Blackturtle interview

KA: Fantastic and as I said um this interview today will probably last around forty five minutes to an hour. We'll check in in the middle to see if we want to take a break um (.) and after that I will transcribe the interview which basically just means writing it all down and then I will send it to you and you can make any small edits or changes um and the transcript will also be made anonymous so any reference to you your name where you live any of that kind of information will be removed so no one would be able to recognise who you are from the output (.) Um (.) Cool so as I said (.) that's everything admin wise. Are you happy for us to get started with the main interview?

Blackturtle: Yeah that's OK

KA: OK fantastic so my first question is just a little bit of an icebreaker um and I would really love for you to tell me a little bit about yourself and this can be anything it can be your likes your dislikes your hobbies. I just want to get to know you a little bit better

Blackturtle: Ahh ((clears throat)) OK for me uh I love watching movies (.) uh ((pause)) I love uh I love football I'm a big I'm a big fan of Manchester United I love them they're my favourite team ((overlaps))

KA: ((overlaps)) ahh

Blackturtle: Yeah yeah

KA: That's cool that's cool ((laughs))

Blackturtle: And uh I spend most of my time with my friends ((pause)) uh maybe playing board games like uh checkers or sometimes monopoly which I'm very good at by the way

KA: Ahh ((laughs)) I'm a really bad loser

Blackturtle: Really?

KA: So whenever I play monopoly it's always a disaster cause I'm one of those people who wants to you know knock the board over when I lose

Blackturtle: ((laughs)) yeah

KA: Cool yeah. And um I know you said you like football I assume is that playing it as well as as well as watching it?

Blackturtle: Yeah playing and watching yeah

KA: Nice nice that's so cool yeah I love it. It seemed like all the boys at my school football was their absolute favourite every break time ((laughs))

Blackturtle: Yeah yeah

KA: Um cool cool well yeah I'll give you a bit of information about myself so we feel a bit more on an equal footing. So as I said in the introductory call my name is Kiera and I'm currently studying for my PhD and it's my second year (.) um so I'm 25 at the moment which feels really old when I do these interviews ((laughs))

Blackturtle: ((laughs))

KA: Um (.) and when I'm not doing my PhD um I really like dance and I really like gymnastics

Blackturtle: Oh

KA: Um but I'm not very good at either of those things but I find them very fun nonetheless um

Blackturtle: Fine

KA: Um and yeah I also and I really like drawing and stuff like that as well (.) um (.) cool. So would you mind telling me a little bit now about how old you were when you were diagnosed with autism and how did that kind of change things for you?

Blackturtle: I was about thirteen years old when I was diagnosed

KA: Mmhm

Blackturtle: And um ((clears throat)) for me it was a very very dark moment because um (.) at first I thought maybe I had some (.) other issues which could just be treated and ah and I'd be OK

KA: Mm

Blackturtle: But with how my development and my character drifted apart yeah that's when I realised maybe these are something that was there to stay and it has been a difficult journey for me so far although my friends have been supportive and they're always there with me here

KA: That's so wonderful to hear that you have really supportive friends I think that that can be something that's really really important and (.) and makes all of the difference (.) um (.) and yeah I guess what signs were there before you got your diagnosis that perhaps you might be autistic? Do you ever remember noticing certain hints?

Blackturtle: Ah yeah (.) ah you know with before ((stutters)) I used to maybe hang around uh a lot of people and then after some time I started (.) uh (.) ah (.) developing some character where I wanted uh things to be done the way I wanted I wanted to spend ah most of my time alone and uh (.) ah with the with the way my friends were being supportive to me for me it was kind of hard to acknowledge or to accept the fact that they were going to be there for me uh it was it was very hard because with being in such a condition most of the time uh it comes with a lot of complications where no one wants to maybe associate with you and you find it hard to make friends you find it hard to keep the friends that you have already made so it has been a rough journey for me

KA: Mmm I'm sorry to hear that yeah that sounds like it (.) it must be really really difficult

Blackturtle: Yes it is

KA: Um yeah (.) and um how about your experiences with anxiety? Would you mind um giving me a bit more detail about your experiences with that?

