Redduck Interview

KA: And yeah, the reason I have recordings is just so that I can make transcripts of those later(.) Um(.) And this recording won't go anywhere just so that we can keep things completely anonymous(.) but I will type up everything that's said and then that transcript will have like your name removed from it. Anytime you say anything that could be identifying like you talked about your school or anything like that would be removed.

Redduck: Oh good ((pause)) So if I accidentally say something ((pause))

KA: It's so easy to accidentally say things so (.) even things like if you mention like a friend's name or something like that anything like that will be removed or sometimes changed for something equivalent. So say for example you were talking about "ohh when I was visiting Liverpool" we would change it to when I was visiting a city in the UK. And yeah, I think that's everything with regards to data stuff um ((pause)) and then there ((pause))

So more practical stuff ((pause)) you have the right to withdraw at any time. That could mean in the last minute of the interview you're like "actually I don't want this interview" you know "I don't want the data to go anywhere" and that's absolutely fine. And yeah (.) yeah (.) you don't need to feel worried or afraid about letting me know that. It happens a lot you know. You also can be free to take breaks at any time or if I ask you a question that you feel a little uncomfortable with you can say "actually I'd rather not answer that" or even "hmm(.) can I think about it a bit and come back to it later, can we talk about something else for a bit?" That's absolutely fine. There are absolutely no right answers (.) I'm not looking for anything in particular (.) I just want to understand. You know (.) you're the most important person here. Whatever my ideas are (.) that doesn't matter. Um. There's also no right or wrong way in how to express those answers (.) Um (.) You'll notice that I say um and like a lot and that is ((laughs)) yeah

Redduck: ((laughs))

KA: That's absolutely fine (.) That's how humans talk(.) Um (.) You know sometimes we stutter or stumble over our words and that is absolutely fine. That doesn't affect the quality of what you're saying (.) Um (.) It also might be you know with nerves or anything or I know sometimes it's just difficult to put things into words. If there's anything you'd like to write down or things like that. We can include that alongside the transcript. So yeah ((pause)) um.

And then yeah we've got the stress ball and the pop its. Tissues are there the toilet is right there and I can show you if you need that at any point. Um but I think that is everything (.) that I have to tell you. But were there any questions you had?

Redduck: Um ((pause)) No not really no.

KA: OK amazing. And again if in the interview you have a question about something (.) or whatever (.) there's never a right time or a wrong time to ask.

And yeah the last thing I wanted to check with you. Um. Were there any preferences you had with regards to communication? A lot of our participants have preferences about eye contact and things like that. Is there any ((pause))

Redduck: No (.) I don't really know ((pause)) I think I'm ok with all the other um ((pause))

KA: Ok! Fantastic. Fantastic. And again if you (.) if throughout the interview you think of anything that (.) you know (.) could make you more comfortable just let me know and we'll see (.) we'll see what we can do. Um. I also will kind of be making notes on my laptop and in this little book throughout so if at any point it looks like I'm not paying attention to you I can promise I am it's just I ((overlap))

Redduck: Yeah

KA: I'm (.) I'm trying to type at the same time. Um

And yes I might as well cover it now as well ((pause)) In terms of what happens after the interview (.) um (.) We will reimburse you for any travel costs um so if you came by train or bus or something and have any receipt of that. If not we can (.) so if you came by car we can reimburse you some petrol money

Redduck: That's ok

KA: And yes, we will be in contact probably a few months after the study is done when we will ((pause)) well first (.) we will be in contact before that (.) like (.) perhaps a week or two afterwards when I'll send you back the written out version of everything you've said

Redduck: Ok

KA: And you don't (.) If you don't have time or don't want to you don't have to look at it. But if you er (.) there is anything you know (.) anything you wanna change. If you look and think you know the way I said that actually I'd want to change that a bit

Redduck: Mm yeah (.) good yeah.

KA: Yeah, because I sometimes say things ((overlap))

Redduck: Yeah! ((laughs))

KA: and then 10 minutes later I'm like that's not what I meant to say I've done and why ((pause)) I did it wrong. So you have the chance to go over anything and make any changes. And then (.) depending on how quick I am with my analysis (.) a few months later probably (.) we'll send you back our drafts for the full paper. Where your interview (.) what our findings are from your interview will be combined with probably like 20 other or autistic adolescents and we'll be presenting like our findings. And again if you have any comments or things you wanna say about that (.) um because yeah (.) sometimes when it's combined with everyone's results, things can look a little different and ((overlap))

Redduck: Ok.

