1800 Seconds 27 November 2018
BBC Sounds

Presented by Robyn Steward and Jamie Knight

Episode 1

JINGLE BBC Sounds, music, radio, podcasts.

JAMIE Hey guys. Before this podcast starts there’s a trumpet coming, just so you know.

ROBYN Turn your volume down a bit. Shall we do it then?

JINGLE 1800 Seconds on Autism with Robyn Steward and Jamie Knight.

[highlights from the upcoming programme]

JAMIE Are you going to cook a meal tonight?

ROBYN Yeah, I think that’s going to cost two spoons to be honest.

JAMIE Oh okay.

ROBYN It’s a lot of spoons. I haven’t got any spoons left now.

JAMIE So, I pulled it out and threw it on the floor and it was like wait, now the fire’s out of the oven that’s probably not a good idea.

ROBYN My parents knew as soon as they soon me definitely something wrong with you because you’ve gone grey and you’re not speaking very much.
[end of highlights]

[End of jingle]

ROBYN Welcome to 1800 Seconds on Autism. The name might give it away but I’m just going to say anyway that this is a programme about autistic life, presented by two autistic people. I’m Robyn Steward.

JAMIE And I’m Jamie Knight, although most people know me as Jamie and Lion, and I should probably explain the lion.

ROBYN Who’s Lion?

JAMIE So, lion is a 4ft long plushy toy that goes everywhere with me. He’s really lovely. He’s here now. He’s waving at all the listeners, which you know doesn’t really make sense for a podcast.

ROBYN And the antelope, he’s waving at the antelopes.

JAMIE Oh yeah, he really loves a good antelope. Lion is about 4ft long and he goes everywhere with me. A big fluffy lion, and he’s one of the ways that I approach interacting with the world as an autistic person. But of course not all autistic people are the same.

ROBYN Yeah. And we have our neurotypical support person, well he’s actually Jamie’s neurotypical support person, Ollie. Hello Ollie.

OLLIE Hello.

JAMIE Ollie is part of my autistic life, so whereas for example a lot of people find it easy to go to loud places or busy places I really struggle. So, we say that Ollie’s job is to make sure that I’m not on fire. Am I not on fire?

OLLIE [said humorously] Currently yes.

JAMIE Good. But he also stops me from getting run over and ending up in the wrong place, backwards, upside down and on fire.

ROBYN And our producer Damon is here.

DAMON Hello.

ROBYN And he'll be wandering in and out as we record.

JAMIE In future editions we'll be having all sorts of guests doing a bit of music, because Robyn is very musically talented, and we're going to be playing with some gadgets. But on this programme we're just going to introduce ourselves, have a chat, settle into this slightly unfamiliar studio. And we'd like you to stay tuned because we're going to talk a bit about sensory stuff and what is and isn't autism friendly.

So, Robyn, the question that the producers of this programme want to know is – drumroll please, can I have a drumroll – is this studio autism friendly? What do you think?

ROBYN Well, I prefer it when the lights are off.

JAMIE Yeah, I think I prefer it when the lights are off as well.

ROBYN Maybe we could ask Ollie if he could turn the lights off?

JAMIE Ollie is very nice. He's a very good friend of mine and he quite often helps me adapt environments so that they suit me better. And with the lights completely off I think that's working better. Thanks Ollie.

ROBYN That's better. Jamie, maybe you should have a wander round and check out the studio and rate it.

JAMIE This is a thing I do when I'm getting used to places; it helps me get an idea of how big they are. So, I tend to wander round them and look at things. I'm going to take my headphones off so I won't be able to hear you, so this should be a blast.

ROBYN So, Jamie has taken his headphones off.

JAMIE And the thing that interests me first is that the glass is all funny angles. So, I'm running my fingers around the outside of the room and I've found a seam in the wall. I wonder what's behind there. And I'm just running the edge around the outside so I get an idea of the size of the space. And it also means that I tend to find things that I might not have noticed. So, I'm now stood behind Robyn, I promise I won't eat you, already eaten breakfast.

ROBYN Oh good, that's good.

JAMIE There's a whiteboard in here for some reason. Here's a sound desk, and I'm not to touch all the shiny tools.