Blackturtle: Uh with the anxiety uh it comes mostly when uh when when I'm around a lot of people (.) uh when you're around (.) around a lot of people maybe people you not gotten used to maybe. So maybe my mum's friends have come to visit

KA: Mm

Blackturtle: I become it becomes hard for be- because I'm used to being alone with my dad. So when other people come to visit me and my uncles my cousins ah people that I have not gotten used to them on a regular basis it becomes hard for me so my anxiety (.) my anxiety gets the better of me so (.) I find myself sometime not talking at all or not even getting out of my room to greet visitors and um it comes hard for me

KA: Yeah that seems something that we hear a lot from my participants that I interview is yeah especially that mixture of I guess social anxiety and also when it's unfamiliar people specifically can be really really difficult (.) um (.) yeah (.) and ((pause)) for some of our participants when they describe the anxiety they have they say that for them it is (.) sort of the same thing as the autism like the two occur together where for other people they say no you know my autism is one thing and then my anxiety is a separate thing. I was wondering do you think the two things are quite (.) um entwined or do you see them as quite separate?

Blackturtle: I ahh think it depends uh but for me I think uh it's not something separate because I think it er the anxiety comes with the (.) uh the condition because I used to be the outgoing type of a of a person where I made friends easily that's why up to now I still have friends who (.) are there for me who I met them when I was pretty young

KA: Mm

Blackturtle: So I think uhh the anxiety and the and the autism I think it's something that they go hand in and I don't see them as separate issues because er I didn't have anxiety before I was diagnosed with er autism

KA: Yeah yeah and you mentioned that you used to be quite um (.) outgoing um

Blackturtle: Yeah

KA: Was this did this change around the time you were diagnosed was this when you were around thirteen or was it a bit before that that you started noticed noticing changes?

Blackturtle: Before I was diagnosed I think some few months before my diagnosis (.) uh I started noticing that ah it was becoming hard for me to make friends it was becoming hard for me to do things like ah playing football with my friends

KA: Mm

Blackturtle: I developed needs where I just wanted to be in my room (.) and to just focus on things like movies listen to music and just be there all alone and uh (.) with the with the with the condition developing I started having (.) I think ah (.) a trait where I wanted some things the way I wanted them ah not caring if they affected other people

KA: Yeah

Blackturtle: And that led to me now losing other friends and not being able to (.) to go out more

KA: Yeah

Blackturtle: So they develooped around the time that my the diagnosis was done yeah

KA: OK that's yeah that's interesting because yeah I think we tend to see (.) for a lot of autistic people that you know these traits are something that's been present since they were quite

young and it's a little bit unusual to hear um of things developing later in life. But then I suppose around the age I guess you would have been around twelve if it was a few months before your diagnosis (.) um (.) I can imagine that's a very difficult time with changes surrounding school and stuff

Blackturtle: Yeah

KA: And it's it's certain that that could have sort of um (.) I guess triggered these changes in in your well-being. Um (.) yeah (.) um (.) moving back on just to anxiety for a second um I wonder if you would be able to describe to me how anxiety feels for you?

Blackturtle: Pardon?

KA: Um I was wondering if you could describe for me how anxiety feels for you?

Blackturtle: Ah for me it's err (.) for me I can say it has become uh ((pause)) it's really not uh not me to maybe push people away and er not uh associate with people because from a very young age uh I have been a talker I've been someone who hangs around other people I've been someone who makes friends easily

KA: Mm

Blackturtle: So for me it has taken a huge turn because now I'm the complete opposite of (.) uh what I used to be (.) uh (.) these days I enjoy ah being by myself uh whenever I'm in the presence of uh new faces or a crowd of people or many people let's say at school it becomes a little bit hard for me because now I feel like uh everyone is uh like judging me in some way or maybe giving me some kind of treatment ahh (.) to (.) to point out that I'm special cons- compared to other kids and this is really hard for me

KA: Yeah

Blackturtle: Because I just want (.) I just want people to see me as the person I was as not the ah (.) the kid with autism yah

KA: Yeah that must be really really tough especially having that as like quite a significant change where things were one way before and um now it's different

Blackturtle: Yeah yeah

KA: Um sometimes when we talk about anxiety we like to split it up into four different sections. Um so the four sections that we talk about a lot are our emotions (.) our thoughts (.) our biological sensations um and our behaviours. And we say that we can see anxiety in all of these four different things um but for some people certain things are more noticeable for them when they're feeling anxious. So some people know that they have really horrible thoughts other people know that they feel physical things like their heart beating a lot. Um I wondered out of these things you know what is the most noticeable to you when you feel anxious?

