



Interviewer: Mrs Helen Emery – Operations Manager

Interviewee: Professor Andrew Hugill – Deputy Director, Institute for Digital Culture

Question 1

Helen: Please, can you introduce me to autism?

Andrew: Yeah. So you want me to answer the question now?

Helen: Yes.

Andrew: Okay, so this is the hardest question out of all the ten.

Helen: OK

Andrew: And the longest answer. Before I start, there are three things I should mention, the first is that the answers that I give can be short, long or very long. But I think it's probably best that you specify whether you want the short or long or very long, because I can talk for like two hours on any one of these questions without stopping. So long, long is sort of reasonable, short is going to be very crisp. And the second thing is when I'm talking, I'm quite likely to interpret things you say literally, if we get into a discussion. So, if you think, I've misunderstood what you're saying because I've been too literal just say: you're being too literal, and explain what you mean. Third thing is - kind of unnecessary at this time of the morning - but my spoons are at more or less maximum at the moment. "Spoons" is a way of describing energy loss. You start the day with, let's say, ten spoons. Various activities take spoons away, until you are left with none. The trick is to manage your spoons through the day. It's not easy to get it right. Activities which take spoons away may not be the ones you'd expect. For example, if my breakfast routine is disrupted, that can take a whole spoon.

Andrew: Okay - so can you introduce me to autism? So, this really has a quite a long historical evolution as a term. And I think it's true to say that it's still changing - our understanding of what it is. I mean what hasn't changed is there's always been autistic people, you know. So, what has happened over the last hundred years or so is that we've identified a set of characteristics or a neurotype – a type of brain - that conforms to a set of characteristics that is noticeably different from the way most people's brains are configured. And I think that's the essential thing. It's a sort of noticeable difference like that, in the way, the brain is constructed. But the history of it is quite turbulent and quite controversial as well and continues to be so, to some extent. It's full of some weird errors and strange ideas that have emerged. To give a few examples, in the early days, back in the 1940s, 50s and 60s there was this notion of "refrigerator mothers", you know, the autism was caused by mothers being too cold and distant with their children. And this I think was, apart from being completely wrong, was very damaging for the whole notion of autism because I think then a lot of mothers whose children were autistic, became reluctant to... wary of having that diagnosis because it was, it would be really a diagnosis of them rather than the child, you know, which is really unfair. So that was a problem.

Another theory that that came up not so long ago. Now, is that it's an extreme maleness, what they call an "extreme male brain". Well, of course, you know, the legions of women who have failed to be diagnosed as autistic would disagree and I think increasingly we recognize that gendering it in that way is probably not helpful. I mean, I think, you know, the psychologists who came up with that idea had a slightly different thing in mind from the obvious, you know what it sounds like. But even so, it's not a helpful notion. Probably the most controversial thing, of course, is the theory that was put about that it was caused by vaccines and it was some kind of reaction to vaccination. Which was published in The Lancet, you know. People forget this, because it is now regarded as a conspiracy theory and sort of so outlandish, that who could possibly believe it apart from people who are into



conspiracy theories. But actually, you know, it was published in The Lancet - it was regarded as a serious medical discovery for quite a long time and it still kind of persists, that idea, you know, that somehow there's some cause of it that is nothing to do with the way you're born and it is something to do with what you do to yourself. You know, that somehow, it's somebody's fault that you're autistic and I guess what all that shows is that there's a general attitude to it that is pretty negative.

To answer your question directly: there are really two answers to the question “what is autism”? One, is what the diagnostic manual tells us autism is, and the thing that you need to kind of conform to if you're going to be diagnosed with autism, and then on the other hand, there's what it actually is in terms of people's lived experience and the two are quite different.

So, in the diagnostic manual the psychologists call it Autism Spectrum Disorder. What they mean by that is, first of all that it's a spectrum - that's to say that there are many, many different manifestations of it - and secondly, that it's a disorder. They use words like “impairment”, “deficit” and so on. And this is the typical model. To get a diagnosis - I've had a diagnosis, you know - you have to accept these labels, which, of course, is pretty damaging for you as a person - you think that: there's something wrong with me. And of course, all of society tends to think the same, you know - there is this idea that somehow you have a deficit. Deficit is normally a term applied to social and communication issues, and to what they call fixed and repetitive behaviours. Those are the two main ones and then there are a few others besides that - sensory issues is another one, which I think is a lot more important than people realise. Those are the areas of deficit. Then you may or may not have a learning disability as well. That, I think, is usually regarded as what they call a comorbidity - lovely word (sarcasm) - which is something that isn't necessary to have a diagnosis of autism, but can often go along with autism. So, you have autistic people who are learning disabled or even non-speaking or whatever. Although you see the weird thing about this is: when I look at these people - this is going to sound very strange because I mix with you know, highly articulate, intelligent and literate people - but when I talk to people who have these supposed learning disabilities or can't speak or whatever, I feel more in common with them than I do with a lot of the people I mix with. I understand them better and I don't think they're learning disabled at all. I think often they are highly expert in certain things.

So, that's the kind of medical definition, but the lived experience is really quite different to that. And I like to see things in a more positive light. So, I like to think of it as a series of strengths, really, a series of reasons to be positive. So, for example, a very clear and direct communication style. A very good attention to detail and ability to focus, hyper-focus on and go really deep into things. A way of achieving a kind of flow state that is highly prized, I think, in the non-autistic world because it's regarded as exceptional, but I think for autistic people, it's common I think - it's just the way we live. And just generally a sort of very unique understanding of the world, you know, which has a lot to offer in terms of different perspectives and different ways of thinking. Of course, this is not to diminish the problems that this creates. I mean, it really does. Life can be very hard, because you are seeing the world in a very different way to the way most people see it. This often produces friction and you end up making mistakes and rubbing up against people, the wrong way and all that kind of thing. But on the positive side, it's something that that is a cause of joy quite often. There's this wonderful experience of the world and for me that's been very important because a lot of what I have done in my life relates to the sensory experience of the world. So sensory issues, which I mentioned earlier, are very important to me and in a way are more pronounced in terms of difference in the social and communication issues that are normally characteristic of autism.

Helen: Do you want to just explain in a brief way the sensory issues?



