

## **Wendy Lawson in conversation with Ilona Roth, Chair of SK124**

### **Ilona:**

We are very lucky to have here at the Open University Dr Wendy Lawson, to talk about her experiences as a person on the autism spectrum and also as someone who has written about and studied autism.

### **Wendy:**

Yes.

## **CHILDHOOD EXPERIENCES**

### **Ilona**

Wendy, you were diagnosed as intellectually disabled as a toddler but you were not diagnosed with autism until you were an adult. Why do you think that happened?

### **Wendy**

I think that probably occurred because I couldn't talk. I didn't speak till well after my fourth birthday, and so my parents, their complaint if you like, to my local doctor was that they had this child who seemed very distant, non interactive with them, and with my older brother and younger sisters, and just a very different child to the ones that my mother had; I was one of four. Upon testing I didn't respond to any of the materials in the office that I was supposed to play with, I just sat and rocked in a corner or stared out the window, so I think that possibly back then- that is going back 56 years nearly, there wasn't as much awareness of autism and the assumption was that they had a child with an intellectual disability.

### **Ilona**

How did your parents react to this diagnosis and to the way you were as a child?

### **Wendy**

My parents reacted to my initial diagnosis of intellectual disability with some frustration and I was pretty much seen and not heard. My parents are from that generation, I think, were embarrassed that they had this child and not sure what to do with me, unfortunately, so it wasn't a positive response at all.

### **Ilona**

You have talked a little about your childhood and you've written about your childhood; in what ways did you feel different from others when you were growing up?

### **Wendy**

I know that I didn't experience life in the same way as other children simply because people kept referring to things which didn't make sense to me, everyday things, children's games, things that adults required of you, things that were said. When people said things like they would just be a minute, but they weren't a minute, they were much longer, I used to feel lied to and get very angry about things which other people, other children, kinda took in their stride, so those sorts of things I think I experienced very differently.

### **Ilona**

Would you say that you felt lonely as a child?

### **Wendy**

That's a difficult one because I don't think I felt lonely. I often felt alone, because of being misunderstood, the isolation of not connecting to understanding, which is actually quite different to feeling lonely, I think.

**Ilona**

And looking back now how do you think your autism manifested itself in your behaviour as a child and adolescent?

**Wendy**

I was very obsessive, I had interests that just took over all of my being really, mostly interests in insects, in animals, later on in my teens very obsessed with engines; piston engines in particular not into rotaries, and I think that was very noticeable because my sisters and my brother were not interested in those sorts of things and the things they were interested in often varied so they would be interested in something for a very short time and then that would change, whereas my interests, my passions, were very passionate and stayed with me for quite a while. Other things that were quite different was I didn't talk for quite a while and then when I did speak I tended to monologue or talk about the things that I was interested in and not so good at listening or turn-taking-those sorts of things; very noticeably different to the ways my sisters and brother interacted with their peers and with each other.

**Ilona**

How did your parents react to your obsessions and your focus when you were a child?

**Wendy**

They found it quite difficult because they would tire quite easily, of things that I wanted to talk about or was interested in. I loved libraries and would spend hours and hours in the library. My parents and my family weren't really into reading and the sorts of things I was interested in so it was difficult and it was hard for my family to appreciate the passionate way that I got involved with things. They didn't understand why anyone would want 100 mice, for example, little white mice with purple eyes that I bred in Smiths Crisp tins covered with chicken wire in the garage, and they didn't understand why I collected beetles or why I would line up my insects and race them. My sisters wouldn't do those sorts of games, they played tea parties and dolls houses and I wasn't interested in those sorts of things and I remember, I was a bit destructive I suppose, but I remember taking the arms off of one of my sisters dolls and lining those up and that didn't go down very well at all. I really didn't intend to upset my sister I just wanted to see what would happen if you dismembered the doll and put it in a different order really, yep.

**Ilona**

So it sounds as though your parents wouldn't or couldn't support you in your rather different view of the world, what or who gave you most support in your upbringing?

**Wendy**

The most support actually I got from outside the family. I was very intrigued by the local travellers site, the gypsies that were around locally had a beautiful horse and dogs and lots of activity, colour and music and seemed to be really much more interesting and interested in sharing my life. They'd let me ride the pony bareback; I didn't have to have a saddle and this sort of thing so I spent a lot of time away from home and my parents didn't really seem to miss me if I didn't come home at night. No-one seemed to notice, sleeping out living in the local woods with other traveller group people and Jenny a local traveller who became a good friend, she didn't go to school, she was being home-schooled, she became a friend, and later the church,

church people were very good to me and church, as an adolescent church became my life for many years.