Blackturtle: I think mostly uh it's my thoughts

KA: Mm

Blackturtle: Uh my thoughts are kind of a (.) kind of a rush as compared to before (.) I start over thinking about certain issues I start um having questions with no answers in my head uh let's say when

I’m in a when I'm in the presence of er new faces or a big crowd so in my head I'm just thinking what if what if they don't see me as the person I am what if they are just being nice to me because of my condition and all that? So it's really it's ((stutters)) really something that plays in my head a lot (.) and sometimes when someone maybe reassures me about everything being OK (.) uh what you think of is just ah maybe they're being nice because of the condition you're hiding and uh it's really hard for me to differentiate between people who actually care about me and er those who are just pretending because of the condition I have

KA: Yeah that must be really really difficult um

Blackturtle: Yeah yeah

KA: You know I understand that you don't particularly want pity you know you want people to be authentically there for you so I understand why that must be a struggle (.) um (.) yeah. And focusing now on I guess the more physical side of anxiety which is what we research in my lab (.) um do you notice things when you're anxious like do you notice your heart beating really fast or feeling shaky or anything like that?

Blackturtle: Yeah yeah I do (.) uh it depends on ah the kind of a situation I'm in uh on other situations I just uh feel my heart uh pounding uh very very very fast and um (.) uh sometimes people around me might uh not notice that I'm in that state because uh (.) sometimes when it's uh in minor minor uh states where I’m kind of uh controlling the situation at the moment and maybe the (.) my anxiety is maybe trying to outweigh uh how I'm controlling the situation sometimes my heart just uh beats fast but people might not notice

KA: Mm

Blackturtle: But uh there are sometime- there are situations where um my anxiety now has uh taken (.) uh (.) I can say the control of over me or over my body and uh I start uh shaking and trembling uncontrollably

KA: ((overlaps)) Oh right

Blackturtle: So it uh takes maybe someone who is really close to me to maybe sit me down and maybe take me to another room and try to (.) talk me uh out of it and that’s when I return now to my normalcy

KA: Mm

Blackturtle: But uh it all depends on the situations

KA: Yeah that sounds really tough and

Blackturtle: Aw

KA: I'm glad at least there are some people who know you well enough to be able to look out for you when you're in that state um because it sounds like it can be quite scary um ((pause)) yeah ((pause)) um (.) Is there you know you say going being perhaps on your own is one thing that helps you when you're feeling that anxious are there any other things that you can think of that (.) make you make you feel better when you're anxious?

Blackturtle: Uh I think mostly er the (.) maybe listening to music and maybe playing some board games I think that uh takes my mind off uh the situation I’m in (.) yeah

KA: Yeah

Blackturtle: Just by myself

KA: Yeah yeah ((pause)) no that sounds like really good advice. Um and now something that some um autistic adolescents tend to experience and others don't um is referred to as a meltdown or shutdown. Is that a term that you're familiar with?

Blackturtle: I am familiar with this but I don't really experience uh

KA: You don't?

Blackturtle: Yeah

KA: OK that's absolutely fine we can move on past those questions then um (.) And yeah what we're going to talk a little bit about now is something called alexithymia um now alexithymia basically means a difficulty in identifying or describing your own emotions and it used to be that people confused this a lot with autism and whilst a lot of autistic people are also alexithymic you don't always see the two occurring together. Um but if you are alexithymic for example you might (.) feel something that feels very very intense (.) and let's say you

Blackturtle: ((coughs))

KA: feel that your heartbeat increasing um but you don't necessarily know whether that's because you're very excited or you're very scared for something um so you can notice the change in your body but you're not really sure what that change means in terms of your emotions um so I just wanted to ask, is this something that you've experienced before? Does that kind of sound familiar to you?