Andrew: So, let's run through the senses one at a time, shall we? Because that's basically what we're talking about. I'm triggered by every sense, but let's start with sound because that's the one that I've made a career out of really. That's the one that I'm most heavily involved in. I run a project called Aural Diversity, as you probably know, that is all about hearing difference and includes autistic listening. So, you know, from an early age, I had a kind of extreme sensitivity to sound - I suppose you could put it like that. An ability to hear detail other people can't hear. For example, hearing electricity in wires, hearing bats, and then hearing minute differences in pitch. So, you know if you played the note on the piano, for example, what I would hear - and I now realise this is completely extraordinary, but at the time it didn't strike me as different at all because that's just the way I heard things; I just assumed everybody else heard the same - but what I heard is all the overtones first and then the fundamental. So, you know, when you play a low note on the piano, people would say what note's that? You'll say, oh it's a C because the fundamental frequency is the most dominant frequency - it's loudest. But actually, I would hear the high frequencies on the overtone series and then come down to the lowest one. And then being triggered by sounds - so finding some sounds really disturbing and things that often people wouldn't be bothered by. I mean, people are generally familiar with sounds that are disturbing like, you know, fingers being drawn down a blackboard and all that kind of thing. But I have that with all sorts of sounds.

And then there's synaesthesia. I'd always seen colours in association with certain sounds, particularly musical sounds. For example, an open E string on the violin is red. It always has been red. That's the way I understand the open E string on the violin. Not the fingered E, interestingly. It is reddish but not red. You know, it's the openness of the E string that makes it red. And there's loads of, hundreds of examples, that I could give you in fact. So, synaesthesia is where your senses get confused. So, you experience sound as something visual, or you experience sound as a taste, which I also have, a particularly visual stuff as taste. So, during the lockdown my hair was getting really long, my wife got me a tube of that stuff - gel - that you put on your hair. And I looked at it and I said, "I can't use this. It tastes foul". And my wife said "what are you talking about"? I mean this was just an instinctive response, she said "you're not eating that you're putting on your hair". It was the colour, it was kind of a purple colour and it was one of those synthetic colours that you only see in hair salons, and it just produced this absolutely disgusting taste in my mouth, just by looking at the colour. So that's synaesthesia.

Then let's go to sight. Well, I mean, I have a big problem with lighting, particularly fluorescent tubes, which flicker, and I've always had that problem. And I realised that, you know, one of the reasons why I performed badly in exams at school was because the room had fluorescent tubes. And of course, you know I could never understand why I was getting top marks in everything. And then I go into the exam and I couldn't function. I thought nerves or I'm just not very good at exams or something. No, it was the physical environment that was just stopping me and of course when you're autistic, you don't understand what's happening. So, you can't articulate it, you just experience it. It's like supermarkets are a bit of a nightmare, you know, too much visual confusion, patterning that is irregular, asymmetry. These are all problems that affect me, you know? And then you add colour into that and of course you then start to get a riot of sound as well as sight. So, every environment is like being in some kind of wild kaleidoscope with sounds.

So that's sight. Taste - not so much but still there are some things but it's more as I said before, mixed in with the synaesthesia so it tends to get linked to. So, for example, I taste stuff all the time. Like the other day, somebody sent me some polystyrene and I ended up tasting it, you know. It was wonderful as it started out bitter, and then became neutral, it tasted of nothing.

Helen: you didn't put it in your mouth?



Andrew: I couldn't but I licked it. I didn't eat it. I just tasted it. I do that quite a lot - taste things. I love licking things like that, that taste of nothing. But I also like things that have strong taste, you know, certain curries and so on, that have a very powerful taste. But I do remember Bakelite. It's a bit like formica. It's a kind of hard, brownish substance. They used to use it a lot on railway carriages as a kind of trim. They don't use it anymore and not quite sure why. Anyway, when I was at school, we were asked to look at Bakelite in the classroom as part of our science class and I remember licking it as I used to habitually do, in secret of course, and it was absolutely disgusting. And coupled with the brown colour, this really revolted me, to the point that, years later, when I was living in London, I would avoid the Bakerloo line, because the colour on the tube map was the same colour as the Bakelite and also Bakerloo sounded a bit like Bakelite. And it was a railway, so there might be Bakelite in the railway carriages. So that combination of sight, sound and colour all combined to make me wary of the Bakerloo line and I used to go out of my way on journeys to avoid it. So that's taste.

Touch - it's an interesting one because it depends on how aware I am at the time of the touch. I'm not always that aware, but sometimes I become hyper aware and I'm not quite sure why, but you know, certain textures of surfaces give me a problem and I suspect what's going on is linked to other things. So, there's some other problem in the space, and the texture becomes a kind of expression of it. I stim quite a lot - stimming is, well it's really a form of fidgeting, I suppose, it's a kind of repetitive action that regulates yourself. So, I have a little stim toy in my pocket, that I use. And it's got this surface here, a smooth surface, and a rough surface. And I like that contrast in texture in there, so I do play with that quite a lot.

And then there are slightly more unusual ones that are massive for me. Proprioception. Proprioception is not normally listed. When you say: how many senses do you have? people always list the common ones, but they don't know about proprioception.

Helen: what is that then?

Andrew: Proprioception is your sense of your position in space. So, it's kind of linked to balance and I have a balance disorder too that tends to amplify issues. But I've always had issues with this. So how does it manifest itself? If I'm in any space where I can't see the corners, I have a problem, because I can't orientate myself in the space. I start to lose touch with myself. So, I become like this sort of blob and I don't know where I am. And this gets very overwhelming, very quickly. So typical examples, you know, airports, total nightmare for me. I need disability support to go through an airport because I just can't function for many reasons. The proprioception is a big one because you know, they are vast spaces and I just can't locate myself in that space. And then another one is interoception, that is: the perception of what's happening inside you. So, you know, my perception is, shall we say, a bit weird in that there are things that happen in my stomach that I can't quite tell what is going on. But I perceive things that aren't there, or I don't perceive things that are there. Same with the heart, you know. So, there's a heartbeat and I'm never quite sure, you know what, it's hard to explain this, but basically my perception of my interoception is different to what it should be.

So those are the sensory issues - quite a long list. So, you put all that lot together and every day becomes a kind of ... you know, you fight your way through to the end of the day. This is why spoons become an issue.

Helen: Please explain spoons to me?

Andrew: Okay, so spoons... several years ago, there was a woman in a restaurant and she suffered from some kind of chronic pain. And she was trying to explain to her friend how she got through a day and she had a load of spoons to hand. So, she put the spoons on the table and explained "I've got nine



spoons. I start the day with nine spoons. This activity takes this spoon away. This activity takes another spoon away. And gradually, as you go through the day, you run out of spoons. And when you run out of spoons completely, you shut down”. And that's what happens to me: I shut down. Or you melt down, which is a different thing - we can talk about that, but I don't do meltdowns really - I shut down. And so, this has become a general-purpose metaphor for a kind of imprecise, bespoke notion of how much energy you've got, basically. So, activities that a lot of people would regard as just normal, you know, just easy, for example, getting into a plastic packet ... my wife says one day, she's going to come home and find me dead on the floor, clutching, a plastic packet that I'd been unable to open, because I struggle with these plastic packets. So that can take a whole spoon: just trying to open a packet of something. You know, a whole spoon! Whereas giving a lecture to 2,000 people: half a spoon, maybe. That gives you some sense of the scale of this. It's nothing to do with the apparent effort involved in doing something, it's all to do with how it affects you from an autistic perspective. And so, once you start loading in all these different things, all these sensory issues, very quickly, your spoons start to dissipate.