KA: Yeah, cool. So first question do you want to tell me a little bit about yourself? This can be anything ((overlap))

Redduck: Ok

KA: Doesn't even have to be relevant to the interview

Redduck: Um ((pause)) I don't know where to start ((pause)) um(.) I was er (.) I guess (.) I was (.) er (.) diagnosed when I was fourteen. Um (.) and that was following a misdiagnosis for anorexia so that is kind of what led me to being diagnosed autistic. Cos I unfortunately um when I was

growing up during those key years um ((pause)) well I guess it's hard to put it into a timeline ((pause)) But I guess the place to start would be um in year six. Um I had my heart set on getting into uh my local grammar school and um *I didn't manage to pass my 11 plus due to high anxiety (and being undiagnosed autistic)* because I just freaked out I froze and I couldn't process um doing the actual test and I completely in the lead up to it I couldn't even face to look going through my revision or or any of that. I was just so (.) it felt like it was being ((pause)) It was very extreme for me even though I know wasn't (.) at the time it felt like if I didn't pass that test I had no future (I struggled to see the bigger picture as I felt so fixated on the test). I guess ((pause)) Um. ((laugh)) And so I um then went to my parents decided it was best for me to go to the nurturing sort of school because I don't think I'd get on with the public schools so uh I was fortunate enough to go to a private school um for my secondary years. And I was there year seven and then (part of) year eight. As I started to start to mature it started to get really confusing for me. *Friendships were challenging (unfortunately my year group wasn't a particularly friendly group of girls, I had to try hard to fit in and this didn't feel very comfortable)* (.) the environment felt very closed in (.) and I had teachers left, right and centre cos everyone knew everyone because it was I only had 20 girls in my year (.) um. *I was getting picked out a lot for being different (I wasn't as 'out there' or 'confident' in comparison to most of the other girls, this was seen as a negative that I needed help with to build my self-esteem and resilience, when really I was just happy not being the first to volunteer for everything all the time, or put my hand up a lot in class) essentially.* But they sort of just thought it was anxiety. I think they thought it was dyspraxia at one point and all sorts of different random things and um. But I was just confused as to why um I was being focused on and I had to do weekly anxiety sessions with the school nurse and things. And I didn't know why because I didn't (.) I wasn't (.) Anxious. I was just (.) You know (.) *My friends weren't real friends (I was in a tricky friendship with one particular girl, who turned out not to be who I thought she was, which hurt me quite badly) and I was in a school that wasn't really right* (.) I guess. But a lot of stuff was going on at that time and uh it did get too much for me and I did reach my breaking point and my coping mechanism for that was that I had to substitute that (.) feeling of anxiety with a feeling of sort of emptiness, I guess I felt very numb. And so I stopped eating and drinking (.) um (.) that's sort of the way (.) because that's the way (.) the only way I thought I could show people I do need your help (.) but your help isn't the right help ((overlap))

KA: Mm

Redduck: I'm confused ((pause)) Um ((laughs)) didn't happen

KA: Mm

Redduck: But I didn't know that (.) I wasn't deliberately not eating for the intentions of what's typically um associated with anorexia about body image and all of that *(I don't know if it is helpful, but as a part of 'internal feeling' and interception, I was also petrified of growing up, I didn't like the idea of my body changing or pains associated with periods etc., this may have also acted as a slight trigger for my behaviours as the education I had been given in school surrounding these changes was generic and not fit for my autistic brain, so I took the information very literally and couldn't really process it)* and I had no awareness of that because I was still I guess emotionally very not matured with the rest of the girls in my year. Um but it was (.) it was (.) quite... I lost my train of thought again. It was quite weird

((laughs)). And so I um (.) obviously I um (.) because I wasn't eating my health declined quite quickly and that got picked up on and not what I was doing that for (.) to get picked up on. Which shocked me cos I was like I wasn't doing this for this reason but um. So I was (.) then uh then went into hospital and I was in hospital um for a couple of weeks and it did nearly get to the end point and then CAHMS came along and it just sort of took off from there (.) um (.) and when CAHMS first intervened (.) me and my mom (.) we had no idea what was going on but we were working really well together and I trusted my mum and and she knew it wasn't that illness. She knew it was ((overlap))

KA: Yeah

Redduck: Something different. So she was just helping me and I was slowly you know getting myself back together and then had full intentions of I love swimming and running so I had full ideas of going straight back to them. And it was all that (.) um ((pause)) But CAHMS changed the way that my mum saw me and how I saw myself because they were told it was anorexia and they sort of misled my parents and me (.) um (.) almost like brainwashing. It was quite brutal some of the stuff that they would say to us um. You know like I wasn't their real daughter (.) I was (.) there was another part of me cos of like ((overlap))

KA: Oh!

Redduck: Like two different people in in the brain and all of these very overwhelming concepts. Um so my parents didn't really see me as a human and I didn't see myself ((pause)) see myself as human (.) um (.) So then sort of from that and when I was improving my health um CAHMS's reaction felt very negative because if I improved my health they (.) sort of didn't really care about me. And they (.) they were just like "oh OK, she's actually fine (.) she hasn't really got this (.) she (.) she can do it"

KA: Yeah

Redduck: and then I was like oh but no I still I do still need help. So obviously that then made me think oh ((pause)) if I stop doing this I'm not getting the attention I need so I need to keep doing this to get somewhere because I didn't know where I was going and um (.) So then I started to back off from my mum and isolate myself and I wasn't in school. I've been taken out of school at this time um (.) and it just got progressively worse and it got to the point where I was just ((pause)) had to be rushed into hospital because it was about to be lights out and ((pause))

KA: Mm

Redduck: I still can't believe it got to that point but um ((pause)) it was horrible and so I was in there for a bit and then CAHMS decided it was best for me to go to a clinic (.) um (.) so I was in a clinic for the anorexia for five months I think? Um (.) and again one of the most horrible experiences of my life

