

Autonomy and independence: an interview with Jamie+Lion

1. Can you tell us a bit about yourself?

I'm Jamie Knight, I'm a Senior Research Engineer at the BBC which is the posh way of saying that when there's a Jamie-shaped hole I fill it. I'm kind of a recovering developer. I develop recreationally at the weekend. And I float around the BBC making sure that we, our apps and services don't disable the audience. So might be working with iPlayer one day, the people who write the annual review another day, talking about alt text. I have to try and make sure that when somebody comes to the BBC the technology we use doesn't disable them. I also build kit cars and a piece of software that detects fraud which services about \$3 billion of transactions a week which happened kind of by accident, but that's a story for another day. I'm a student pilot 'cause they wouldn't let me learn to drive, so I learnt to fly instead. There's less to bump into in the sky.

2. Could you introduce us to Lion and tell us about him?

This is Lion. Lion has gone everywhere with me for a long time. He says he's 17. But he has been saying that for about five years. He just makes me feel happier but he also has this function, he's quite expressive, so this is the worried Lion, the oh my god I've left the oven on Lion. And also sometimes if I'm in a meeting people say you can tell if I'm annoyed as Lion'll be sat there, tapping a paw, or flicking a tail. But he also acts a little bit like a white cane. So for blind people, it's signifying that they're blind using a white cane can be a very good way to communicate to the environment their needs. And Lion kind of works in a similar sort of way. He does make people take a slight double take. He's also the best icebreaker of any meeting ever. I can walk up to a group of people and go, it's okay, the Lion's been fed. And almost some, almost every time someone'll go, ooh, I've got Teddy name. I wish he could have come, that sort of thing. So it's a good way to get into conversations and stuff. It's just nice to have him around. He hasn't eaten anybody for a while, so yeah, we're good.

3. Why is autonomy, independence and employment key to you achieving happiness?

So autonomy, independence, and employment they form a kind of triangle. One of those 'you need two of the three to get all three' sort of thing. So autonomy is

about decision-making. Making decisions about my life. Independence is then carrying out those decisions. And then employment is kind of the decisions I'm making. So I might choose, for example, I access support at home to help me with cooking and prompts and keeping a routine which frees me up to have enough energy to then do my job for the BBC which is helping people. And then the money the BBC pays me then pays for the support so it kinda goes 'round in a big circle. Any one of the three missing can be very brittle indeed. If you have support and independence but no employment and no income stream then you're going to be very limited on the support you can access. If you have employment and independence but you don't have autonomy then it's very brittle and it'll break very often so that's the old, yes Jamie's completely independent, he can cook one meal. That's not really independence. Being able to do something yourself because you have no other option isn't really autonomy. It's not really independence. It's kind of being trapped in a situation you can't get out of. So yes, so all three kinda add up to being a foundation for what I think makes me happy.

4. Can you tell us your views on the importance of the social model of disability and why professionals should use it?

So the medical model is one of many lenses. But the same as I need two lenses in my glasses to see properly and in 3D, if you approach every problem with only the medical lens, you are missing the depth of the problem. So whilst the medical lens, I wouldn't say the medical lens is a bad lens, but it's not the only lens. And if you use only the medical lens, you miss out on more obvious things. So I can think of examples from my own background where somebody would go, ooh, Jamie didn't do this because his autism, because he had anxiety, because he had blah, blah, blah. And I'll go it's that flickering light in the corner. If you haven't ruled out the environment, then you're not ready to actually focus on the person and I think because we tend to pathologise autism and autistic people we tend to jump for the answer inherent in them before we look at the environment. I think a lot of professionals may adopt the social model without knowing it. Certainly in my experiences, one of the strongest things about the social model was the move in my internal model of myself. So, as a kid, I knew I was broken. I knew I was difficult. I knew I couldn't do things. But when I learnt about the social model I started applying it to my life and said, look, it's not that I'm defective, it's that the environment is disabling me. So if I start modifying the environment, it will stop disabling me. I'll still remain impaired. I'll still have trouble crossing roads or whatever. But I can stop it from having a negative impact on my life. So then I started focusing on the environment, not myself, because after 25 years of trying to fix everything by trying harder, I had no harder to give. So the social model is a

great lens to start with. I don't think there is a best lens. But it's certainly the simplest. It's a place to start and then you kind of spider out from there.

5. You have discussed before how you are disabled by a badly designed environment - what would be a well-designed environment?