Helen: and this the term spoons is used quite broadly or is it a new thing that you established?

Andrew: No, it's pretty well known. I think not everybody uses it. It has advantages and disadvantages. I mean, the advantage is: it conveys to someone who's not autistic, what it's like to... you can say, well, I haven't got many spoons left, and if people know the theory, they can say, okay right - we need to be careful. But it's not helpful in the sense that it's not very precise and it varies from person to person. So, something that would take one person lots of spoons, doesn't necessarily take me a lot of spoons. But it's just a good sort of shorthand, otherwise, you just end up explaining: I've got all these sensory issues; this, this and this affects me; I haven't got much energy left. By the time you've explained all that, it is great, long-winded thing, to tell someone that, actually, we need not to do this now, because I need to conserve my energies. So, having spoons as a shorthand is a convenient thing to do. So yeah. Yeah. But it is quite well known.

Helen: thank you. I'm going to move down to the next question

Andrew: Okay. was my answer too long or too short, or that was perfect?

Helen: No, it was perfect. I think it was a long answer, yes, but we captured an awful lot in it for me to understand what it's like to be autistic.

Andrew: I do like the Maori word for it, which is Takiwatanga, which means: in your own time and place. I think that's rather lovely; you know. And it doesn't contain any of the kind of medicalised “deficit” language. And I think that is what it's like really. You're kind of living in a kind of unique world, so you feel like the world you're in isn't quite yours, you know.

Helen: One thing you referred to in your previous answer was the label. How can we try and move away from being classed as a label, to try and move forwards to help others?

Andrew: Well, I mean what we call things is terribly important and it's also quite a controversial area. Personally like most autistic people I like the word “autistic”. It's straight, it's direct, it's simple and it doesn't embellish. There's a tendency for people to use person-first language when talking about disability. So, they say “people with autism” and I really don't like that. And a lot of autistic people don't like it and the reason is that it implies you got some kind of disease, you know. So, the argument for it is that you're putting the person first, so: you're a person first and then whatever your condition is secondary, but you do have the condition. Whereas I'm saying that well, no, because you can't separate the autism from myself. It is me; you know, I am it. We can give it this label of autism, but



basically, it's what you're talking about is something that I was born with. To change it would mean having a different person, you know, and you can't, you can't do that. So, I don't like “person with autism”. The other word that is being used a lot now is “neurodiversity”. I've mixed feelings about neurodiversity as a term. On the positive side, it tells everybody that there are different brain types - something that I would've thought was pretty obvious, but actually people have, I think, generally assumed was not the case. Autistic people started using this word neuro-diverse because it woke people up to the idea that there might be a different brain type to theirs. So, in that sense it's very positive. But the word neurodiversity just describes normal state of a group of people. For any group of people in a room, you've got neurodiversity, you know? There are always going to be differences in brain type. So, it's not really saying very much. I mean it's just like biodiversity just describes a general state of affairs. Neurodivergence is more specific, in that you are diverging from a particular norm. So, you'd say that the dominant neurotype is what we call neurotypical, and you're different from that. Therefore, you are neurodivergent. But my worry about this term is that it's become a kind of polite way of avoiding saying “autistic”. And of course, neurodiversity includes lots of others, ADHD, dyslexia, dyspraxia, a great long list of other neuro types, some of which autistic people have, of course, because there are quite a lot of dyslexic autistic people, quite a lot of autistic people with ADHD and so on. So, I just think: why are we avoiding saying the word autistic? And I think it's because people think it's impolite. They don't want to label people with this label and I just think, no, let's call it what it is. You know, it's a recognised thing, we get a medical diagnosis, people generally can sort of recognise it when they see it, however imperfectly. So, let's be up-front about it.

Question 2

Helen: Thank you. This is a two-part question here and we can break that down if you need to. When were you diagnosed with autism and was your loss of hearing diagnosed at the same time or separately?

Andrew: So, the hearing loss was separate. That resulted from something called Meniere's disease, which is a balance disorder. I was diagnosed with that in 2009. It is pretty horrible condition. This is sidestepping from autism, but just to show you how different it is. It's a balance disorder, which means that you basically, you can't stand up. I would have three vertigo attacks a week. Each lasting about five hours. Constant vomiting. And then, after each attack, it would take me a day to recover with brain fog and unsteadiness and you lose your hearing as well. Your hearing goes, from the bottom up, so you lose your bass frequencies first, which is not how hearing typically is lost – normally you lose the treble first. So, I've lost all my bass frequencies which kind of emphasizes even more the overtones. I had a treatment that involved chemically destroying my balance function, that then stopped the vertigo. But the problem is now, I don't have a very good balance, so if it's dark, I fall over. I balance with my eyes. So, that was 2009.

And then autism - I was diagnosed as autistic in 2018, so only five years ago. So, very late diagnosis, and this is happening a lot at the moment, there's lots of late diagnosed autistic people out there. I'm really glad to have the diagnosis. I'm kind of envious of younger people who have got a diagnosis, because I think if I had known then what I know now, life would have been a lot easier for me.

Question 3

Helen: Thank you. Please can you explain to me your love of music and composing?

Andrew: This is a fun question that this is much easier to answer than the first question! But the usual things you want short, long or very long?

Helen: I think let's go medium and see how we go.