KA: I'm so sorry

Redduck: Because um it was solely based on that and I reckon half the girls there were probably autistic as well

KA: Yeah

Redduck: Definitely. I think one of them even had an official diagnosis of autism and just being in that environment is just so (.) so wrong and um (.) it still makes me upset. But um I eventually got out of that and I was then back with CAHMS again but um there was no support after that. It (.) once they got me back to my healthy state sent me back home and that was kind of it

KA: Yeah

Redduck: And obviously I've just been isolated from my parents and the clinic was at least two or three hours away from home so I'd seen them rarely. I just felt like an alien in my own house. And I didn't know what to do. I didn't know where my future was. I couldn't go back to the school I was at because ((pause) it just ((pause)) I was lost. And um ((pause)) so my parents (.) they're just the most amazing people ever because they (.) saw past that and they saw it still wasn't right. And so they (.) my mum found a way to get us away from CAHMS and to sign us off from CAHMS completely and we started looking into our own way to ((pause))

KA: Mm

Redduck: Find out what was actually going on and that's what led us to autism (.) eventually after going through multiple different people and uh then I was diagnosed. Uh (.) we have to go private because the waiting list was too long and um that whole process. But eventually got diagnosed ((pause)) and it just changed the whole perspective of how we looked at what was actually going on for me. And so then I changed schools and I went to a public school which (.) I couldn't actually attend the public school. So I ended up getting myself somehow on track by (.) um (.) halfway through year eleven (.) that I was going to actually do the GCSE's (.) so with about three months to go to the exams (.) I started just studying all the content at home.

KA: I mean that's incredible.

Redduck: I don't know how I did that. It still kind of phases me but um

KA: A lot of willpower I can imagine

Redduck: I think I sort of got my act together at that point and realised I'm that the only one that could do something

KA: Yeah

Redduck: Cos everyone else I'd been talking to over the past couple of years just ((pause)) confused me even more. Um (.) so I did that and I managed to get all my GCSEs and I managed to get what I needed to go to a grammar and now I'm exactly where I want to be.

KA: Amazing!

Redduck: And it's amazing. But the journey it has taken to get here would have been so much simpler if autism had been identified when I was in primary school and that's sort of where I keep coming back to I guess.

KA: I think it's really frustrating because we see it a lot where mental health professionals have been trained to spot autism as how it presents in males typically

Redduck: Mm

KA: And then it can be looking them right in the face with females and they're like “it must be this thing (.) it must be this thing (.) it must be this thing” (.) and yeah. It's (.) I think especially um with eating disorders (.) there are people who've done some interviews with um autistic adults in the past that you know (.) I've been reading up on (.) and so many of them were (.) so many of the women (.) were given anorexia diagnoses even though the criteria is a preoccupation with thinness and a preoccupation with the aesthetics of losing weight. And they say “we can't relate to this. The issue for us is the sensory aspects of food or using food to numb overwhelming and intense emotions” but it's almost like...

Redduck: ((laughs)) they’re like “that can’t be right” (*yeah, it felt like even when I was diagnosed autistic and saw autistic specialist therapists, anorexia is such as scary and dominant illness, I guess, in the professional world, that any other considerations or reasoning were just immediately overlooked. Every time, no matter who I spoke to, ‘anorexia’ was put first, when this was just the coping mechanism for a much deeper and hidden challenge, I didn’t understand how, without addressing and facing the real the root of the problem, instead of just what they could see and know, they could help me!).*

KA: Yeah yeah of course of course

And so you mentioned there a bit about (.) um (.) you (.) kind of your motivations there for the periods in which you weren't eating was kind of (.) I think you said about um (.) trying to like, numb those emotions and not feeling anything. So I have a few questions now um about I guess that emotional experience. And I know this can always be a bit tricky to talk about because talking about emotions in general is (.) is hard (.) um. But I’m gonna introduce you to maybe a new word? Maybe you might have come across it if your family were like doing a lot of research into it. And that is alexithymia

Redduck: I have heard of it ((pause)) I can’t remember what it is.

KA: Amazing! Oh no problem the fact you've heard of it is like ((laughs)) that makes me really happy because I'm such a nerd about my PhD subject and I love it when people have heard of it

Redduck: ((Laughs))

KA: So alexithymia here is something that is very very common in autistic people and it basically means a difficulty to identify or describe your emotions um and that's something that we think might be quite linked to both eating disorders and anxiety and things like that (.) um (.) so (.) yeah

Obviously part of that is then in turn recognising those emotions in other people but I guess today we're more concerned with just how do you recognise your own emotions

Um (.) so a bit of a vague question now (.) but do you find it easy to tell whether you're really happy or really sad? Or are there times when you feel intense and you can't quite tell what

Redduck: Um ((pause)) it is pretty much a constant battle in my head over the simplest things. And that’s not always a negative um battle in that sense it can be over a very simple thing that I wanna do but it just feels complex. Like um I'll be trying to do one thing or thinking that I want to do one thing but I’ve got a million and one other things that I’m trying to process at the same time (.) and so I’m never really present in that one thing if that makes sense?