ROBYN Is this helping, Jamie?

JAMIE I think it does. It helps me get an idea for the space. And we've already adjusted things like the lights. So, I'm going to pop my headphones on and then come back into the radio world.

JINGLE You're listening to 1800 Seconds on Autism.

ROBYN Recently I read your blog on Network Autism where you were talking about support, and I know that you have paid support and support from friends. Maybe you could tell us more about what that means in your daily life?

JAMIE Yeah sure. The way that they, they're really great actually, so a couple of years ago I got into a bit of a sticky situation: I was really struggling to live alone and I was very ill, as I think you know, and I got a flat nearby. It was very quickly apparent that I wasn't going to be able to live on my own. Weirdly at first they did all the support, but they needed help, so we literally found a babysitter. We just went on to findababysitter.com and went, uh, we've got an autistic adult who needs help with dinner, and we found a babysitter. And she came and started my evening routine.

And then over time my evening routine evolved and I got paid support to help me with dinner, bath, all that sort of stuff, laundry. And then my friends provide the more kind of adventure support. It's kind of important to me that my friends are friends, not carers. Do you ever get this with things where you find that the care element of a relationship makes it a bit complicated?

ROBYN I wouldn't use a friend as a carer because of that, because it's important to keep them separate. Do you mind having a babysitter? Does it make you feel like a child or you don't mind?

JAMIE I don't mind. The lady was really nice. She worked in a special school so what she did is, actually in a way at that time I really needed someone to help me structure things, and that's what she did all day at school. So, we put together routines, visual timetables etc. etc. These days I tend to use a more traditional care agency because I've got a care budget, and they're nice – it's a different thing, professional care is different from friends. Over time I'm looking forward to when the care is more isolated from friends, because then I can spend time with my friends being friends. Does that make sense?

ROBYN Yeah. I don't really have a lot of care. I have lots of difficulties doing everyday things because I have, well if you count autism as a disability then I have ten disabilities, but if you don't count autism then I've got nine. Personally I count autism but not everybody would. Things like cooking, for a long time I just lived off ready meals, or if my parents sent me a food parcel. But recently I've been using a recipe box service and that's been really helpful. I've tried a couple but I can only really cope with six instructions and they need to be clear, and I need photos that are big and taken with a bit of perspective rather than taken as a bird's eye view or as you would see it being the person doing the cooking.

JAMIE That's interesting. Cooking is this collection of steps, isn't it, and the instructions are never complete. Many years ago I was living somewhere and I'd been on trains a lot, and you get on a train but really you get in a train, anyway I'd been making these pizzas in a microwave and this carer, I'd say to the carer, oh these pizzas they're bloody awful, they're so crunchy, they make my teeth hurt, I can't finish a whole one. And she'd be like, oh well, we know you like them so try them for another day. And then finally somebody stopped to watch what I was doing and I'd confused in and on. So, I was following the instructions to the letter, I was walking up to the microwave, opening the door, putting the pizza on top of the microwave, closing the door and turning on the microwave, because I'd mixed up in and on from these trains. So, I also get this thing where unless instructions are incredibly clear and I understand the concepts I really struggle.

With the cooking I actually think I go the opposite way to you in that I see food as a thing that has to happen and I want to get it done and out of the way as efficiently as possible. And I think if I had to prepare a meal every day, an evening meal, I probably wouldn't have the energy left to work and do the things I do well. So, that's one of the reasons why we have support for it because they can do in ten minutes what would take me 45 minutes and ruin me for the rest of the day.

ROBYN Yeah. I mean, cooking for me can be difficult because it does take up a lot of spoons.

JAMIE Actually I’ve got some spoons here. Shall we explain spoons?

ROBYN Oh yeah, explain spoons.

[We hear the sound effects of metal spoons in the background]

JAMIE Okay. So,
these are spoons, these are physical spoons, but spoons are actually an analogy. Let’s pretend that we had a two-spoon day. I’m sat opposite Robyn. Hey Robyn.

ROBYN Hi.

JAMIE So, if I’ve slept really well I get ten spoons a day. But let’s pretend that Robyn has slept well. Hey Robyn, here’s two spoons.