**Ilona**

How do you think your childhood compares to that of children growing up with autism these days, do you think its better now, or whether perhaps things that were easier for you in your childhood?

**Wendy**

In some ways I think life was easier for everybody all those years ago, because there weren't the restrictions. I didn't have television, I was an outside child, I ran everywhere or cycled. I used to borrow people's bicycles and ride on them or ride on a friend's pony, a lot of outside life which I think was really, really useful. Today I would hope that children who are diagnosed with autism, I would hope that they have access to more structured support at school which I didn't have. I didn't do well at school and I wasn't at school as much as I should have been- I used to just not go. I would hope that life for children these days because of technology and the advances that we have in understanding autism, and that parents are better educated and more supported. I don't know if that actually pans out. I hear a lot of parents saying there isn't enough support and there still isn't enough understanding at school for the children, but I would certainly hope that things have changed for the better.

## ADOLESCENCE AND ADULTHOOD

### **Ilona**

As an adolescent do you think that you went through the kind of normal traumas that most adolescent girls go through?

### **Wendy**

I tend to think that my understanding or discovery of being a teenager was delayed. I tend to think that at 13 I was closer to the sort of experiences of a 10 year old, so by 17 I was a bit more like a typical 13 year old, things took a lot longer for me to catch on to. Physically I started my periods at the age of 10, so physically I was an older teenager but not emotionally or socially- I didn't have typical friends. My biggest friends were my pets-my dog my cats my mice etc., so perhaps not as other teenagers might. There was certainly a longing to fit in, as I got older, and I started talking with an American accent like the cartoons and television and I tried really hard to be what I thought might be what people would like but didn't succeed, so by the time I was 17 I was really just wanting to go to sleep and not wake up again, and my first attempt at suicide was as a 17 year old.

### **Ilona**

So at the age of 17 you were obviously very unhappy and you were actually diagnosed with schizophrenia, can you say how that came about?

### **Wendy**

Yes I was diagnosed with schizophrenia at 17 and I think that came about because of attempted suicide. My mother took me to our local doctor who spoke to mum about me and mum said, "Wendy lives in a world of her own, she's not on the same planet as the rest of us". The Doctor asked me a couple of question-he asked me if I heard voices, which seemed like a really silly question because as far as I was concerned voices are actually designed to be heard and most of us, unless we are deaf, hear voices, so I said "yes", he said "what do these voices say to you?" and I said "well it depends on whose voice it is", he said "do you hear more than one?", and I said "yes I hear many". He then asked me if I see things, which also was a strange question because I'm not blind, although I only have sight in one eye, so I said "yes I do see things". So he concluded I lived detached from reality and that I had auditory and visual hallucinations, which equates to being schizophrenic, so he said to my parents that their daughter was mentally ill, that she was schizophrenic, would need anti-psychotic medication, and in fact they put me into a psychiatric hospital, I was on a ward with lots of older women who were completely nuts and it was terrifying.

### **Ilona**

You eventually came out of the psychiatric institution, and then you got married and had children. Can you say a little bit about the years after you came back into the 'real world' if you like.

### **Wendy**

I was in and out of the mental institution for 25 years and I had times as a day patient where a taxi would pick me up from home and take me into hospital and then take me home again. During that time, one weekend at church I met a young man who had a very nice matchless 500cc motorbike which he had built up from 250 twin cams-it was really nice. He used to take me to youth group meetings on the bike. And it was really motorbikes that kind of drew us together. Eventually I was on long enough lease to see David a little bit more and by the time I was close to 20 we then got married. We got married because somebody at youth group, one of the youth pastors, had said "you two are like an old married couple", we said "we are not