Blackturtle: Uhh not really

KA: OK yeah ((pause)) Do you find you tend to be quite good at knowing exactly what you're feeling at a given time?

Blackturtle: Yeah yeah yeah I like I told you before uh (.) before my diagnosis I was uh an outgoing person I was an outspoken person so it was uh really hard for me- it was really easy for me to express what I'm feeling

KA: Yeah

Blackturtle: So since (.) since my diagnosis it's I was I've been uh holding onto that kind of strength so it's not really hard for me to express myself because I still feel I can go back to how I was before (.) so I fight the urge to keep things to myself and try to (.) to express what I'm feeling as uh (.) as clearly as I can yeah

KA: Yeah and I think that's really really good for you to be able to do that because (.) yeah we all know that you know talking about our emotions can help us to process them and deal with them um

Blackturtle: Yeah

KA: So to use an example now let's say that you were feeling really really happy. How might you (.) you know describe that feeling of being happy? What kind of signals do you look for?

Blackturtle: Umm mostly for me my facial expression will just do the the (.) uh the trick because I'm really not (.) I'm really not that kind of a person who hides uh how I'm feeling

KA: Mm

Blackturtle: when I'm happy about something (.) uh the excitement can be seen all over my face and I tend to be happy and laugh uh all the time even on something that's uh really not that funny um but I tend to (.) to laugh uh in an exceeding manner where anyone around me will just know this (.) uh this person is happy uh yeah

KA: Yeah oh that's really nice you're a very smiley person then ((laughs))

Blackturtle: Yeah

KA: Um (.) yeah that's great I think I'm the same in that people can always say they can see the emotions on my face which is good when I'm happy but it means that when I'm a little bit grumpy at someone they can (.) they can see right away which is a bit embarrassing sometimes um

Blackturtle: Yeah yeah

KA: Yeah. And um (.) what about now again we (.) we kind of talked a bit about how anxiety would feel um but if you're focusing on kind of I guess how you recognise your emotions when you are a bit let's say nervous or excited for something. How does that feel to you?

Blackturtle: Uh for me when I'm nervous about something I tend to ((clears throat)) I tend to maybe go to my room and just (.) think about it. I don't really (.) engage with others when I'm kind of nervous I just try to (.) to maybe keep things to myself ah uh depending on the situations

KA: Mm

Blackturtle: Um but when I'm excited about something I think anyone around me would just no- notice on the first on the first uh (.) on the first view they have of me because I'm (.) I'm not really good at hiding things yeah

KA: ((laughs)) yeah

Blackturtle: I'm not someone that people don't know

KA: ((laughs)) Yeah yeah OK fantastic. Um so I've just noticed now we're around the halfway point of the interview um now you have a choice we can either keep going with this or if you'd like we can take a short five minute break. It's completely up to you

Blackturtle: Uh it's ok we can continue

KA: Continue cool yeah (.) that sounds good (.) Um now as I said at the beginning I research something called interoception which is the ability we have to feel signals that come from inside of our body and how we interpret these signals and then the effect that this can have on our mental health. So to give a really common example of that (.) some people um when they're just sitting there doing nothing (.) they can feel at all times their heart beating in their chest and for other people they can't feel their heart at all. Um so I wanted to ask you you know it just sitting here now in this interview do you think if you want to take your pulse or anything would you be able to feel your heartbeat?

Blackturtle: Uh yeah I think so

KA: Yeah and where do you feel that is it kind of in your chest or in your hands or?

Blackturtle: Uh (.) in my chest I think

KA: In your chest (.) yeah yeah. Um and that feeling you know you have of your of your heart beating are there times when you notice that even more?

Blackturtle: Ah yeah it depends on the situations I mean

KA: Yeah

Blackturtle: Ah when I'm in the presence of um a lot of uh people who I don't really know I think with my anxiety I can (.) I can almost hear my heart beating yeah

KA: Yeah yeah. And then do you think sometimes like when you hear that heart beating when it's really obvious to you does that make you even more anxious?