ROBYN Thanks.

JAMIE Now, Robyn’s got the spoons because she slept well and whatever she does during the day costs spoons. So, for example hey Robyn, are you going to cook a meal tonight?

ROBYN Yeah, I think that’s going to cost two spoons to be honest.

JAMIE Oh okay.

ROBYN That’s a lot of spoons. I haven’t got any spoons left now.

JAMIE So, therefore Robyn’s run out of energy and she can’t do anything.

ROBYN Yeah.

JAMIE So, spoons are a metaphor for managing energy. I also would sometimes refer to it like battery charge. The thing about a lot of autistic people, and certainly myself, even if I sleep really well I only get ten spoons a day, and things like crossing the road might take half a spoon. Certainly getting here this morning took three spoons. So I need to very carefully manage that budget. It’s a bit like mis-spending by a pound when you’ve got £10 versus mis-spending by a pound when you’ve got £100.
So, that’s what spoons are if you’re wondering, and we happen to have some spoons in the room right now. I’ll put these down because they’re quite loud.

ROBYN Yeah, so I only cook three nights a week, but it could be on a weekend. But then when I’ve done that I really struggle to, say, do the washing up. And it depends a lot on the recipe. Like the recipes that are sort of familiar things they’re a lot less work, a lot less spoons, like sausage and mash potato is less spoons because it has a relatively small number of steps and you don’t have to wait for many things. A lot of the recipes involve waiting; I’m not very good at waiting. We should have a campaign for clearer instructions.

JAMIE Yeah. Well, the one that also gets me is: do until cooked. Well, what does cooked look like? You mentioned sausage and mash; that’s actually one of the meals I can make. But the way that I do it is I have the sausage stick, and it’s a brown stick that’s in my kitchen and when the sausage is the same colour as the brown stick it’s cooked. And that’s kind of like my only real way of telling these things.

ROBYN Sausages I find easy but only because the sausages I buy are really lean and I don’t mind if they’re slightly burnt on top because that way I at least know that they’re cooked properly. I did once burn some mince in a Bolognese and that was pretty horrible.

JAMIE I set fire to a lump of lamb once, which was slightly alarming. I had to call a friend and go, I’ve had a small fire.

ROBYN How did you do it?

JAMIE I left it in an oven and then kind of noticed fire coming out of the oven, which didn't seem like a thing that should happen. So, I pulled it out and threw it on the floor and then was like, wait now I'm just spreading… now the fire is out of the oven, that's probably not a good idea. So, I threw a towel over it, which turns out to be the right thing to do which was lovely. The lamb afterwards was delicious but I probably shouldn't cook it that way in the future. Actually since then I've not cooked any lamb because it's kind of terrified me a bit. Chicken is another good point as well. You know when they say cook it until the juices run clear, I don't have a clue what that means. It's like do I pick it up and squeeze it? Do I stab a hole in it? There seems to be all this implied knowledge like if you're stabbing a hole in it you need to stab it in a certain place or a certain hardness or a certain type of fork. And in my day-to-day life I can make more good in the world – because that's my goal, my goal is to make things good, use my skills as much as I can – I don't have cooking skills, they're not there. So, if I can use my technology skills to build things to help other autistic people, but I accept that somebody else is going to help me cook or somebody will just cook it for me that's fine.

ROBYN So, I think we can agree that we've both had difficulties with instructions not being clear enough.

JAMIE Oh yeah.

ROBYN Do you think there ought to be a campaign or something to make them clearer?

JAMIE You see there already is. There's this thing called The Crystal Mark, it's a standard for written communication. You quite often see it on bank letters and stuff and they certify things. But it's really hard to set these sort of clear language guidelines because language maps to concepts, and if you don't understand the underlying concept then the language will never make sense. Something that the Government Digital Service do who make all of the government websites I think they have a list of all words that are expected to be known by an eight year old and they try and design everything to only use words from that list. They have some really nice clear writing things, so all sentences under 25 words, words from this list. So, I think that helps. In fact the digital communication guidelines, called the WCAG actually now from this year onwards include simplified content as one of the success criteria. So, autistic people are being listened to but I don't know if there's any autistic involvement with Clear Mark.