married”, and he said “well you should be”, so Dave and I looked at each other and said “well alright then” which is not really the right reason to get married, and we married on 6 May 1972 we eventually had four children, and I was still going in and out of the institute and would take the children with me as they came along. I was still on a lot of medication. I spoke to the psychiatrist after many many years, and said to him I had just finished reading a book by Donna Williams, a book called *Nobody nowhere*, and I said to Simon, the psychiatrist, “whatever is happening for this lady who has written this book I have just read, I think is happening for me, there are so many things about her story that I actually relate to”, and I asked him to read it and the social worker, June, and they both read the book, took them six months to get back to me and they said “we actually think that you might be right” and they suggested that I be reassessed, which once you have a mental illness assessment it is very rare to actually have someone suggest you go back to be reassessed. So I went to the autism team at the Melbourne University in Clayton in Australia where I was living, and the team of people there had me for the day. And they did some IQ testing and some interviewing and some more testing, and they concluded that I had very uneven pattern of ability and that actually I was high functioning autistic, not schizophrenic, and they wrote a report which took another six months and eventually that report got back to the psychiatrist. Five years later they took me off the anti-psychotic medication, and it was a very very long journey to actually being recognised as somebody on the autistic spectrum rather than somebody living with schizophrenia. I don’t have a lot of memories-I think I blocked a lot of the actual time out in the psychiatric hospital it was very very, really awful and that misdiagnosis caused lots of pain. The anti-psychotic medication really messes you up on the inside, constipation, lots of horrible things, it leaves you with sensitivity to the sun, so in Australia that doesn’t go down well. I had to wear long sleeve shirts and gloves, hat and keep myself covered up if I went out because the reaction to the sun was pretty bad, pretty horrible, and yeah, I think that coming to terms with that whole reality-the only understanding of autism I had really was *Rainman* the film, *Raymond/Rainman* and that wasn’t the way that I felt or lived. It was quite strange initially being given that kind of diagnosis because I didn’t feel like it was quite me, although I certainly felt like I wasn’t schizophrenic so there was relief and there was “I need to explore this more”.

### **Ilona**

Your marriage eventually broke up. Was it your autism diagnosis that contributed to the break-up of your marriage?

### **Wendy**

That’s an interesting question, my marriage broke up: was it autism that contributed to the marriage break-up? I don’t believe it was. I think that the common ground that David and I had, which was piston engines really, that wore off. David I believe would qualify for an autism diagnosis himself, and possibly he has a mild intellectual disability, it’s hard to know. He certainly has speech impediment and he found it very difficult that he had a woman who in his opinion, he had five sisters and women were meant to be in the house doing women’s work, and the first time I threw a tea towel at David he threw it back to me saying he didn’t do that kind of thing. And he actually became quite abusive and the reason we separated in the end was; it became obvious it wasn’t just me he was being abusive to physically and emotionally, he started on the children and I asked him to leave, which he eventually did. He didn’t think I would last very long without him, and he gave me a week, actually, but yeah, I think it was more the abuse and the lack of being able to relate that caused the marriage to break down.

## AUTISM AND FAMILY LIFE

### **Ilona**

What was the impact of your autism diagnosis on your children and the rest of your family?

### **Wendy**

The impact of the autism diagnosis was quite profound. My children, I think, because they were old enough were able to make a lot more sense of mum's behaviour, the interesting thing was my youngest son was also diagnosed at a similar time. I got my diagnosis only about a month before he got his, so it just made sense as a family, yeah. We made sense an awful lot more of the things that hadn't made sense until then. It also caused a lot of problems, people, some of them family members, said we were using autism as an excuse for not coping with life, and that we needed to be more proactive and get on with things, things that I couldn't do. I knew, I now understand that I can't do them. I accept I have some limitations which are because of being autistic, rather than pushing myself to be more sociable in ways that I know I can't be. So there was on the one hand more acceptance and understanding and on the other some 'is this just an excuse, or is this for real?' It took a long time to work those things through.

### **Ilona**

In what ways do you think your autism has influenced your role as a parent?

### **Wendy**

I would hope that it's made me more able to focus in on what my kids need and less aware of things that might potentially upset, because I don't get embarrassed and I am sure that is connected to my particular autism. And therefore I stand up for my children perhaps more readily. On the other hand I couldn't get involved with parent activities, parents that would run around for their children as in drive a car and take their children to all these different activities. I don't drive a car, I couldn't manage a tuck shop, I couldn't do all sorts of things that parents did for their children at school and I couldn't actually explain to anybody why I couldn't do those things, so that was very difficult. I have a daughter who in some ways became mum to her brothers rather than their sister, which is a bit sad because she missed out on her own growing up I think, and her own friends, having friends, because she stepped in and did so many things just naturally that she knew her brothers needed that I didn't pick up on, and I wish that wasn't so. But I am very proud of Katie, she is great.

### **Ilona**

How did you and how do you adapt your lifestyle to accommodate your autism Wendy?