Andrew: Right. You may have heard this phrase ‘special interests. A lot of autistic children – and adults - have special interests, things that they particularly focus on. One of mine was music, which I was interested in from an early age and I started composing music aged 11 - my first composition was written when I was 11. Trying to understand this in autistic terms, I think there are several things going on here. The first is that, I think it enabled me to understand emotions. And I think that was something I always struggled with, and I still struggle with, because of something called alexithymia, which a lot of autistic people have, which is you experience emotions, but you don't know what they are. And I still struggle with that - it usually takes me about two days to figure out what I felt about something. This is why I struggle with the question, how are you? Because I never know how to answer, you know, and it's really difficult. I understand that it's just a kind of meaningless question that neuro-typicals like to ask, because it sounds like you care about the other person, when you don't really. I always try and find an answer, but it's very difficult. So, I think music helps with that. I think music was a form of communication, which wasn't words. I was a hyperlexic child. I read from a very early age and I read voraciously everything I could get my hands on. And I think I found that quickly that words were not enough to explain to others what was going on. So, I started to use music as a form of communication, trying to express in music what I couldn't say in words, and I liked the fact that people would have to listen. My mother produced, a program of a concert that I gave in the family home when I was 11 or 12 and at the bottom, it says, “the audience must remain silent throughout the performance” in capital letters. And I think this was, this was really important that people would listen to what I was saying, because I was trying to express something. It was really hard to express it, but I knew that I was trying to say something. As regards to the music I listened to: that was a different story. Most of the music I was made to play on the piano, I had no interest in. It was only when I was given some Béla Bartók to play that I started to get interested in the sounds I was making. Because Bartók famously has quite a lot of discordant sounds and is quite unpredictable, the rhythms change and so on. And I found myself responding to that really well. And I didn't understand why I liked this music. So, I developed a taste for the avant-garde at a very early age and I was listening to Stockhausen, Boulez, all these famously difficult composers. I was listening to in my early teens and loving it and really not having any interest in Mozart, Beethoven etc. At the same time as that was going on - in our school, someone had put together a music library which had all the records arranged in alphabetical order in blue jackets - I can still visualize them now - with the name of the composer on, and I listened to that entire library from A to Z systematically. So, I started off with, you know, Arne, Arnold and then worked through to Zemlinsky. I spent a lot of time on B because it has a lot of Bach, Beethoven and Brahms, but I did listen to loads and loads of music trying to understand it. But fortunately, as I say, one of the early sets was a box set called Avant-Garde - so it came in the As - and that's where I heard Stockhausen, Berio, Boulez, for the first time, and just loved it. So, I was loving this very discordant music and of course people hated it. I tried to write music like it and people were saying “that's the wrong note”. And I said: no, it's not - it's not, it's the right note! I got quite angry. But why? Why was I interested in this?

Sorry - is this still medium answer for you?

Okay, so, so in 1974 or 3 - something like that - I went to a concert at the Bath Festival, because I was at school near Bath, and it was the world premiere of a piece by Peter Maxwell Davies called ‘Ave Maris Stella’. And this was for a small ensemble and in the ensemble was a marimba. Well, I'd never heard a marimba before. A marimba is like a big xylophone basically. And the marimba player in this solo, which was wonderful, played these very low marimba notes, and the harmonics of them, suddenly, I heard the overtone series pure because, of course, of marimba is just a bar over a tube - over a resonator. I was “wow, that's what harmony sounds like”. And of course, it took me a long time to figure out but now I know - as a Professor of Music I've lectured on this, many times - because of course the piano is out of tune. The piano is a ... the strings are wound metal over a resonator, but



then there are twelve notes to the octave and they've all been detuned slightly to make them all the same, so that basically, when you play in C major, you can then play in F major. and it's exactly the same sounds, just transposed to a different pitch, either higher or lower, that's all. And this is called equal temperament. Bach wrote famously the Well-tempered Piano, meaning it was tuned to equal temperament which was a novelty at the time. And of course, that's our music system. So, the piano is a fundamentally discordant instrument. So, when you play a C major chord on the piano which my teacher would do and say: what chord is that? I'm sat there. First of all, I'm hearing all the overtones and not the fundamentals initially. Then I've got all the lighting in the room mixed in with the overtones and then he's saying "it's really simple" and I'm saying: it's not simple at all, it's really, really complicated! I was having to kind of work back and I kind of see this now as a corollary with autism in that, if all the notes are the same, there is no difference, and actually I'm hearing differently and I am different. People used to say to me, because I listened to Stockhausen and so on, they'd say: oh, you're just trying to be different. That's what they used to say, "you're trying to be different" as if being different was somehow cool, you know. This used to really upset me.

Helen: ...of course you weren't diagnosed at any of this time...

Andrew: No, no, I had no idea what, you know, there was no name for it. All I knew was that that it was real. I knew that this was a real difference that actually I wasn't trying anything. There was no benefit to me to try to be different. I tried to be the same as much as I could, or to fit in, but I didn't do it very well, you know, and so I had to develop all kinds of strategies for dealing with this. But I was certainly not trying to be different, but what I knew was that these sounds reflected what I was hearing much better ... Stockhausen reflected what I was hearing much better than Mozart.

Helen: You went on to start composing your own music?

Andrew: Yes, I suppose it was an attempt to assimilate what I was hearing. Like a lot of composers, you know, you basically start with models and you try to assimilate those. So, I tried to write like Varèse, who was a big hero of mine, I tried to write like Bartok ... these kinds of composers, you know. So, a lot of my sort of childhood pieces resembled those. I remember writing a piece for piano and percussion that was basically an imitation of Varèse. And I remember ... it was in a competition at school and the local music teacher came and judged the compositions, and there was another lad who composed some jazz and he was a very good jazz pianist. He got a trio together and they played some of his tunes and it was really slick. And then I came on and performed this piece that sounded like, you know, a sink falling down the stairs, as far as the audience concerned. They booed it, they laughed at it. Oh yeah, yeah, yeah. And the music teacher, bless her, gave me the prize and that was a key moment for me because it was like, oh, hang on a minute. I can even despite all this ridicule, I can actually communicate with somebody – it is getting through to somebody. But yeah, it was kind of wild. I remember the percussionist who was a school chum of mine who was a punk rock drummer... he hit the wood block with such ferocity in this piece that the stick broke flew into the air and everybody just fell about laughing. Well, that's ruined his piece. But actually, it really helped because that was that was the character of the music. It was really kind of gritty, tough music, you know? And I liked that at the time. But that was how I felt, you know - the world was gritty and tough and I had to write music that reflected that what then happened....

Andrew: Do you want me to go on a bit?

Helen: Yes, just a little bit more. Just a small amount.

Andrew: So, I recently wrote an article about this in the journal Interdisciplinary Science Reviews. I edited an edition of this journal on [‘music and/as science’](#) and this this is about to become a book. My



introductory essay... I talk in it about autism... What happened after I grew up a bit was that I began to think: actually, nobody's interested in me. Why should anybody be interested in me, particularly as there was loads of other composers? Who am I? Nobody special. So, I started to consciously move away from writing music that was about me and my lived experience, into writing music that was systematized some way. So, I was forever developing systems and structures that had some kind of underlying logic to them that may or may not be apparent to the listener. And really, that was my career, you know? And so, I ended up becoming a [Professor of Music](#) out of that. So, what I thought I was doing was removing myself from the music because I just thought self-expression. That kind of communication was worthless. It's all very well wanting to say something, but who the hell wants to listen to me? And of course, what I then realised, post autism diagnosis, is actually that process in itself was itself highly autistic. Ironically, by going through what I thought was a distancing process, I was getting more personal.

That's been quite a revelation, I have to say. I'm now going through my whole back catalogue, which is fairly extensive and rethinking a lot of these pieces, you know, and realising things about them that I just never perceived before.

Helen: Thank you. I know you're talking a lot. So, if you feel you are running out of spoons, please let me know?