KA: Yeah

Redduck: *So trying to deduce how I'm feeling* is pretty impossible sometimes because normally I won't get a signal as such until it's got to its breaking point so I won't know that I'm um like anxious for something until I'm walking up the front like the steps and I'm like it's suddenly it just hits me and I'm like ((pause)) no I can't do this. *(Again, I'm not sure if this is entirely relevant or helpful, but an example of not being able to register physical sensations daily occurs when I am doing the washing up or washing my hands. I can't really feel the water temperature as such, or at least the burning sensation in my hands doesn't seem to really connect with my conscious at the point of washing. This is why my hands are always quite red and dry, I go through a lot of hand cream. I have tried to wear gloves when washing up, but I cant stand the texture or feel of wearing them, and on normal washing I just don't seem to register the water temperature quick enough before the damage is done? I feel like adapting and registering temperature changes is really challenging for me, with warming temperatures now, I have quite a hard time judging the weather and how my body will feel at various points of the day, often meaning that I end up getting overheated. I usually rely on making use of my local swimming pool during very hot days!).*

KA: Yeah

Redduck: And um I might then still do the thing but afterwards the impacts it can have on me uh (.) seem quite silly in in some sense and that's the trouble I'm having with my school at the moment because I don't (.) um I do my study at home so I only going to the school for my actual lessons because I can't study in the study environments um and like if I have to do an additional thing or like or if something's gone wrong at school I will mask it the whole time I'm there and just conform and act as I think I'm meant to. And then when I get home like I'll try and do something that would relieve my stress (.) like I'll try stretch or like go for a walk or something and my whole brain will just collapse on me and it just happens suddenly. I have no control over it. I normally start hyperventilating. And it's usually when I stretch because I like doing the splits and stuff (.) I like that feeling

KA: Ahh!

Redduck: So I I try and stretch like once in the morning and once in the evening (.) and I have like my routine with that. Normally my anxiety comes out during that period because it's the one time of the day where I'm not using my brain and such because it's like unconscious for me to stretch um ((pause)) I don't know. And so I'll just start hyperventilating whilst I'm trying to stretch and it's quite frustrating but I can't control it at all (.) um (.)

KA: Mm

Redduck: And so I guess that's more like negative emotions but it can be over positive situations as well. Like I finished my UCAS exams the other day and I hyperventilated when I got home because I was so happy that I'd I finished them. But it was in that transition into oh I don't have exams anymore (.) I don't need to study 24/7

KA: Yeah. And the way that felt from a positive situation was the same it would feel ((overlap))

Redduck: Yeah

KA: Right!

Redduck: So the feeling doesn't really change. And that is what is kind of weird to me I guess.

KA: Yeah ((pause)) that's really interesting actually (.) um and it kind of links to sort of the next topic that I wanted to talk about and this is another another word (.) I'm throwing all of the sciencey words at you today! Um (.) but that is interoception. And I think that might be what I talked about a bit in the video with Ollie [[*Redduck was recruited after reaching out when they saw me in a video on Tiktok, talking about my research*]]. But yeah it's our ability to pick up on signals within our body um and it's what ((pause)) well ((pause)) there's a lot of research on this (.) but it's what we think as a lab is a huge contributing factor to alexithymia because if you can't detect these internal signals sometimes it's a bit tricky to pick up on what your body is trying to tell you. Um (.) so yes, some examples of interoceptive signals we might have are like how fast our heart is beating (.) how fast we're breathing (.) how hungry we are (.) how badly we need to use the bathroom um. And yeah it's kind of an abstract concept but so if you were to feel your pulse. Like ((pause)) feel it on your wrist. ((Pause)) And you can kind of feel the beating of your heartbeat. Some people just without touching their wrist or anything can just feel that in their chest the entire time. Not sure if you can or can't?

Redduck: Um

KA: You can't?

Redduck: Not unless I'm like (.) physically exerting myself, then probably not

KA: Yeah! Yeah I'm exactly the same (.) I have (.) I don't understand how people do it. I'm like ((laughs)) how do you ((pause)) like? No I ((pause)) I don't have it at all unless I've yeah if I've done a big run. I can kind of feel it afterwards

Redduck: Or if I've just entered just fight or flight or something.

KA: Yeah

Redduck: Sometimes I get it. Like I think that's more flutters. I don't think ((pause))

KA: Yeah but maybe we could chat a bit about you know (.) are there any of those signals you can or are there any that you really can't feel?

Redduck: Um I guess the two hardest ones for me are probably um knowing when I need to eat and drink and that's why I have to have a very set routine that (.) I think I said in the email yesterday.

KA: Yeah

Redduck: Cos otherwise I (.) and it wasn't (.) I don't. This part I don't understand because it wasn't as big of a deal when I was younger (.) um. I don't remember ever ever feeling hungry or thirsty. But I don't remember having any second thoughts about eating or drinking. (*After reflecting, my lack of second thought may have been because my parents, especially my mum, as she was home raising me and my brother in our early years, had a very set weekly routine with when we washed/ what we ate/drank and when, what we would do everyday/ planned activities/ playdates etc., which I must have really enjoyed as I look very happy in earlier childhood photos! I never had to really think or worry about my basic human needs until I become more independent around year 4/5).* I don't know whether that's a consequence of my

experience and knowledge I've gained or uh a consequence of growing up and maturing (.) um (.) I don't know. But um (.) those (.) it feels like when I sort of from the age of 12 onwards all of my signals did either get progressively worse or progressively intense um

KA: Right

Redduck: Like sensory wise (.) um (.) my senses definitely heightened um when I went through um that period or ((inaudible)). But they're definitely getting much much stronger because a lot more things like overwhelm me I guess?