ROBYN Do you think that it would stop you eating a frozen pizza frozen?

JAMIE I'm not sure if it would have because at that time I was really struggling and I'd inverted the words in and on in my head, so no amount of pointing it out to me would have noticed it because I'd misunderstood the concept. And I find this often happens to me. For years I thought that Fireman Sam the fire escaped and he went and caught it and brought it home. Because if you watch the episodes there's nothing that actually stops you from believing that. And because he was a fireman I assumed he would walk around on fire. So, that sort of literalism can be very difficult to capture. I needed to be shown not told, and I think that happens quite often. And in fact in my day-to-day life when I have the carers I give them permission to tell me to do things, because as someone starts asking me to do things I tend to get a bit muddled up and I'm not sure what they mean. Do you ever get that when people say, ooh would you like to da, da, da? Would you like to have a bath? And you're like, is that an instruction go and have a bath because I smell, or is that a genuine question would I like to have a bath or would I prefer a shower – the context isn't there for me. Do you ever get that?

ROBYN I tried hard to learn about context. There's a book by Peter Vermeulen called Autism is Context Blindness, because most non-autistic people communicate within context, so I try to learn to be able to think my way to of it. But my mum did tell me once to go and put some bread in the toaster, which I did, and then about five minutes later she asked had it popped up yet, and I said no because you asked me to put it in the toaster. And she said, oh well I meant put it in the toaster and pull the handle down. But now I know that I'll remember to pull the handle down.

JAMIE The trouble for me is I don't remember those things and there are so many of them that I just can't really keep a database of them in my head of every single little weird thing that I need to remember. And I tend to make the same mistakes multiple times, and people think that I will learn by getting it wrong, and I tend not to.

The way that normally works for me is to modify the environment in some way. So, for example for a while I was going out without my shoes on, so we put a big thing on the back of my door saying, wear shoes, kind of like a checklist. And we followed it this morning leaving the flat: shoes, watch, ear defenders etc. Although we did have this idea that we should pull up my rug and put some Lego in front of the door so if I try and go out without shoes on I'll know about it because my feet will hurt. So, that sort of thing, modify the environment to tell me what I need to do rather than try and expect me to remember things.

ROBYN How far from home did you get without shoes?

JAMIE I've got all the way to the end of the street without shoes before. I've actually got all the way to the end of the street, picked my foot up, pulled a stone out of my foot and then noticed I wasn't wearing shoes. I sometimes can't feel my feet, they're a bit dodgy, so it's surprisingly hard to notice if you've got shoes on or not.

ROBYN Do you ever worry that you're going to forget your door keys or something.

JAMIE I forget my door keys quite often. Within a five-minute walk of my flat there are three people with door keys, and I also have access to people via [track? 15:24] systems so that I always have some back-up options available.

[a crash noise happens in the background of the studio]

ROBYN Oh, I think Ollie fell of the chair or something.

JAMIE I think Ollie's chair broke.

OLLIE Yeah, I think it broke a little bit but it's okay.

ROBYN Your chair broke a bit.

JAMIE Were you falling asleep?

OLLIE No.

JAMIE Carers do this often: they fall asleep. So busy. Because if you think about it…

OLLIE It's a hell of a responsibility.

JAMIE Yeah, it's a hell of a responsibility. So, he's got me here safely this morning and I haven't got run over, which is good, but it does mean that he has to be very aware of things. In a way there's kind of this balance of I know that by accessing support I'm making my impairments affect other people, but as long

as it’s an equitable set-up, you know Ollie’s paid for his time, it’s a fair pay, and there’s a genuine win-win situation then I think it’s okay.
If I didn’t have any support I would probably just about live independently but there’s no way I’d be working. I’d just be a stressed out incredibly tired all the time muddled up mess. So, the little bit of support that’s there really does support my life.

