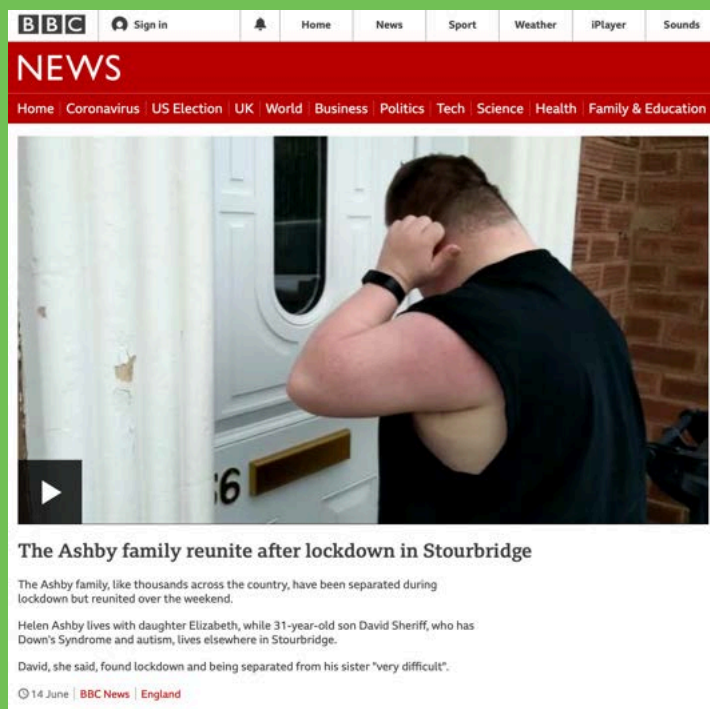
Each month since lockdown Helen has taken a range of photos of David in different activities and has had these printed as individual photo journal books. David likes to look at these photos to choose what he wants to do and they also act as a way of recording what he's been up to during lockdown. Helen has also used the photos to explain to him what is happening around the country with COVID-19. Helen has always used photographs to help explain the world to David. In order to explain how in the first weeks of lockdown basic supplies were not available in the shops, Helen took photographs of empty shelves and put them into this book. David has also been taken for a ride in the car to see for himself that the pubs, theatres and other places he likes to go are closed. This approach has really helped David understand lockdown. David already uses a range of visual prompts in his life, so taking photographs of lockdown has helped him understand the situation.



In addition to the photo journals, David has a range of visual planners which enable him to understand what is happening around him and make choices. David has a book made up of small photos with Velcro on the back. Each photo represents what David wants to do the following day. David chooses what he wants to do and sticks the photograph of what he wants to do on his Daily Planner every evening with staff. He also has a Staff Board in the kitchen; each of his staff have a photo taken and this photo is put on the board each day to show David who will be working with him.

Another way that Helen has explained lockdown to David is by calling Boris Johnson, 'the man'. Helen has explained that 'the man says you can't go out today'. David also understands that he has to wait for 'the man' to say what he can and can't do.

David, like us all, is a social being and during lock-down has missed being with his friends. He especially misses the parties and the food! David has met some friends over the Internet through online platforms but he doesn't think this is as much fun as being with people in his own home.



Thinking creatively, Helen has organised afternoon tea deliveries, cheesecake and ice cream deliveries, as well as a few Chinese takeaways to keep David's life as normal as possible. As lockdown is gradually easing, David has been on socially distanced picnics and his social bubble is now extended so he can visit his sister Elizabeth and their pets including a snake, hamster and hedgehog.

The story of David's reunion with his sister was featured in the BBC news in June.



In March 2020, David was due to have his bathroom turned into a wet room but it was cancelled because of the lockdown, and this caused him a lot of stress. However, it finally went ahead in October but this meant he had to spend 11 nights at the Premier Inn, eating his meals out. This wasn't like a holiday as there was no entertainment but he coped very well and he went back home on the 29th of October. As his birthday is 30th October, Helen made the decision to move his birthday to the 29th, as David doesn't remember the date. So he came home to a wet room, decorated lounge, presents, a birthday cake and best of all for David, a hot tub. David desperately wanted a hot tub but it had been difficult to source one throughout the summer as they kept selling out. David has missed sensory pool sessions and swimming but he is loving the hot tub, spending hours at a time in it saying, "I love it".

Having a direct payment

David has a direct payment for care and support that covers wages for staff. Helen manages the package including staff recruitment and staff training. David has an advocate who is the 'nominated employer'. She uses a local authority approved 'management' company that does payroll. This means she does not handle the money directly, and so protects herself against allegations of financial mismanagement or abuse.



Helen is really clear about the advantages and disadvantages of having a direct payment:

"It's 100% better than a care agency. Care agencies pay staff poorly, the staff can also be of a poor standard and have a low threshold in terms of what they judge as good. It's also difficult to get people with integrity. I wouldn't do it any other way now than having a direct payment. I feel more able to give David control of his happiness and more able to direct staff to keep him happy, healthy and safe.