Andrew: no, spoons are fine, I will go on like this, you know, so do shut me up if I'm going on too long.

Question 4

Helen: No, that's fine. And now you've touched on Academia and your career. So, can you tell me about how you got into Academia?

Andrew: I got into Academia in 1986. I had been working with a composer called Gavin Bryars. He's quite a well-known composer. I was working in Paris and Lyon on a couple of operas as his kind of assistant. And then he said to me, "do you want to come and do some lecturing"? I said no, that was my initial reaction, no. Fortunately, my brother was with me at the time who heard this conversation and said, "Andrew you really need to listen to this". Basically, I was unemployed you know, I couldn't get a job or do anything, so I was in quite a lot of poverty and you know I was going nowhere, really. And my brother fortunately spotted this mistake on my part and pushed me into doing it.

And so, I started in 1986 and I haven't looked back.

Question 5

Helen: So why did you stay in Academia? And what is it that suits you? And what's good about it? So, you had a very difficult time coming in, but you're still here?

Andrew: well, I think the first thing to say is that I'm very good at it, you know? I mean, I am good at what I do.

Helen: student feedback is good?

Andrew: Oh yeah, yeah, yeah! The student feedback has been fantastic and, of course, I became a National Teacher Fellow and then a Principal Fellow of the Higher Education Academy. The Principal Fellowship application had to include student testimonials. So, I contacted loads of ex-students and got this fantastic roster of positive comments and so on. I worked out that I'd materially improved the careers of 57 people. Many of whom have gone on to be Professors. So, I'm really, really good at what I do. You know, I'm good at research, I'm good at teaching. I find often people who are good at research tend to be good at teaching as well. You know, if you're good at one, you tend to be good at



the other, although not always the case. But often. What do I like about Academia? I think it's the structured environment. The fact that interactions including this conversation are formalised, so I think I understand what's going on, you know. So, there's routine. There's a structure to the year. It has a rhythm that has, you know, we know where we are at any given week in the year. I can look at it and say, okay, I know where I am, I'm in week 11, this is happening, this is happening, you know. So, it's got this kind of structured existence which fits with my autism, but also you know you meet lots of really interesting people and lots of really interesting ideas. The thing about me and my interests is that if I'm interested in something, I'm really, really interested in it. If I'm not interested in something I'm really, really not interested. There's no kind of shades of grey here, but I guess what has happened is that I've done what I think is the correct way for autistic person to be educated. I've done it in the teeth of the education system. So, one of my pleasures is making this happen in universities, this is why I instigate so much, you know, like this, this new Institute, previously the centre down in Bath and the IOCT, and before that the music technology course at De Montfort. You know, I start things up all the time and the reason is, because I have these ideas about how we, how the world should be in terms of knowledge and education. Which I can summarize very quickly if you want me to.

Helen: Yes. One thing that's on my mind of what you just said, I think we're correct in saying that Academia gives you the platform for you to follow through with your ideas?

Andrew: Yes, - oh completely, yes. I still find that despite all the goings on that there have been politically and so on at universities, I still find that it's the only place where I can follow an idea. And you know, follow my nose as it were, and kind of get away with that you know? And fail as well, because failure is terribly important. You do you have to fail a lot to get to something good. So, you know, so I find myself getting excited by things and then realising that, hang on a minute, this is.... So, like Aural Diversity - you know - the idea that everybody hears differently? This is such a simple idea. And yet, you know, it turns out nobody's really thought about it. It's like it's blindingly obvious and yet, and yet, you know, people need telling. So, I get these invitations now, to talk to the international network of acousticians or the, you know, Internoise, the noise scientists, who are sort of really excited to hear this other point of view.

Now, I find them affecting the law because, you know, there's this notion of the man on the Clapham Omnibus as a typical person in the law. And what I'm saying is, if you take account of Aural Diversity, the man on the Clapham Omnibus is not typical at all, apart from being gendered an out-of-date, but leave those things aside, you know, it's just not a typical you know that there is no typical person. So, I mean only 17% of the population hear “normally”. Everybody else hears in an unusual way. Well, why are we taking 17 percent of the population as our standard for what's normal? So, there's all sorts of things like that. Now, that wouldn't happen were it not for the academic context and the feeling that, you know, we're sitting underneath the great vast weight of books here, and computers and so on - floor after floor of books. I love this. This is this is my natural environment.

Question 6

Helen: Academia relies a lot on interaction with other people, how do you manage this?

Andrew: I manage it by understanding the purpose of the conversation and the nature of the relationship of the people involved. So, even in an informal setting, I can converse quite happily with other academics, students and with people who are interested in the same kind of things as me. Because, it's always clear to me what the rules of the conversation are. The difficulty I have, is in unstructured random conversations, especially with strangers. So, to give an example, I will quite happily sit in the pub and talk for hours to a group of academics about some interesting topic, but if a random person on the next table starts talking to me, I have a problem with that interaction.



Question 7

Helen: Okay. So, you might have a reasonably long answer to this one. You mentioned to me previously, the work that you've completed for the Phoenix in Leicester. And how this has transpired providing a space for those with autism, please can you explain that in more detail?

Andrew: Yeah. So, the [Phoenix](#), the current Phoenix, because I was involved in the previous Phoenix which used to be over by the multi-storey car park near De Montfort you know, I was involved in that too. In fact, I wrote a Fanfare for the opening of... the reopening of that, as an Arts Centre. But anyway, the new Phoenix - I was involved in the design of that building and a lot of the decision making in 1999. And one of the things that I was asked to do was to create a digital gallery, because, you know, they wanted to do digital art, but they didn't know how to build a space for digital art. So, would I design a digital gallery for them?

Of course, at the time, I didn't know I was autistic, you know, I just designed the space that I wanted to design, you know, and I often find myself in this position, people look to me as some kind of authority and ask me to do things and I just do what I want. So. it's very self-indulgent, really. But anyway, so as you came into the, the Phoenix, on your right was the cafe and this was a kind of open space and it was horrendous. I mean, absolutely the worst, one of the worst places in Leicester as far as I was concerned. You had bright shiny seats in orange with metal legs that scraped on the floor. You had shiny surfaces everywhere. You had the smells of the kitchen coming into the space. It was all just a nightmare, and so I thought, well, I'm going to do the opposite of that.

So, I built this space. You go down a little corridor and then you turn right, and there was this space that was basically just an empty white space that was floating on supports. So, you could come in from underneath, you come from above, you come from the side. We had computers all around but out of view, and the lights were dimmable. And of course, you know, this was a gallery space - it looked like a gallery space and we had exhibitions in it, but of course what I now realise I did was I created an autism friendly space. And this is what I do wherever... I've done it here! Look at this where we're sitting. Basically, I've hived off this little area we're in now as an autism friendly space, you know. So, this is what I do wherever I go. I just create these spaces that are where autistic people can hide.