JINGLE

FEMALE VOICEOVER: Coming soon to 1800 Seconds on Autism:

[highlights from episodes in the forthcoming series]

// WOMAN’S VOICE
I think I was trying to do the normal thing and it wasn’t working for us. So I was taking him to these god awful music groups that you take toddlers to which were absolute hell for my son. He was trying to escape I now realise. //

// ROBYN What is it in particular that makes you interested in Dr Who?
GUEST Big question. I don’t know.
ROBYN It’s okay, don’t worry, our producer Damon is neurotypical and that was a neurotypical phrased question that I was just repeating back. Sorry. //

// MAN’S VOICE
I’ve come to the conclusion that we’re all like light switches: we’re either on or we’re off; we either love something totally or totally hate it. //

// JAMIE Yeah, that’s an interesting poem and I like several parts of it, although one part of it is sticking in my memory quite strongly.
ROBYN [very funny infectious laughter in background, then a slight bang noise]
JAMIE Robyn fell off the chair!

FEMALE VOICEOVER
Hear more from Jamie and Robyn by subscribing to the show on BBC Sounds.

FEMALE VOICEOVER
Send any questions or thoughts to stim@bbc.co.uk.

[End of jingle]

ROBYN Well, we’re settling down nicely in our studio aren’t we Jamie?
JAMIE Yeah, I quite like it. It’s nice and dark, lovely people, lovely time, all good. Hey Robyn, you asked me about my keys. Is there any reason why you asked about keys?
ROBYN Well, because if you’re not wearing shoes then that probably means you haven’t gone through your routine for going out, and if you haven’t gone through your routine going out you might not have your door keys but you need to get back in to get your shoes to keep your feet safe from stones.

And yeah, so I have a short routine when I leave my flat that before I close my door I check that I've got my keys by tapping them [keys jangle] like that, and that my phone's in my pocket by tapping my right pocket, and if it's hard that means my phone is there, it feels a certain way. And then I tap my left pocket and that feels a certain way and that's where my wallet is. So, I do that every time before I leave my flat, before I close my door, just to double check that I have my keys and my phone and my wallet, because I know that I need those three things to really be able to survive. But it always gives me a lot of anxiety about forgetting those kinds of things. You're lucky to live near loads of people that you know.

JAMIE It wasn't luck. We set it up on purpose. The whole idea is I live in an environment where if I have a really … the way that we've built it is that if I have the worst possible day I can have, which is no speech, no ability to communicate at all, really struggle with a panic attack or something, the support is in the environment. Now, in my life the way that we have it set up at the moment is that I have support overnight. This is again one of those trade-offs of the cost in spoons, basically if I'm alone overnight I'm not going to gain any spoons, and if I'm not gaining spoons then there's nothing else I can do. So, for now we're putting the support in place overnight. Now, my hope is that by the end of the year I won't need it.

I'm currently in the process of moving home and as I'm moving home we're trying to change the environment as much as possible to make things safer, to make things more comfortable. So, a good example of this would be we're fitting fire doors so if there is a fire it is actually safe for me to stay in my room. We're also doing things like I have Piperline set up which is like an emergency response button that goes through to a call centre, and we have them set up that if I moo at them it means that everything's okay; if I press the button and they don't hear anything then they send somebody.

I'm never a good judge of when it's an emergency. So, if I hit the Piperline three times in one night because I'm ill, they don't care, I don't care; again we just recover from [20:13?] quickly. But that's why it doesn't go to friends, it goes to a call centre.

ROBYN Why did you choose moo as a sound?

JAMIE Because I can say moo even when I'm non-verbal most of the time. Moo is one of the few noises I can make when I'm really struggling with speech. And it's also really clear over a telephone. So, if I moo at you it generally means everything's okay.

Do you ever get that words just kind of dribble out all by themselves and then you need to try and stop them all falling out? It's like words all over the floor and then you feel like you're going to have to clear up a mess?

ROBYN Um…

JAMIE No?

ROBYN I echolalia sometimes, particularly if I'm stressed, which means that I repeat things like, mind the gap.

JAMIE Yeah, echolalia is repeating things. I used to do it, bless my friends, one of my friends was called Tabby and when I was really struggling with my speech the first speech that I got back was, bad Tabby! Which was something that someone had said to him when he spilled a drink, but I echoed it back to them over and over and over again.

I get the same thing with Thomas the Tank Engine lines sometimes in that very occasionally if I'm really stressed I'll spit out some random Thomas the Tank Engine dialogue from 20 years ago.