### **Wendy**

I am fortunate enough to have a full-time carer, who is also my partner, and between us we share the load with household chores and everyday things. For example I am no good at budgeting, I am not good with filling in forms, I am not good with paperwork, I am not good with money, I can do statistics but not numbers, which sounds a bit odd; formulas are a lot easier to work with than everyday math. So I have family who take charge of those sort of things that frees me up just to focus in on my writing and lecturing and touring to talk in various ways about autism. If I didn't have that I'm not sure quite how I'd cope. I feel very strongly about Viktor Frankl's understanding about meaning in life and the meaning for me is sharing about what autism is. So I suppose that is how we separate the roles in our family. I adapt by accepting my limitations. It's hard sometimes accepting that I am not very

good at crossing roads. I have only been knocked over once this year so far which isn't bad. Even though I know academically about looking in all directions and listening whilst crossing the road, what tends to happen is that I get so focused on noticing that the truck has now gone, I forget again to look the way that the truck came from just to check there is nothing else coming. Things like this I find quite difficult but I realise that I have these limitations. so I tend not to travel alone and I have a lot of support.

## COPING WITH LIFE EVENTS

### **Ilona**

You have experienced some great traumas and tragedies in your life- we have touched on your admission to a psychiatric institution, and tragically one of your children was killed in a road accident. What would you say carried you through these difficult times?

### **Wendy**

The things that have carried me through difficult times such as the time in the institution, the mental institution, and then later my 19 year old son's tragic death, very, he was killed by a very drunk driver going the wrong way up a dual carriageway; Mattie didn't stand a chance. They are very different things actually: the time in the mental institution I don't remember much about in some respects and I don't connect to a lot of what was going on for me in that time maybe because of the drugs and medication- I was zombied out. But what happened with Mattie, I wasn't on medication and I was very very much with it, and the hardest thing, which might sound strange to some people, was all the actual arrangements for a funeral: getting the right measurements for the coffin because he was a 6.6 tall young man, he didn't fit a standard coffin, and who to phone and how to go about it and how to put notices in papers. There was lots of organisational stuff that I found very difficult but I had a lot of support again from church people, from family and friends, and really it was the delegation of who should do what that guided me through that time. The sadness and the things that people often talk to me about, I can't say that there was a sense of 'this should never have happened', you shouldn't drink and drive, of this disaster should never have occurred, I almost have been very angry, but once Mattie was dead and I could touch him lying in that coffin and he wasn't there anymore, as far as I was concerned he was gone. He had had, I think, a relatively good life, he had achieved a lot in his young life, he was a very messed up kid, who came good the last two years of his life, so he had achieved, in my opinion, more in his young life than sometimes some people achieve getting to grow old and be 80. So once gone, it was like the whole event had gone and we moved on. The rest of my family, my daughter 10 years later still cries and misses her brother, whereas I don't have that sense; he has gone and I don't have a sense, there is nothing to feel or grieve over because he is not here, which is hard to explain to people. But yes, it was sharing the load and having support that got me through both of those events.

### **Ilona**

Would you say your reaction to your son's death was coloured by your autism?

### **Wendy**

I would say the reaction to my son's death was coloured by my autism, but I am not sure that's a negative thing. Because when I see my daughter who is still upset on Christmas or Mattie's birthday at times when she remembers him in particular, it makes me sad to see her grief and I wish that, 'cos she is still very depressed about it sometimes, she has even had times when she not wanted to go in a car, she is scared of being on the road, and I feel, yeah, that it must be awful to have to go through and I am pleased that autism protects me in some respects from some of those emotions. I certainly had them initially but they didn't last for anything like the length of time tha my daughter's experienced, so yes.

### **Ilona**

How have your experiences of being on the autism spectrum enabled you to help others in a similar position?

Wendy

I think that being on the autistic spectrum means that I probably have an advantage in helping or supporting other people with what they are going through because I can share from a personal perspective. I can share from what I know my two boys go through with their autism, and as a researcher and a psychologist I think that I can share from the literature, so I feel in a particularly good place if you like to be able to support and teach and educate hopefully about what it means to be on the autistic spectrum and what might be useful for those of us and their families who are living with autism.

**Ilona**

Writing poetry plays an important role in your life, can you explain what this means to you?