Blackturtle: Ah yeah it does make me more anxious because uh (.) I start thinking maybe people around me have noticed the sudden change uh in my character or how I'm perceiving things (.) so I think it really uh (.) It really affects how (.) yeah

KA: Yeah yeah definitely definitely (.) Um (.) We it sounds like yeah you get quite worried that almost like other people will perceive that you're in a state of anxiety and yeah that definitely links to what you've said before about your concerns about people treating you differently um and things like that

Blackturtle: ((overlaps)) yeah yeah

KA: Um (.) yeah and (.) um as well as the heartbeat there are other signals in our body um that we you know can either detect or not detect as well and I'm just going to talk through a couple of them and maybe you can give some comments about whether you think you're quite good at detecting these things or not but so the next one is sort of how hungry you are. Um so do you find it quite easy to know whether you're hungry or not or is that something that's a bit more difficult for you?

Blackturtle: Uh I think that's ah easy for me because I'm a foodie so I just find myself in the kitchen

KA: Ah ((laughs)) that's great that's great. You like cooking as well?

Blackturtle: Yeah

KA: Aw that's so cool yeah um

Blackturtle: And I love chicken

KA: Ah is that your favourite?

Blackturtle: Yeah

KA: Nice nice I am (.) I'm meant to be vegetarian but I think chicken is the thing

Blackturtle: ((laughs))

KA: that I always I can never resist it's so good especially like chicken wings they're my favourite

Blackturtle: Yeah yeah

KA: ((laughs)) great great. Um (.) and (.) yeah I think another one is as well like if you're thirsty or not do you find that's something that's quite easy to notice or?

Blackturtle: Ah yeah it's that's easy for me to notice yeah

KA: OK great yeah yeah. Um (.) and then another one that's sometimes a little bit embarrassing to talk about so we can move on if you're not comfortable but when you need to use the bathroom or not is that something that you think you're quite good at being able to (.) to tell?

Blackturtle: Ah yes yes I'm good at that. Uh I kind of think uh I have some issue with my bladder or something because at night I go to the bathroom at least four or five times (.) before I wake up

KA: Oh wow wow so you're constantly getting out of bed and yeah

Blackturtle: Yeah yeah

KA: ((sigh)) that must be that must ruin your chances of getting a proper rest I imagine if you're up and down the whole time ((laughs))

Blackturtle: Yeah yeah

KA: Yeah and (.) are there times with any of these bodily sensations when any of them become a bit overwhelming to you and that can be any it can be, you know the heart rate the hunger the thirst. Do they sometimes get a bit too much?

Blackturtle: Uh (.) I don't really think so

KA: OK

Blackturtle: Yeah

KA: Yeah OK awesome (.) um (.) and ((pause)) yeah just sorry just having a little look at my questions here. Um (.) yeah these signals that we've talked about as well are they just neutral to you or are any of them very positive feelings or any of them very negative feelings?

Blackturtle: Ah I think uh neutral or positive I they don't really uh fall on the negative side (.) because it's something that you want to do

KA: Yeah

Blackturtle: Or ah you have to do so being able to notice (.) ah you need to do something or to maybe look for a bite or help yourself in the bathroom. I think it's ah a bit of a positive to me yeah

KA: Yeah yeah. And um (.) this again links a bit back to the anxiety that we talked about earlier. So for some people when they're feeling anxious as we said the heart rate increases and also the breathing increases and things like that ((pause)) um (.) and for people who experience that for some of them it helps to focus on these sensations so to focus on their heart beating a lot or focus on the fact that they're breathing a lot and try and slow these down and that's something that we call biofeedback. Um and you also see it a lot with like meditation and mindfulness and things like that. So I wondered is this something that you've ever tried to try and combat your anxiety?