And I'm now currently in because they're refurbishing - they're taking out that gallery and they're going to develop it more. I'm now involved in their group for disability looking at how the extension could be. So, very properly, they're asking lots of disabled people to comment on the proposed new design plans. So, I've been talking to them about chairs and tables and signage and, you know, and of course, noise and lights.

Question 8

Helen: Please can you explain more to be about the ‘Autism Friendly’ spaces that you have built?

Andrew: the main benefit you can give is to enable an autistic person to actually go somewhere. I mean it's as simple as that, you know. If I know that there's a quiet room that is designed with autistic people in mind - and by the way, that's quite easy to do - then I will go somewhere. If there isn't a quiet room, I've got to have a really hard think about whether I will actually go to that place and what I typically would do in that situation - because most places don't have a quiet room - is I would get photographs and videos of the place that I'm planning to go to I look at it and make a judgment about whether I really want to go there or not.

Helen: And that's having an impact. Not only is it in your social activities that you would choose to attend a building, a venue. But even with employers/organisations, in your circumstance, you



weren't diagnosed until very late on in life, there must be in large organisations a lot of people that would benefit from an autism friendly space, because we don't know everybody that's been diagnosed.

Andrew: That's quite right. You can guarantee in Academia, there are far more people who are autistic who are undiagnosed, than are diagnosed, or there might be those diagnosed but unwilling to admit it, - or disclosed to use the technical term. But the thing about this is ... what you find is, and I've found this repeatedly: if you create something that suits autistic people, everybody likes it. It turns out nobody likes supermarkets that have loud beeps at the checkouts. Nobody likes to have the lighting up high. Nobody likes too much music. Everybody likes clearer signage. Everybody likes calmer colours, you know. I mean there are a few people who are sensation seekers - and some autistic people, by the way, seek out sensations - so it's not the case that every autistic person hates sensation, you know some of them really seek it out, but generally speaking you know, the improvements you make that benefit autistic people, actually everybody likes them. So why wouldn't you do it?

Helen: Why wouldn't you do it in the first place? And it's thinking about the broader element of everybody in society, isn't it?

Andrew: Yeah, so this campus, you know... It's improved a bit, but it is pretty hostile, I have to say, from my point of view. Some of the lecture theatres... one time (famous occasion) I actually refused to teach because the lecture theatre I was put into was so disturbing and I couldn't, I just couldn't do it you know, I couldn't be in there for more than five minutes, but you know the campus is generally quite hostile for autistic people. The more kind of quiet spaces, but I mean, I'm in a privileged position because I can commandeer my own space and make it suitable for me. But you know there are loads of autistic students who haven't got access to this who really would love a quiet room.

Helen: I think that's something we perhaps ought to try and look at, see what we can do with this to take this forward with the university to try and utilise our conversations for the benefit of students across the whole campus. It's understanding with what support networks that the university does provide on an individual student basis, as they go through their degree programs. And I think what we need to be able to look at, is, can we provide them a space? Like, you've talked about an Autism friendly space to bring them together that they can if they wanted to mix with each other, if they don't, that's fine. But it's a quiet space to come to, to get away from the noise that campus can give.

Andrew: exactly. Yeah, exactly. And I think there are there are two kinds of safe spaces or autistic-friendly spaces really. One is what you might call a kind of neutral space that doesn't have anything particularly in it, but it's just got the right level of lighting the right colours, the right kind of environment and that's easy to provide and it is very welcome. The other is a little bit more, where there's some attention paid to the kind of things that autistic people like to do. This would have some kind of sensory apparatus in. I'll give you an example. A few years ago, I went to something called the Autism Show which is a kind of industry - there is an autism industry, believe it or not, people are making lots of money out of this - but they had a quiet room. And in that quiet room was a projector that projected, sort of green laser dots that moved around across the ceiling and a kind of purple cloud, and it looked like the night sky, but a kind of a highly artificial night sky. It was fantastic. I just sat there, and my wife said, "okay I'll leave". Half an hour later, I was still there, just staring at the ceiling, and so we bought one for my bedroom and it's really great and it's the kind of thing that... here I am, a 65-year-old Professor - I shouldn't be so entranced by this kind of thing, but I am. That's autism. Something like that or some kind of sensory tubes, you know, you see them a lot with bubbling water in, lava lamp type things. You know, these kinds of things are very reassuring for autistic people. So



that's a different kind. I would call that a sensory room rather than a quiet room, but both kinds of room are valuable.

Question 9

Helen: Okay, thank you. Do you have any advice for parents with children who have autism?

Andrew: Yeah. Well, the first thing is they don't have autism. They are autistic.

Helen: And that's a change of my question, now we've had these conversations.

Andrew: So, you know, it's not a disease. It doesn't need treating. So, avoid things that claim to be treatments. There's a famous one called ABA which is very common in America, not so common here, which is applied behaviour analysis. Don't go there. Because what happens with this is it modifies the behaviour of the autistic child to the point where they can appear to function in neurotypical context, but it does so at the cost of the autistic child's mental health and long-term it causes damage. So, I wouldn't go there.

So that's the first thing: to understand that this is something that the child is just born with. The second thing is to recognise that the environment plays a massive part in how the child manifests their autism. So, if you've got what is often called challenging behaviours going on, a lot of the time this is to do with environmental factors and the difficulty is the child can't explain that and can't understand and doesn't recognise it themselves. So, you do lots of reading and research.

I'd recommend a great book by Luke Beardon, called [Avoiding Anxiety in Autistic Children](#), which really summarizes all the issues that your child is likely to experience and try and see the world from their point of view. Another thing, if they have a meltdown and a lot of autistic kids have meltdowns, they're not throwing a tantrum - that is at something different. I'm not saying autistic children don't misbehave. I think they're just like any other child in that respect. But you have to recognize that when this is, this is actually a meltdown and not a tantrum, because it looks like a tantrum to a lot of people - onlookers, who will often express disapproval but actually, they can't help it. It's an overwhelming, just completely overwhelm of everything. You know, they're at the mercy of their autism in that sense.

Helen: Difficult for a parent as well to differentiate the difference between a tantrum and a meltdown?

Andrew: Well, I think because of the way it's depicted often people do get confused between the two, but I think it's not so difficult to tell. You can tell when a child is trying to manipulate you to get what they want. I mean, like, I say this, I'm not a parent myself. Well, I have a stepson who came to me age 10, but I've never had my own children. And that is partly, honestly, because I didn't want them to experience what I experienced in life. So, I just chose not to have children that reason.

Helen: So, if a parent would understand the build-up to what would be probably a tantrum if a child was asking for something, and they won't be getting that toy or sweets in a shop, that's the build-up to a tantrum? The build-up to a meltdown, do you want to explain?