But it comes at a cost for me. It's emotionally intense and means I am on call 24/7 so when you have staff that are sick or if we have a vacancy or we need additional 2:1 time, it is me that fills the gap on top of my contracted hours.

It has also become the whole of my life. But seeing how happy David is now, how much he's grown in independence and how well he handles choice, I wouldn't want to go back to working with providers. The focus is not always on the people they support. It is on the bottom line, contract negotiation, risk aversion, and often ends up with staff and managers exerting unnecessary power and control over people they are there to support. I don't want David to go back to that.

Direct payments are not for everyone; it's not an easy option. Working for your adult child isn't for everyone, and definitely isn't the easy option, but for us both these decisions were the right ones."

The Sheriff-Ashby Approach to Personalised Care and Support

The Sheriff-Ashby approach to personalised care and support was designed by Helen Ashby, mother to David Sheriff. Helen and David have summarised the elements of effective support.

There are 10 main points to this approach:

1. Staff have the privilege of working in the person's home; the person does not have the privilege of living in their workplace. Treat the person's home with respect and care.
2. Keep the person safe while using the least restrictive support. Keeping the environment protected and the person safe does not mean being risk adverse or overreactive.
3. Encourage the person to learn and use new independence skills. Staff are there to support the person to do as much as they can for themselves, not to do everything for them just because it is easier and quicker.
4. Support the person to make as many choices as they can about how they live their life, and allow bad decision making, as long as it does not risk their health or safety. Support them to make appropriate choices in all areas of their life: do not dictate when they eat, what they eat, when they go out, where they go and for how long. A person's activities should not be dependent on staffing abilities or shift hours. You need flexible staff.
5. Help the person to manage their health needs and explain why they should or shouldn't do certain things. Support them to go to appointments and to follow medical advice.

6. Facilitate community access and integration for the person. They are an individual within a community, not a person excluded from their community.
7. Continually be looking to create new opportunities and experiences for the person so that their life is enriched. Encourage them to live, not exist.
8. The person is a person first - a diagnosis or a label is not who they are, but a part of them. As for all of us, their physical and mental health needs are fluid and vary day to day. What is appropriate one day might not be necessary or appropriate the next.
9. Always advocate for the person's best interest, not what is cheapest, easiest, quickest or most convenient for staff.
10. Always ask yourself, 'would I be happy for someone to say this, do this, or behave in this way to me or my loved one?'

*Staff are there to support the person to be Happy, Healthy and Safe,
while living a meaningful and fulfilled life.*

Every situation for care and support needs is individual, but historically, everyone with a similar 'label' has been put into the same pot of care providers. These providers have always done things a certain way. Some often struggle to see new ways of thinking, and fail to see the people they support as individuals with individual wants and needs, as they are more oriented towards thinking about how they can fit so many unique packages into their business model and financial goals.

Our Unique Situation

David has Down's Syndrome and Autism with some complex medical and behavioural support needs, and requires 1:1 support 24/7.

David has spent time in a residential school, college and home, and in supported living managed by a national care provider. He now lives in his own home and I, his mother, am his DWP appointee, nearest relative, next of kin, and the manager of his care and support package funded by direct payments from the local authority.

David's direct payments are managed by a local authority approved company, so that I as his mother, have no dealings with his money and thus cannot be accused of financial abuse or impropriety.

We have a nominated employer for HMRC purposes, who is also David's advocate. She is able to oversee all decision making and any employment issues that may arise.

I write all David's care plans, risk assessments, support guidance, and have designed all the paperwork for his support package to be personalised to him and his needs. This is to ensure that all staff work in the same basic way, although every member of his team has a unique relationship and bond with him, and the package allows for this level of flexibility and for trusting relationships to form.

I do all the staff supervisions, back to work interviews and level 1 disciplinaries, while our nominated employer takes over for level 2 disciplinaries. I produce the staff rotas and analyse and correlate all the paperwork, including looking at behaviours and seeing if there is an obvious avoidable trigger for the future. I coordinate his medical appointments, medications, and physical health overviews.

The pitfalls for us

Our only hurdles/obstacles have been around staff recruitment and covering for sickness and annual leave. To have a bank staff pool on zero-hours contracts who are called upon only as and when needed is not practical so it has meant the current well established team, including myself, have had to do a lot of overtime to fill gaps on the rota.

The Sheriff-Ashby Approach can be achieved by a company; it does not have to be a parent leading the care and support package. You do need a committed manager who sees the person in a holistic way and has a passion to help them live their best life possible. Then you need a team with that same vision, who work well together and are committed to supporting the person's well-being. You need this team to be united and dedicated, not to use multiple people from across the company who look after multiple people. You can't achieve person-centred care this way.



**No one is too disabled,
or too affected by
mental health difficulties,
to live an ordinary life**

Changing Our Lives

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