KA: Yeah

Redduck: Which wouldn't have necessarily crossed my mind when I was younger um and (.) the other one that I struggle with as well is knowing when to need the (.) the bathroom. Which (.) I know when to *need* the bathroom. But um (.) I've recently, and I'd never realised this but kind of (.) too much information I guess?

KA: Oh never too much information ((laughs))

Redduck: ((laughs)) But since I was little I've never naturally gone to the toilet (.) I've always had set times I'd go to the toilet and I would force it

KA: Mm

Redduck: Which from studying biology I now know that is not OK. Um (.) and I (.) I used to get really bad tummy pain and so I was um (.) diagnosed I guess with um (.) not um ((pause)) oh what's it called? Not the intolerance to gluten, meat and dairy

KA: Oh ((pause)) Celiac?

Redduck: Celiac, that might be (.) Um I wasn't quite strong enough (.) my blood test or whatever (.) to be diagnosed with celiac but I was put onto a FODMAP plan when I was eight to twelve years old or something like that

KA: Oh it's so harsh isn't it (.) I had to do FODMAP for a bit (.) and I was like no garlic? What!

Redduck: Yep! Yeah (.) but yeah (.) but they put that down to anxiety that I was getting tummy pains because I was too anxious and that's why I was getting a buildup of gas or whatever

KA: Mm

Redduck: And um so since then I've always (.) um (.) so I've really just really become conscious of how much I do force that and so only within the last two months I've had to like stop doing that which is hard for me because then I have no set routine of (.) when things can happen which messes with my head. But ((pause)) I'm getting better at that. It's better than getting all the problems you can get from (.) not doing it

KA: Yeah

Redduck: So um. But that was another one that I had never really come across that again, kind of weird I guess, but ((pause))

KA: Yeah (.) well, yeah (.) that's very interesting though. I think (.) yeah (.) another one that we find quite interesting in our lab is like the heartbeating one as well. And you've ((pause))

you've said that you don't feel it. But I wonder specifically when you talk about like the hyperventilating and things like that. Can you (.) do you tend to feel your heart beating more when that's happening or ((pause))

Redduck: Not (.) really my heart? It's more my throat. Like I can't (.) I tend to go (.) I know they call it ((inaudible)) but I don't really (.) I don't experience that in the same way I think as some other people describe it. But I can't talk because my throat constricts (.) feels like (.) and it just feels very very like sandpaper. Just really really sore

KA: Ahh

Redduck: And the feeling does spread throughout my whole bod but it's kind of like ((pause)) I don't really know how to describe it because my most anxious states were sort of when I was not healthy as well so I don't know whether some of these physical symptoms do might clash. So when I wasn't very healthy and had sort of panic attacks and hyperventilation sort of my whole body probably because it was malnutritioned would just start shaking and I'd feel like I was about to faint because I'd just be so overwhelmed with emotion and I wouldn't be able to process it (.) um (.) whereas now I don't experience those bits but I do still have that where ((pause)) my mainly my throat just closes up ((overlap))

KA: Right!

Redduck: And I can't talk and I can't breathe properly and I just have to wait for it to pass as I haven't found yet anything that I can really do

KA: Yeah (.) well that sounds really scary. I'm sorry (.) I'm sorry you go through that

Redduck: It's ok. But um (.) it can be avoided and I've found strategies to avoid that like not being in school all the time

KA: Mm

Redduck: Because it is like I've found that it's a build-up of events (.) it's never one sole thing for me that causes a meltdown or a shutdown or things like that. It's normally a very large collection of events ((overlap))

KA: Right OK

Redduck: That can lead to that. And they can be lots and lots of little things or quite a few bigger things (.) and sometimes they're random (.) and um and then it comes out of nowhere sometimes for me. My mum normally predicts it better than I can

KA: Yeah

Redduck: But I think that's cause she's she sees it outside (.) um I don't know (.) yeah

KA: Yeah yeah. Um (.) it's interesting that you mentioned I think the throat as well um because obviously that would be something I guess that you feel when you're eating

Redduck: Yeah I don't like that

KA: Yeah. You don't? Like ((overlap))

Redduck: I hate swallowing

KA: Ok yeah (.) um.

Redduck: I tend to um (.) I don’t know ((pause)) avoid things. Because I can’t stand my jaw (.) the sound of my jaw (.) I can’t (.) I think I put that in the email as well

KA: Yeah, yeah

Redduck: I really struggle with that sound. And I don't know why but that experience for me that's why I might like a certain food but I can't eat it if it's the wrong texture even if I like it. Because I just I don’t want to put myself through (.) that's why I’m a nightmare. When it’s like (.) when things aren't planned and we just have to go out and find a random restaurant I'm just (.)