ROBYN So, some people say that echolalia is just something that happens when you're a child but we both experience it as adults.

JAMIE Yeah, it's just part of being autistic. It's the same as stimming when I flap and other bits and bobs. I get this feeling sometimes when if I can't pick words then my body kind of defaults to the nearest communication. So, for example most of the carers in my life have never heard me speak, which is why it's a bit odd when I give them this podcast link because they haven't normally heard my voice. But when they arrive at the door the best I can normally squeeze out is a hello, or hula, it's just the word that will come out. But very occasionally if something is going very well they'll get a little bit of echolalia out of me. And I think part of it is because they're very important people in my life that I'm very dependent on and I know that communicating the wrong things can easily be misunderstood there's a bit of anxiety there.

My speech has been on and off for ages so it's not anything new, and for the most part we just ignore it, we just let it happen. Because eventually, it's like building up momentum, it'll start off as a bit of echolalia, or many years ago I think we did an event together with Temple Grandin and I started my presentation by reading a poem because the poem got my speech going and a bit of momentum up, and then I could start picking my own words. So, speech is something I find quite difficult, which is kind of ironic considering I make podcasts and do public speaking as part of my job.

How do you find speech, Robyn?

ROBYN I'd say 99% of the time I have speech. Only if I'm very ill I tend to go very quiet. When I got diagnosed with irritable bowel syndrome I went to the doctors complaining of abdominal pain and they said that I should go to A&E if it continues, and I thought well that's not going to be good for an autistic person, A&E, and autism on their own, that sounds like a bad combination. So, I went to my parents, because my parents kind of act like a triage.

JAMIE Yeah, my friends do the same.

ROBYN Yeah, so I went and my parents knew as soon as they saw me, definitely something wrong with you because you've gone grey and you're not speaking very much. Definitely something wrong. We're not sure if you've got appendicitis but totally see that there's something wrong. And so they got me a GP appointment and they took me because I needed someone to advocate. I couldn't understand the questions; I needed the questions rephrased.

JAMIE Yeah, this is exactly the same as basically any time I go to the doctor I go with a friend or with a support person because that's the time when I need to be able to communicate most accurately, but by definition I'm least able to communicate. It's actually kind of interesting because you have to have a lot of trust in the other person's ability to read you, and that can take years and years and years to develop. It takes a long time.

ROBYN Yeah. So, then the doctor said that I had irritable bowel syndrome and she gave me some medication for it and then that made a lot of difference. As soon as I took it I went to sleep and then when I woke up I was much better.

JAMIE That's good.

ROBYN I wasn't cured but over a two-week period I got much better.

JAMIE Yeah, we get a similar sort of thing. I've had ear infections persistently for months because I don't feel the pain from them, so until there's dribbly stuff coming out of my ears I don't really notice. But now they're gone I can tell that my head feels better and that I can think better and that I have more energy. But if you'd asked me before, oh do your ears hurt, I wouldn't have been able to say yes or no. And again sometimes it's the people around me going, Jamie's quieter than normal or Jamie's sleeping a lot more than normal, and then they have to kid of almost do a debug routine of kind of like, can you feel your feet today, how about your ears, how about your teeth. And then we finally work out what's wrong.

And weirdly I have a feeling that when I was a kid I was actually better at this; but as I've got older it's got harder and harder to read my body. I don't know if other autistic people experience that.

ROBYN Well, your body's bigger than when you were a child.

JAMIE True.

ROBYN And you probably, I'm not a man so I don't know if it makes a difference, but you probably have hair on your chest and your back and your arms and your legs and you wouldn't have had that when you were a child.

JAMIE Yeah maybe.

ROBYN So, that might mean that you get different – I know everybody's got hair but…

JAMIE Yeah, I know what you mean.

ROBYN So, I mean maybe that. And also you have to have more sensory experiences because you have to have a shave.

JAMIE Shaving was a thing that took a long time to master. I can't do it in front of a mirror. If you put me in front of a mirror to shave I can't coordinate it because there are too many signals. So, I learnt to shave by borrowing a dull razor, which sounds silly, but I borrowed a dull razor and just learnt how to feel my face and run a razor over it opposite to the way that it cuts and then kind of built up from there.