Andrew: So, what happens with a meltdown is that gradually... it's a bit like spoons... gradually things accumulate. So usually, the meltdown begins way before you actually see the meltdown, because it's like, you know, constantly filling up a jug, you know, not emptying it out. So, if you go through the day and you fill up this jug eventually it's going to overflow. Unless you tip some of it away. So, what you need to do is, build in some activities that enable those energies to dissipate, to avoid the meltdown scenario and you need to understand what the kind of things that will trigger a meltdown. And, as you get to know your child, you'll figure that out and it will be different for each child. But, you know, that's



its completely different to a tantrum. A tantrum will happen spontaneously, very quickly, when a child doesn't get their way or whatever. You know, there might be two or three things that precede it but basically that's it and it will blow away as quickly as it arrives. Meltdown is completely different, it's a long-term thing it'll take a day to materialise or even a week. The other thing I'd say to parents is routines are really important and allow the child to have a routine and reinforce it. If they eat the same thing every day, it's not going to kill them. And you might think it's very unhealthy, but actually, that is what they want.

Helen: That's healthy for their mindset?

Andrew: Yeah, yeah, so allow that, don't just try and contradict it because you think somehow, it's bad, you know. Autistic people are different, they see the world differently and you have to recognize that and acknowledge it and allow it to be and yeah, just try and understand what it is in the environment that is affecting the child. It might be you, as well. That's the other thing, is to bear in mind that you could be the problem, if you're a mother who wears perfume, you may not be aware of it, but you may be actually having a big effect on your child.

Helen: Back to the sensory issues...

Andrew: The sensory issues are really really important, I think. I mean communication of course as well and but the sensory issues to me is underestimated all the time, how significant those are by autistic people as well. I think people just don't recognise, because if you have these sensory issues you don't know, you have them, I'm still finding out about mine. Thinking, oh, hang on a minute "You mean everybody doesn't have this"? And these moments of sudden revelation that happen all the time. Every day I get these little micro-epiphanies where I just go: Oh, wow, okay, so you mean that's different, you know? And I think that's what you have to recognise, is that these differences are something that the child won't necessarily themselves be aware of, but they are there.

Helen: I've recommended the book to a couple of people. I haven't received any feedback yet on their thoughts of the book.

Andrew: I'll be interested to know, because I'm actually cited on the cover of that book, I think it's a terrific book, obviously.

It's not just the parent who's learning about the autism. It's the child as well. The child is gradually learning. You have to learn together, really. And the other thing is persist: it will get better. I was talking to a lady in the street the other day whose child is autistic. We got talking about autism and I said, "you know, it does get better" and she, she burst into tears. She was obviously having a really hard time and I said, "Here I am. A testament. Stick with it. I know it's difficult for non-autistic people, but stick with it and just persist, and it will get better".

Helen: And I think this is why we are having this conversation and we've had a few conversations beforehand to help it get better in society, is understanding, everybody understanding what it is like and how they can contribute to making somebody's life a little bit better. Whether that be at school, at home, in the work place, in society in general, and if you're visiting a venue. You've covered so much where some simple things could change to make all of our lives a little bit easier.

Andrew: Yeah, absolutely. Brilliantly put. Awareness and acceptance, you know. I think there's a lot of talk about Autism Awareness, which is important, but acceptance is the real toughie because it's all very well being aware that an autistic person having this issue or that issue but you know, accepting that that is how it is. I've seen some heart-rending things with parents saying basically, you know, their child is not the child they dreamed about having, and all this. And that, that saps your soul, it really



does, because you just think that, you know, autistic people have so much to offer. Their wonderful people and, you know, it's so joyful when you see the world through their eyes and yeah it can be difficult at times but, you know, actually you get so much from them too.

Helen: That's what we want to try and do, and understanding is seeing the world from their eyes.

Andrew: Another sort of misleading idea that is around a lot is this idea that it's a superpower. I'm very wary of this because, you know it implies that in order to be valuable as an autistic person, you've got to be somehow gifted in some way, you know, you have some special ability, you know, like Rain Man you can count the number of matches that fall out of the box, or you can do a Rubik's Cube in 5 seconds or something, and this is really not it. Being a savant like that, I mean, they're usually autistic but that's not the point of autism you know. You're just another person but you've just got a difference. That's all you are different.

Question 10

Helen: My final question, can you explain to me how the fire alarm activating affects you? We went on a little journey together with that and we've not finished yet because I think there's more work that we need to do to support you. Please could you explain this to me?

Andrew: So, well, I've explained to you about sound already. So now I've lost a lot of my hearing, fire alarms are designed to cut through everything, which it does very effectively. And so first of all you have a sound that is completely overwhelming and loud and you know just obliterates everything else in its path. And it's unexpected. And this is a big problem for autistic people is the unexpected, you know, sudden changes in state. So, you go from being, you know, in a state of normal daily working, with your spoons wherever they're at, doing what you're doing. And then suddenly this thing comes, you know, and inserts itself into your existence. It says your state has to change immediately and dramatically into a different state where you have responsibilities that you have to discharge immediately. But you can't think about what they are, because the bloody noise is so loud. So, then you've got this thing of: what do I do? It's like suddenly there's this enormous demand, you know, that it's being made on you. So, you've got a massive change, you've got an obliterating sound and you've got a terrific demand that says: if you don't do this, you will die! and other people will die, too! Possibly because of you! It's basically screaming at you.

Helen: As if it's telling you to panic?

Andrew: So, I'm suddenly faced with this, this little trident of doom, sort of just... and I'm afraid I just go to pieces. I can't function. I just go into shutdown. What happened the other day when we had that problem was that the alarms in the Ken Edwards building have talking in them as well. So, you get this, the obliterating alarm and then a voice says something like: "there is a fire leave the room immediately" or words to that effect. Now that was in its way equally disturbing, but, because it wasn't a loud sound, I had just enough ability to move to actually exit the building. So, because there was a gap in the alarm, I ran at that point past people, all sat at their desks just normally working going: that's just a fire alarm. What's the problem? Fire, alarm, test. So what?

So, I'm running out seeing all these people looking up going, what's up with him? As I dash out the building in the state of kind of complete mental collapse, and then I stand there, sort of beating my head, because that's what I tend to do that. It's like hitting myself to make myself feel, you know, I don't know. What am I doing? I'm trying to kind of bring myself back to some kind of reality, you know. Because at that point, anything could happen. It's actually incredibly dangerous. I mean, you know, if the alarm had continued, if they've been a real fire and the alarm and continued without that speech in, I would be dead now, because I wouldn't have been able to move at all. And that actually happened



to me in Europe. Brussels. I was working for the EU and we're in this big tower block, and the alarm, fire alarm went off. Of course, I just went to pieces and couldn't move. Fortunately, what happened then was there was a lot of other people around and they kind of manhandled me out of the building. So, they kind of propped me up and sort of just pushed me. Yeah, I just froze, they kind of pushed me down the stairs and shoved me out into the street. At which point I burst into tears and started playing Pokemon, because that was my way to kind of try to ground myself again.