Blackturtle: Ah yeah I've tried ah before

KA: Mm

Blackturtle: Ah I have friends who we kind of uh (.) uh do (.) maybe visit some parks and try to maybe subject ourselves to different things different experiences which might trigger anxiety and try to deal with them as calmly as possible to maybe now start working on how to combat uh that anxiety. And uh it has uh been showing a lot of progress because there were some things some things which I couldn't stand some while back but now I'm getting better at them. I'm getting better at perceiving uh things and trying to control myself when I'm in uh new ((stutters)) places and new experiences and all that yeah

KA: Wow that sounds so interesting. Um yeah so can you give me maybe some examples of some of these (.) these things that you and your friends do to (.) to try and trigger anxiety?

Blackturtle: Ah ok ah like me and my friends ah we (.) we uh go to the parks sometimes we visit ah (.) I think our colleges and schools that have older kids than us try to relate with them try to interact with them and uh

KA: Ah

Blackturtle: Yeah

KA: Yeah that sounds very very sensible. And when you're you know in your in this situation when you're trying to kind of like deal with that anxiety and I guess kind of get used to the feeling what's going through your head what are you trying to focus on?

Blackturtle: Uh (.) ah for me mostly what I'm trying to do is ah (.) I want to subject myself to uh many many more different experiences (.) I want to subject myself to different scenarios ah so that I can ah I deal with my anxiety. Uh I think maybe for my friends they want to maybe associate with other people but for me it's more of like feeling good with my situation so uh my goal is mainly to try and beat ah situations where my anxiety will rise once in a while (.) so um my main aim on such experiences or on such situations is to be able to deal with my anxiety once and for all yeah

KA: Wow that sounds like a really amazing like proactive decision to make and it's really inspiring actually to hear how you're taking your own mental health into your hands like that so (.) yeah well done on that it sounds like you know such a (.) such a helpful thing for you to be doing um (.) amazing. And the last thing that I wanted to talk about was just masking. So have you ever heard of the term masking used before?

Blackturtle: Um not really

KA: No (.) so some autistic individuals find themselves doing something called masking and masking is where you're a bit worried that perhaps others will judge you for you know the way you want to act or for being a bit different so you deliberately behave in a certain way that will attract less attention and so you you know fit in more with others and that's called masking. Now I know you probably never needed to mask prior to the diagnosis because I know you said you were a very (.) um you know social person but I guess since getting that diagnosis have you found that you mask some of the time?

Blackturtle: Ah yes I (.) I ((stutters)) do that most of the times when I'm around new people but when I'm around my friends I don't really need to do that because they understand me and I know they understand me

KA: Yeah

Blackturtle: And I don't feel that my friends ah would uh go out to judge me or something but when I'm around new people I try as much not to draw attention or try as much not to have them uh picture me or uh treat me um (.) subjective to ah (.) my condition I just want them to treat me as their equal

KA: Yeah

Blackturtle: So I try to avoid things that draw attention here

KA: Yeah yeah um and do you find it tiring to have to mask or is it not too bad?

Blackturtle: Uh (.) for me I don't think it's tiring because I just take it as uh not being a nuisance to others not ah (.) not ah being in the spotlight when you are around new people for me it's uh (.) I think it's uh a good coping mechanism for me

KA: OK yeah (.) yeah that's interesting (.) that's interesting. Um and when you're doing that masking um (.) Do you notice that the way that you notice you know the signals from our body that we were talking about earlier um is your perception of those affected by the masking at all or not really?

Blackturtle: Ah (.) I don't think uh they are affected by the masking

KA: OK (.) yeah (.) cool. Well that's super useful to hear. Um and I think that's pretty much everything (.) um just actually the last question I had for you was just surrounding your schooling at the moment. Um so are you in school full time or home-schooled or what's your situation?

Blackturtle: I'm in school full time because uh (.) my condition is ah not really critical where I can't totally engage with people

KA: Yeah

Blackturtle: I have my friends who (.) uh help me with things maybe relating to things that I'm not able to do but I'm in school full time

KA: OK great that's fantastic to hear. Now as I say we are pretty much at the end of all the questions I had for you but I wanted to ask you is there anything that you think that I haven't asked about that you think maybe I should have asked about or anything that you would like to bring up to me before we finish up the interview?

Blackturtle: Ah not really I think we've covered uh most of the things (.) that I was supposed to talk about here

KA: OK amazing. Well thank you so so much for participating. I'm just going to stop the recording now