So a well-designed environment for me, Jamie, is an environment that meets my needs and that respects choices that I make. So a good environment, this would be my home because, of course, we've built it to fit my needs. So let's kind of start with the lounge. A lot of people when they walk into my home. I'd say that it's minimalist. My family tend to refer to it as empty. Because there's a lot of visual noise and clutter. So I tend to keep only in view the things that I actually need and use. 'Cause it's like, I'm very good at remembering things. But I'm not very good at filtering that list and know what the important things to remember are. So if I have 155 items on display in my lounge: Lego models, books, book covers, I will remember them. But that's then just an overload of information. And anytime I want to think about something I have to wade through that information first. So reducing clutter and just making things very tidy. My flat's kind of an interesting colour. It's like a slightly off-gray. And then I have white skirting board and white ceiling board thing. That's so that I can see the edges of the room so that they're very well-defined. 'Cause otherwise it's quite easy to, for me, at least, to get lost in the space and my body will go from feeling this space is really big to this space is really small and then I bump into something in one step. That perception will change as I'm moving around. Which I can only describe as a bit fun. It's makes you very wobbly and a bit disorientating. So that kind of clear shape of the room followed by the muted colours followed by very little clutter is a good starting point. The other thing that I think when I think about well-designed spaces is about having spaces support the activities you've got to do within them. And then having clearly defined zones for things. So examples of things like this. Within my home I have my, the office end of my flat. My flat's kind of long and thin. At one end I've got the lounge and kitchen, a corridor, and down at the other end, my bedroom and my little office. The other way of looking at it is this end of my flat is my end, that's private. And that end of the flat is public. And then we actually have a child gate in the middle. And what we do is when the carers leave in the morning, we go 'round and we check the other end of my flat and we go, okay, are all the taps off, are all the windows close, there's nothing on fire, which is rules, eh, do not be on fire. And then we close the gate. And by doing that, it's almost like closing off that side of the flat to my brain so then I can just focus on the rooms I'm in. And then within those rooms I'll have a specific place to sit to do work and a specific place to sit to rest and, of course, I sleep in my bed. So it's about both the design of the environment, but also, design is more than how it looks, it's how it works which is a Steve Jobs quote. So it's also about making sure that if there's an activity that I'm doing often, there is a place

set aside to do it and that place is, if not optimised, at least all of the barriers are removed. It's very effective and it's, a lot of the time, it almost feels like I'm playing tricks on other parts of my brain. And that gate is a really effective way to visually and conceptually say this area I'm in, this area I'm not. And the idea came from the cafe. I spend a lot of time at a cafe. And I had this realisation at the cafe apart from the table in front of me, the rest of the world almost disappears. And I was expressing that to somebody, a neurotypical friend, and they were like, yeah, that happens for me everywhere. I was like, that's the only place on the planet that happens for me. And we went, ooh, that's interesting. So we started thinking about how we could make that effect happen in more places. Have you ever driven down a long windy road and you're, the car feels like an extension to you and you're not thinking about your driving anymore, you're in the moment. That's flow, that's flow states. As a developer and an engineer, flow states are kind of what I rely on. Everyday I need to get into a flow state on a problem and start building that mental picture of this over this box, this firewall, this gate, this system and then be able to flow around that system to get my work done. So anything in the environment that disrupts my flow, like doorbells, or car doors slamming, or whatever, that flow wall collapses and then it takes me half an hour or 45 minutes to rebuilt it again. So that's kind of another way that we've designed the environment so it doesn't disable me. Just understanding that I'm more sensitive to that flow getting broken than most other people are.

6. You use 'spoons' as units of energy. Can you explain this and how it works?

So a spoon, this is somebody else's theory. I didn't make this up. So idea is that everyday, if I've slept well, I get given 10 shiny spoons. And everything I do during the day takes spoons or gives me spoons. So sitting down in a quiet corner with Lion and giving him a hug, having a chill out moment, listening to an audiobook, maybe sometimes playing video games will either be very low spoon-usage or be spoon-positive, it will give me spoons. But doing this interview, trying to cook, which is something I massively struggle with, or crossing roads, or travelling, is very spoon-intensive. Now, the analogy, the reason I like the analogy is I can say that I've got let's say 10 spoons today. I've probably got more like eight, but eight to 10 spoons today. Ollie, my carer, who's sat in the distance there, he has like 50. So in a lot of situations, we look at it and we go, okay, is it worth using two or three of Jamie's spoons to do this thing or is that easier to say, okay, have Ollie do that thing 'cause he's got more to go with. I've got an analogy around electric cars. So an electric car might have really great performance, but it has to stop and recharge and when it has to recharge it takes longer. A petrol car might have less performance, but when it refuels it's quicker to refuel and it goes further on a tank. They're really good analogies for how my spoons work compared to other people.

So I need to build my life around this idea that I need to stop and recharge spoons. And kind of get an up and down, up and down, and keep it within a reasonable limit 'cause if I keep my spoons relatively high, I have more energy left to deal with change and unexpected things which means I get, I'm less often into the meltdown and shutdown situations where I'm not just dealing with the environment but I'm also then dealing with the response from my body. So it's a little bit like in engineering terms we always say that maintenance is better than repair. You keep your system maintained and keep it going rather than wait for it to break and then repair it, similar sort of thing. So, everyday, we take a measure, how many spoons do I have? We also spend some time working out the actual cost of things, so I would love for being home alone to be only like one spoon an hour, but it's probably about one and a half. And that's a little bit too high, so that makes it a difficult place to be on my own for a long period. But by being able to discuss a metric, being able to go, okay, this is this number of spoons, this is this number of spoons, I can kind of engineer a day and then go, okay, so on a normal day, I might do, I might run a bath myself, but today I'm exceptionally low on spoons, so I'll say, actually, can somebody help me run the bath? And I'll save the spoons for being able to dress myself or something. So it's kind of this understanding that effort isn't unlimited. The actual cost of things might be very different from the amount I wish it cost. And if I take kind of like an engineer's view on the day, I want to get the maximum amount of autonomy and productivity out of this amount of energy. And that's kind of how we did it.