ROBYN Do you mean that when you're in front of a mirror that there's too much information from what you're seeing is the opposite?

JAMIE Yeah, exactly that. Flipping it back the other way round I find incredibly difficult. It's one of the reasons why I don't drive because when I look in rear-view mirrors my brain puts them on the other side of the road from where I am; I can't vision them in space. It's another reason why I walk around rooms, because when you walk around rooms you actually find where the real corners are. Because in this room you've got grey in all the corners and it can in one moment feel like it's expansive and 100 miles wide and then the next moment feel like it's a tiny little box. So, having that reference of how big the room is is something that's really helpful for me.

ROBYN We have to say what stimming is because we've mentioned it a couple of times. And our email address, our lovely email address is stim@bbc.co.uk. And stim is the singular of the plural which is stimming [spells], and that's the autism community word – not everybody likes it – but that's generally the word that's used within then autism community to describe what professionals might describe as repetitive routine behaviours.

JAMIE Lovely, got to love how the professionals pathologise stuff.

ROBYN Yeah.

JAMIE You know like when somebody wins the lottery they jump up and down and flap, that's what we do, just more often.

ROBYN Yeah, flapping and rocking and spinning in circles. Did you know that I did a survey of 100 autistic people and I asked them about their stimming? I think that 72% of people had been asked not to stim, 50% of people said they liked stimming, 30% of people said they liked stimming sometimes. And the top three reasons for people stimming were to reduce anxiety, calm down over-stimulated senses and I don’t remember what the other one was. But anyway there are a couple of reasons there, reducing anxiety and calming down senses, whatever.

JAMIE Do you get this sensation that, for me stimming happens in my body and comes out, and the more I let the stims flow the more I feel myself and actually the better I feel about things? When I was a kid being stopped from rocking or stopped from flapping my hands was…

ROBYN Quiet hands.

JAMIE Yeah, quiet hands. So, this is a phrase that I don’t know if we still have it in special schools but golly it was a pain in the butt for me, I had it a bit at primary school and quite a lot at my first secondary school, if I was flapping my hands or clicking a pen lid or something I’d be told, oh quiet hands Jamie. Which I of course took to mean hands faced down like I’m a prisoner on a table. And it used to be the bane of my existence because the moment I stopped paying attention to that and got distracted by something else they’d be back up flapping again. But actually the flapping and the movements and stuff they all helped me to think and work and be part of my own body.

And I think sometimes in the urge to make being around autistic people more comfortable to non-autistic people we actually deny autistic people bodily autonomy, control over our own bodies. And that I think is one of the most corrosive well-meaning things that people do. I know they mean well but it can be really difficult.

ROBYN Yeah, let the flap free.

JAMIE Yeah, free the flaps!

ROBYN Yeah.

JAMIE And as we said before, if you’ve got a flap that you want to send us e.g. an email or something, then please do send it to stim@bbc.co.uk.

ROBYN You can send a photo.

JAMIE Or a video; we’d love to see that.

ROBYN Yeah we would, yeah.

JAMIE Although we’re making a podcast so we won’t be able to show it on air. We’d be able to go, ooh that’s a nice stim.

ROBYN Well, to try and avoid information overload I think we’ll finish there.

JAMIE We’ve talked about lots of things today.

ROBYN Yeah. What are we going to wrap it up with?

JAMIE Well, I’ve got this little bit of script so I’ll read that. That’s it for this edition. I hope you’ve enjoyed it.

ROBYN If you did enjoy it tell everyone about it. And if you didn’t enjoy it also tell everybody about it.

JAMIE In future weeks we’re looking to talk about our home lives, autistic humour, socialising, parenting, all sorts of stuff. And of course if you have any questions or suggestions then drop us an email at stim@bbc.co.uk.

ROBYN We’ll see you next week. Please make sure you subscribe so you get to hear the podcast as soon as it comes out. Anyway thanks very much for joining us and we look forward to you hearing us again soon. Bye.

JAMIE Bye.

JINGLE
AMERICAN SPEECH SYNTH MALE VOICEOVER
That was 1800 Seconds on Autism.