So, it just has this this devastating effect. So, knowing that there is a fire alarm test on a particular day does help, because then I can say, all right, there's a fire alarm test. But what I actually do is, I try and avoid being in the building. Fortunately, in Ken Edwards Building is now it's on a Thursday. I don't work on a Thursday's anyway, so that's that. But this space in the library, has Tuesday 8:50am. So, I don't come in on a Tuesday until after half past nine, to just try and avoid these fire alarm practices. But obviously, you know, the point of a fire alarm practice is to prepare you for what happens if there's a real fire and it's at that point that is incredibly dangerous for you. I've had numerous situations where; it is like I used to frequently nearly get run over in the street because I didn't understand what was going on. I get overwhelmed and step into the path of an oncoming vehicle. I've never actually been hit by a car which is kind of a miracle. But you know so I'm a bit of a danger to myself some of the time, but yeah that's fire alarms.

Helen: Yes, and I think this is something else that maybe we can look to see how we can make some improvements, is understanding the needs of staff and students in terms of the fire alarm. But that goes back to what you mentioned quite a while ago is the non-diagnosis that if people don't understand that they are autistic and they don't really acknowledge that these things are an issue. But I think we still need to provide some training. Some understanding, more support networks in place to help, because fire alarms will go off when they're doing the testing. And it's just making sure that we understand that we've covered all bases for everybody.

Andrew: Yeah, I think so. Not every autistic person would react in the way that I do, so there might be some who are fine, but I think there are quite a lot who would, to be honest. I feel for autistic students. Just lecture theatres are quite a nightmare in many ways.

Helen: I think that's something probably that I think we can try and utilise what we've got here, to try and make a benefit out of it. You know what we're doing, and having these conversations, understanding how we can make improvements just to try and to move forwards a little bit with this.

Andrew: That will be good. Yeah,

Helen: thank you.

Andrew: I was going to say earlier about education. Just one final thought - I didn't quite get to this one. You know the tradition in education is that you give people a broad education covering a lot of subjects and then gradually narrow it down. So, by the time you get to PhD level, you're studying one, you know, one particular very focused area of one field and you're looking to create an original contribution to knowledge, and for autistic people, I think education should be structured in the exact opposite way. You start with the focus on one or two very specialist things, which you go into an incredible depth and then gradually you open them out. I mean by my big thing is transdisciplinarity, so I'm making connections between disciplines. I'm very very good at explaining complicated ideas in a simple way so that people can understand them. And I'm very good at spotting the connections between all these different experts in their different fields and seeing the relationships between people and being able to bring people together in that way. And that's happened. That's been a



gradual process from the very specialist core out to this broader view. So, I this is what I mean when I say, I've done education the opposite way to the way people are supposed to do it.

So, I'm a Professor but, you know, I'm not like, your typical Professor, who is just a bigger expert on some subset of some field than the person next door. I'm a Professor of lots of things. I mean it says on my letter of appointment: Professor of Music. But music to me is a very vast topic that actually includes all sorts of things that you wouldn't recognise as music. But here, I'm known as a Professor of Creative Computing. That again is a vast topic that covers or pulls in lots of different things. So, that, I think is how you should approach education for autistic people. And I've kind of done it for myself against the grain. And I think it would be great to think that an education system could actually be created where the national curriculum consists of like two topics or three topics. But you really, really, study those topics, in so much depth. Then the child has the opportunity to really go into one of the classic examples like trains. You know boys, autistic boys - many of them have a fascination with trains for example and the kind of knowledge they acquire is good for pub quizzes but not much else and you think well actually that's a real shame.

I'd put autistic people in charge of the rail network in terms of the ticketing system and the timetables because things would run a lot better. Maybe not everybody would like the results but I'm pretty confident that the system would work you know. So yeah, it's funny how those kinds of special interests end up over the years. They do dissipate and change, but it would be nice to think that some value in those at the child level. So, the child doesn't feel like they're a freak the whole time. I mean, my teacher used to send me out of the room... my mother always used to say: they went to the parents' evening to talk about me and the teacher just said, well really, I just let Andrew teach the last class of the day because it's just easier that way. They said: but you're the teacher! And she said, but he knows more than I do and he won't shut up in the class. He's always asking questions and talking over people. So, I just let him teach the class, it's easier.

I was what... 6 then. The famous story about me – sorry., I'm rambling now - but a funny story about me my mother always used to tell, was when my grandma came to visit and I was three according to my mother, I think probably I was a little bit older that may be four or five, but anyway, Grandma came to visit and she was looking out of the window. Grandma said, "Oh, look at the lovely Dicky Birds on the lawn, Andrew". And I then promptly recited their Latin names, their breeding patterns and migration patterns, the colour of their eggs. My grandma, she never talked to me like that again. You know, she was horrified! All it was, I read the Observer book of birds, and I just memorized every single page, I knew everything about every bird. And that was it, you know, but obviously that was rather unusual at that time... at that age.

Helen: Andrew, thank you so much.

Andrew: You're welcome. Thank you. Was that what you wanted, was it? Okay

Helen: I think from our conversations we've had before and I think you have covered everything through these questions giving you a good snapshot of what it's like and I think that's the bit that I want to be able to get across, is this is "my story and it is a hidden disability". And how do we express that to others? Inside the organisation and outside the organisation and I think without going on for hours and hours yes, we've caught what would be interesting to somebody else. Reading what we see, I feel it has. Because I think before I met you, this would never have crossed my mind. To have this conversation to how I can make a difference. And how managers at my level can actually think differently in terms of what Operational Support we are providing. What does that look like?



And how can we change our mind-sets and thinking? Well actually we can do that differently. We can make this space a lot better and a lot softer because of these reasons.

Andrew: My general attitude at the moment is to have small victories, small, local victories and that in the belief that this has a ripple effect. So, a kind of bottom-up approach, rather than trying to sort out the issue, some grand statements, that try and change the world. I try and do it one person at a time. And raise awareness and, you know, all that sounds like this will do exactly that. And that's great.

Helen: I think so because I've got a platform where I can share what I've done with the College Operations Managers within our college. And even if that ripple effect just starts off at that level or then we take it we take it wider. As you know, I want to put the story on the website so the public knows what I'm doing. You know, we can start to open a few more doors for the better.

Andrew: Well, that would be wonderful. If I can be helpful in achieving that, that would be great. I'm not thinking about it for me. I'm really thinking about it for the other autistic people, particularly the younger people who are around here.