KA: I'm sure you’re not a nightmare. Whenever anyone says that (.) one time for health reasons I had to be on (.) and this is a bit off topic (.) but I could only eat the most specific foods. I couldn’t have anything that was cooked in a certain type of oil or with I couldn’t have anything with salt or pepper on it

Redduck: Oh wow

KA: I felt like the biggest nightmare in the world! So now when anyone else talks to me about being a nightmare with food and I'm like don't you worry (.) I've got you covered (.) we can cook anything (.) because I know how like frustrating it can be when you wanna go out and have a good time and you have to think about food all the time (.) um but yeah. I guess this like aversion you have to swallowing (.) this might be a bit of a tricky question because it’s quite like airy fairy (.) but is it more of a sensory thing or more of a fear of maybe things getting stuck in your throat or?

Redduck: Um (.) I have similar actually. Um (.) I don’t think I have a fear of things getting stuck in my throat. I’ve had a few traumatic experience (.) not just me (.) but my mum did get something stuck in her throat and I at the time I was only young. I didn’t know how to help her

KA: Yeah

Redduck: So luckily there was someone else that was able to help her but that was quite scary. And um I remember this is very random watching an episode of Young Sheldon (.) where he got scared and he got something stuck in his throat. And then they had to blend everything for him (.) um (.) just reminded me of that for some reason

No I don't think I have necessarily a fear. I just (.) I find it an odd sensation um and like I have quite a few odd sensations with my body in general (.) I think that’s why I study biology (.) I don’t know why (.) I find my own body very weird. Like I have a severe fear of seeing cut open organs and blood (.) but I love it at the same time. I want to know how it works but I don't get it (.) like I don’t know how to describe that. But I think that's why I just I freak out at the thought of all the different complex things that are going on in my body all at once and like it’s amazing but it freaks me out at the same time

KA: Yeah that’s so interesting.

Redduck: I don’t know if that relates (.)

KA: Yeah, I think it does. Um (.) and as you said especially I guess if for some of those things that are going on you don't feel super in tune with them as they're happening I can imagine that

can be quite a an overwhelming thing. But yeah is there anything more? Because I think this is really interesting actually really fascinating to hear you talk about it. But yeah (.) this idea of being overwhelmed by everything that's going on in your body (.) do you want to talk about that a bit more?

Redduck: Um I guess (.) I don't really know how to explain it but ((pause)) I think that's why I struggle with sort of energy accounting like um both mental energy and physical energy because I my whenever I talk to my family or my friends they seem to know exactly what they want what they want to do you know whether they want to go to bed and all these things. And I (.) unless it gets to that extreme point again where I'm literally so tired I'm about to collapse or I can feel my eyes just shutting um or I'm so hungry that like I dunno my tummy's making a noise so loud that anyone can hear it. But if it doesn't get to that point I have no idea and I think that's why it's taking me so long to get back to a point where I'm ((pause)) like established all these routines just so I can be a normal human as such because otherwise if I didn't have all of these routines I feel like I would just like I would think it was fine to go on a six mile run and not have like drank water when I get back and like you see that's I know now that's going to really dehydrate me (.) but that wouldn't have that doesn't cross my mind unless I know that and tell myself that and plan that I have to do that. And that is a little bit scary for me (.) because I think if I don't think about these things in advance and I miss things sometimes and I'll end up not keeping on track with something I need to do just because I have not thought about it in enough detail. Of the basic human things you need to do to survive (.) um. I don't know why it's missing because I can be so detailed and articulate about some things. But basic things that even my brother ((pause)) my brother. Who is a very typical teenage boy.

KA: ((Laughs))

Redduck: He gets those (.) right? And he does it easy (.) and I don't (.) and that confuses me. So I guess when I get overwhelmed by the internal processes I (.) get overwhelmed by the sense I have no control. Even if I have to artificially put in that control (.) in a sense. Because I want to control it but it seems like everyone around me doesn't actually need to control it (.) or artificially control it (.) they just do it. And that's one of the ones that really annoyed me when I was at the clinic cos they constantly pushed for us to do things um ah what's I can't remember (.) I repressed the word (.) Um (.) Spontaneously!

KA: Oh!

Redduck: They used to say that all the time and I'd be like what is spontaneous? I (.) nothing I do is spontaneous (.) everything I do is planned out to a T.

KA: Yeah

Redduck: So um that confused the (heck) out of me. So I guess that's more like what I feel ((pause)) I don't know.

KA: Yeah yeah. That makes a lot of sense (.) and I think it just goes to illustrate why places like CAHMS should be listening to you rather than expecting you to just listen to everything they say (.) um (.)

We are just a little bit over now the halfway point. I just wanted to ask do you want a break? Do you want to carry on? Or ((pause))?

Redduck: Don’t mind (.) I’m OK. Are you OK (.) or?

KA: Yeah! I think I’m OK (.) if we’re OK to go on ((pause)) Cool (.) um yeah (.) uh so the next question is if there ever are signals that you can feel in your body (.) say in the (.) in (.) if there are occasions where you can (.) you’re aware of your breathing you’re aware of your heartbeat or being hungry? Are there any particular ways these signals feel to you? Is it just neutral when you feel them and you’re like “oh ok, I feel that” or can it be a positive or negative experience (.) or intense or not intense?