7. Can you tell us how you use technology to assist you in your life?

I'm gonna first bounce it and define the word technology. 'Cause I think that's a interesting route into that question. Technology or tools. Tools and technology are the same thing. So I think a way to say it is what are the tools that I use? And then when we think about that I could tell you a hundred tools. So how about we rephrase it as what are the tools that have the most impact? Or what are the tools that I couldn't do without? I think that's kind of an interesting approach on that question. Otherwise we'll be sat here for hours as I monologue, I'm about three minutes away from a bar chart, so we need to be careful. I'd say the most impactful tools in my life are my phone and my watch. Because they support my autonomy in the biggest way. One of the things I find the most difficult, one of the biggest impairments in my life is communication and speech which I know sounds kind of ironic 'cause I'm interviewing somebody and I'm sat on a table and we're talking about things. But this isn't real life. This is a fictional place called Birmingham where I am with a friend and I know that I can leave at any point and there's no pressure. That's completely different to being in a queue in a cafe when there's somebody behind you and somebody in front of you and you don't understand the menu and it's loud. So on my phone I have assistive communication technology I can use at

any point. Even if I'm not using it, having it available at any point means that I can take those risks. Or to build on an answer from earlier, if I'm relatively low on spoons, I used to end up trapped in my flat because I couldn't take the risks. I couldn't get close to that line without high risk. But now that I've got the AAC, I can actually go over that line a bit, if I lose my speech it doesn't really matter and we can kinda rebuild up from there. So my smartphone and the communication ability of that. The other thing I have is I have an Apple Watch. I love this thing. The Apple Watch does kind of three features that are really important to me but I hope I never have to use them. So the first one is the Apple Watch has an SOS mode which means wherever I am in the world, wherever I am into trouble, I can press and hold a button and somebody will know. So if I'm out on my own at the cafe and I'm really struggling, I've got a simple almost foolproof way to get help. The second one is it carries a medical ID. So if I do get hit by a car, my medical ID has written in it, in literally bold letters, find the Lion, do not remove Jamie from crash site without the Lion. So that means I go out and not risk losing Lion. I can also tell them I'm autistic and may not be verbal and who to call and stuff, but that's a useful thing. The third thing is that I have a way of paying for things strapped to me so when I used to go into town, before I had the watch, I'd lose my card or I'd forget the PIN, or you'd be under pressure and I have a lot of numbers in my head. The numbers of times that I've tried to type the bus number as my PIN on a bus, that sort of thing, although now I think you do contactless, it's not a problem. It's that sort of thing, or the address of the shop rather than the PIN number 'cause there's lot of numbers in there. This thing I just tap it twice and go boop, and it, I can't drop it, it's literally strapped to me. It also gives me lots of visual prompts. So I've put my calendar on the front. My calendar is covered in emoji so that it's like a rolling visual prompt for the rest of my day. So I think those two pieces of technology. When either of those get broken, they get replaced same day because they have such a massive impact on my autonomy.

8. What advice would you offer autistic people who have difficulty socialising?

The advice that I would give is to find out who your peers are and your peers are probably not the same age as you. So most of my friends, most of the people that I know in the web design industry are 10 to 12 years older than me. And I found them online because I used to be on this really brilliant, I started off as a web developer, or I was kind of coding in my free time. And I was in supported living. Nobody in my life at that point had actually heard me speak, so a lot of people assumed I couldn't speak which is a whole other problem for whole other day. But I was online and I was on this web design forum helping people and then that started giving me work and then I'd start making friendships and people would know me and then I'd start getting called into conversations and before I knew it, I had a little business

building websites. On the internet, nobody knows you're autistic. On the internet, the communication barriers kind of vastly break down. I can take time over composing a message. So most of my friends have come from that era, that time when I was first online and I was making connections with people. And then that eventually led to jobs and employment and going to the BBC and everything else from there. So kind of that idea of finding your true peer group is kind of the first step. And the way that I tend to recommend people do that is go grab things like magazines, go look in the back, find forums, find the name of the people who are writing, if you've got a specific interest like trains or something, go hit those magazines. Also, a lot of the times if you email them and go can I write an article for you? They will be very welcoming to it. 'Cause they're always looking for new voices. And a lot of areas the groups involved are ageing, so for example, trains and engineering. The average age is something like 55 now. So they're always interested in new, young people. Classic cars is another example. So if you show the interest those communities are kind of motivated to be inviting. And to be honest, a lot of time, they're full of a lot of already autistic people, so some social conventions that you might have at school just don't apply. So for example, I love the fact that at a lot of kind of nerdy, geeky events, we don't bother with networking. Networking turns into a bunch of people sat on the room on their phones talking to other people who are also in the room on their phones. And that's just normal IT networking 'cause it's more efficient.