Redduck: I guess like (.) they come in different bits ((pause)) So generally if I’m thirsty it’s very very temporary (.) um (.) and it will usually go away. Which then obviously makes me think oh actually no I don’t need to drink I’m ok (.) but then later on it might come back again (.) and I think oh no I definitely did need to drink (.) um. But I do get (.) a dry mouth and dry lips (.) and I do feel that. But again it’s more like as an extreme (.) when it gets to later on. My (.) most my family they say they’re thirsty all the time and I’m like (.) I’m never thirsty. I (.) I don’t drink regularly (.) I don’t know (.) um which probably isn’t great for me but ((laugh))

KA: ((Laughs))

Redduck: But like um I don’t get that same sort of need to do those things I guess (.) and when I’m um I dunno (.) when I’m (.) my breathing (.) I guess I don’t know. That might be why or part as to why I sort of strive for a lot of for quite a lot of different sensory experiences. Like I love rollercoasters and I love going to themeparks

KA: Ahh

Redduck: Because I get that feeling of your tummy being flipped over ((overlap))

KA: Yeah

Redduck: and like your heartrate increasing (.) and I feel it then (.) um (.) and that like ((pause)) excitement (.) um. I hate that you have to queue

KA: Ahh

Redduck: But um I do like the actual rides

KA: You know (.) I think (.) this is off topic and I think it’s gonna be funny that I’m recording this but (.) my friend got a pass at Thorpe Park for (.) she's autistic and it was like a queue skip thing

Redduck: Yep

KA: That’s so cool (.) it’s so good they do that

Redduck: I know! It’s (.) they are great. I I've got those for pretty much every single theme park

KA: Nice! Nice

Redduck: Um yeah but so I sort of thrive around those experiences and I love like being in the mountains and like really high up places and like skiing and all sorts of those activities and coz they make they give me more feelings somehow

KA: Yeah

Redduck: Um (.) and then the two biggest things that I always had to do since I was extremely extremely little uh were swimming and running and swimming I've just done since I dunno I was like five? And I it's just the best feeling in the world (.) I'm protected in my water bubble

KA: Yeah

Redduck: No one can touch me (.) I can't hear anything (.) I can hear my breathing and like I can hear the water past my ears and I just completely tune into that

KA: Ah!

Redduck: And I don't think about anything else apart from just that repetitive movement

KA: Yeah

Redduck: And that's the same with running as well (.) because it's just that repetitive movement (.) it's in my control (.) I can stop when I want (.) I can go when I want (.) I'm not reliant on anyone else (.) I don't know (.) it's (.) it's rhythmic (.) in a way

KA: Yeah

Redduck: Um (.) I've struggled a lot with team sports (.) um ((pause))

KA: Same. I do gymnastics because that doesn't require me to be part of a team ((laughs))

Redduck: But um (.) so yeah (.) but those two sports have just pretty much shaped my whole life (.) um (.) and I've only just got to the point through doing what I have coz I haven't been able to do them for so long (.) um (.) where I'm getting back into cross country again. I've missed the boat with swimming (.) I can't get back into my competitive squads or that (.) um (.) I'm just to old now (.) um. But with cross country I still have quite a good chance with that so um.

KA: Yeah, that's amazing. I'm so glad that you have these things that you can kind of fall back on (.) like your happy place

Redduck: Yeah

KA: Yeah, that's fantastic. And I'm sure even if you feel like you've missed the boat for like competitive swimming it will always be a hobby.

Redduck: *(Just on the note of hobbies/ Emotion and sensory processing- I also find that other escapes help me to tune in better with my body, like I've found that I purposely read more intense, dystopian themed books- like the hunger games or maze runner series- to lose myself in a false sense of adrenaline and excitement, especially before bed to help me sleep. I also tend to selectively draw more involved and surrealist images, which I find helps me to release some of my emotion or process any recent events more efficiently).* I still go swimming

KA: Yeah

Redduck: I still do it casually every week so uh

KA: Yeah. And it's such a shame that I guess CAHMS were dissuading you from going down that route. Of course (.) you know (.) understandable had you had an eating disorder as your primary concern. But it does seem here like (.) you know (.) these were these were escapes for you (.) and um

Redduck: And it just sucks that that was my coping mechanism

KA: Yeah

Redduck: I could have picked anything else but no ((laughs))

KA: ((Laughs))

Redduck: Anything else in the world (.) but yeah

KA: Well (.) I've got a few questions now about your experiences of anxiety (.) and I know we've kind of already spoke a bit about not feeling it and not feeling it and not feeling it and then suddenly it's a lot (.) um (.) but yeah if you were to describe anxiety to someone who has never felt it before (.) how do you think you would describe it?

Redduck: Um ((pause)) don't know if I can (.) um (.) it's (.) I guess it's very individual to everyone ((pause)) for me (.) it's just (.) it feels like I am completely and utterly isolated trapped I have no solution (.) I cannot think logically I I just have to keep moving because I have to by moving I'm moving something I'm going to get to something eventually. And standing still gets me nowhere. But (.) I still can't get anywhere (.) I don't know (.) It's like I'm trying to run but I can't even walk (.) and it's just like a massive conflict because my brain will be coming up with solutions to overcome the anxiety (.) like oh you could do this or you could do that (.) and then the other part of my brain will be like no I can't because of this (.) but but but there's this you haven't thought about this about this (.) and it's like I never get to a compromise (.) my brain just doesn't compromise at all ((pause)) um and even if it's something I really want to do (.) um (.) I just (.) I can't (.) I and it (.) and I and that's why I've been I've been labelled so much as not resilient and not you know I need to get some grit. I need to be more determined and all these things I've had every single sort of synonym of that thrown at me. And I've always thought. I ((pause)) I'm not not determined (.) because I do want to do this thing (.) but I just can't rationalise how to do this thing because the way you're telling me to do this thing ((pause)) it's not happening

KA: Yeah

Redduck: Um (.) so it is kind of just like a an ongoing battle ((overlap))

KA: Yeah

Redduck: That I can't solve and the way I usually overcome anxieties is through far more time than the average person (.) um (.) and a lot a lot of planning things through (.) planning things in advance (.) getting all the information I need about that event or what I'm doing and like in in exams I get 25% extra time which is really helpful because I sit down and look at the paper and I skim through the whole thing so I know exactly what's coming up so I don't get anxious about what if there's going to be a question on this and that and um it also gives me time if there's like random noises (.) I have time to think about the noises because I'll forget my train of thought (.) and then go back to it. So I guess like time if anything

KA: Yeah

Redduck: I just (.) sometimes my anxiety can take far more of my time than I wish it would

KA: Yeah

Redduck: Because there's things that I'd wanna do and get on with but I can't because I'm crying and it's going to mess up my work or something I don't know

KA: Yeah yeah I can definitely relate to that

OK (.) um (.) we have kind of pretty much covered in amazing detail um most of the specific questions I had for today (.) um but I wanted to know is there anything that you think might be relevant to like what I'm studying and what I'm looking at that you would want to discuss with me now?

Redduck: ((Pause)) um ((pause)) I don't know (.) I think your questions were great and I think that sort of covers everything I could really think of. But I think like um as you were saying (.) autism is generally viewed as an um a psychopathology and put under that bracket and um I get why because of a lot of people do see the negatives of it and think that we're in a constant state of high anxiety and constantly having meltdowns and constantly not being able to conform to certain things and all of that (.) and I get that. But um from my experience as well it's ((pause)) there's a lot more that goes on than just sort of those elements and ((pause)) I don't know how to explain it coz it's ((pause)) I feel like there's a lot of research out there for autism (.) and there's a lot of people with a lot of good knowledge (.) but that knowledge is staying concentrated in those areas and it's not getting out there and I guess that's why I was so happy when I saw you were doing this because I thought (.) there needs to be more of this I guess

KA: Yeah

Redduck: There needs to be more good information put out there about autism (.) because we're still trying to I mean the whole um the DSM change as well to the DSM 5 categorization of ASD with it all being under that one umbrella term as well (.) I think that's misleading I mean that's very controversial (.) a lot of people are much happier that we've got rid of Aspergers and the functioning labels and that. But I still think it's very unclear and it's very hard for people to understand what autism is because it it's such a big spectrum and we're sort of squashing it under this one label and (.) so people have their schemas of what autism is and they don't ((pause)) not open to changing those I guess

KA: Yeah

Redduck: So you'd kind of like see it as oh it's a child that um it needs to go to a specialist school isn't academically capable or needs high support needs (.) or you have it on the other end where they're like Sheldon Cooper. And it's like ((overlap))

KA: Yeah

Redduck: There's no real understanding of what those experiences are actually like (I find that the diagnostic criteria as published by the CDC based off the APA's DSM-5 criteria, is very 'deficit-focused', which I don't think is very human or representative of ASD and the fact that ASD is even a part of the DSM and classed as a 'disorder' is a question in itself, in my personal opinion of course. I understand that the spectrum is very vast, but to me this is why autism is so misunderstood, we still don't have the correct terminology or diagnostic classification/ criteria relevant to access the whole spectrum representatively).

KA: Yeah

Redduck: Um ((pause)) I guess *(I also just thought I would add that I feel like the key developing years, especially the transition from primary to secondary school, seems to be a real struggle for many autistic people. Personally, I have felt this and have definitely noticed my interoceptive signals have changed significantly, as well as the usual physiological and psychological changes that occur during child development. This is why I feel very grateful that you are researching in particular at, what I believe to be, this key age range where lots of complex and often confusing changes are occurring between 14 and 17)*

KA: No completely completely. And it's something that we yeah as I said we really feel strongly about in our lab and it's why we wanted to actually do participant led research. Doing the interviews first before you know claiming that we know stuff that we don't have that knowledge about and yeah (.) I think it's really interesting to hear different perspectives and things like the DSM categories and things like that because yeah (.) as a psychology student so much we were taught was like OK this person did this study and this research he did this study and it kind of takes away from that the actual human lived experiences of something (.) and yeah (.) I'm glad that you like (.) I guess you're echoing kind of thoughts that I've had in the past and it's always useful to to have someone you know back that up. But yeah (.) I think that's everything from my end

I also wanted to say (.) you're so articulate. At the beginning you were like "oh, you know (.) I say um and like too" but yeah (.) I mean (.) you should (.) I can see you doing like public speaking or something that was so lovely (.) or even writing because your descriptions of things were so beautiful

Redduck: Thank you

KA: So yeah thank you so much