**Wendy**

As a child growing up I would think in rhyme most of the time and sometimes I actually have to stop myself from rhyming words when I am talking because it is so natural to me. When I write poetry it's like a way of reflecting back an experience I am having so it actually slows the experience down and helps me connect to the concepts behind the experience, to what it might mean for me in particular and what I might need to do about it. It's a bit like filming something and then watching it over so you can slow everything down and see what happened. I love words and that's another way I guess of putting words in the right kind of order, sequence and manner to help make sense of things, so yup, that's what poetry is for me.

**Ilona**

So what would you say to people who claim that those with autism think visually?

**Wendy**

Do you know I think when they say that people who are autistic are all visual learners or think in pictures it stumps me a bit, because I know a number of people who are not visual and who would tear the pieces of the posters and paintings and things up on the classroom wall because actually they get in the way of them thinking. And I am an auditory learner and if I am then certainly lots of other people must be as well. I think we have to be a bit careful, we don't assume everybody is visual-lots of people will be but possibly equally lots of people won't be.

## AUTISM THEORIES AND PRACTICAL ADVANCES

**Ilona**

You have formulated your own theory of autism-can you explain your ideas on this.

**Wendy**

I have a theory about what autism is, and it's really to do with how our brain is configured or wired up to work with attention. I know everybody learns differently and we are all very different people and I know that in autism we are much more different than we are alike, but the one common denominator that I come across constantly is that those of us on the autistic spectrum are really good at homing in and attending to things that we are interested in to the exclusion of all else, and I put that into a study project, a PhD project, and I explored the various cognitive theories of autism and came up with lots of gaps in those theories; that an understanding about how the brain is configured to work with attention seems to plug those gaps it seems like 'ahah' kind of moment, that actually in autism what's going in is we are single minded, we are black and white, we are literal because we use attention in a specific way connected to interest. It's almost as if without interest we can't attend. If no interest, no attention, no awareness. People try to get us to attend all sorts of different things that we are not interested in and we physically can't notice them, we physically almost repelled by them we don't connect, but the minute interest is introduced, there is a switch that goes on in our heads and we can notice things. So yes, the theory that I have about autism is connected very much to our ability to use single focus, single attention and single interest.

**Ilona**

So let's look at your theory alongside one of the other main theories, for instance the theory of mind theory of autism. Now if we take the social difficulties in autism, the theory of mind theory would explain those in terms of the lack of social understanding, the lack of ability to understand what other people are thinking and feeling, or at least impaired ability to understand what other people are thinking and feeling. How would your theory explain the same phenomenon?

**Wendy**

The theory of mind theory about autism suggests that those of us who are on the autistic spectrum are not able to kind of put ourselves in somebody else's shoes, we are not able to kind of connect with what might be happening with someone else we are mind blind, is a common expression. And if you can't put yourself into someone else's perspective or point of view then socially it makes it very difficult to have a social interactive time which is part you part somebody else. You've got to be able to share interests, you've got to be able to let go of your own interests to accommodate the interests of somebody else. The theory of mind theory suggests that in autism we lack empathy; we don't connect to what is going on for others. What I believe is going on in autism, we are not very good at marrying our interests with the interests of somebody else, because we only connect to what is of interest to us. Now that is a very very different understanding of autism. I actually know from the research that people on the autistic spectrum can be very empathetic but that empathy tends to be when we're connected, it tends to be when we're interested, it tends to be when there's something that turns on a switch for me. I know that even when, I was very attached to my pets for example, and when my dog died, I still feel, when I talk about Rusty and what she had to go through, when she suffered when she died, I still feel the pain. It's harder for me to feel that with my son Mattie because for one thing we weren't very connected. I was very attached to him as a young mum when he was a young son, but as he grew older he left home at 14, he went to live with his father-our paths were in different places. He was quite a difficult child and it was difficult to

relate to him. There wasn't the attachment that I had when he was 3. When he died he was already a stranger and I think that's got a lot to do with my lack of perhaps ongoing grief over his death in the way that my daughter feels who was very connected to Mattie. Whereas I do feel this ongoing pain, even though it was a long time ago, that my dog died. I still feel as if she were here yesterday, today I could draw her and relate so many things about her life. I would find that quite difficult with Mattie. That's not an empathy, per se thing, it's a connection thing, which is different, if you take autism as an attention, interest, connection idea. It makes a lot more sense than I believe the theory of mind theory about autism.

### **Ilona**

When we look at the big theories of autism these days, the theory of mind theory, executive function theory, central coherence, systemising/empathising, its quite common to say that these theories are complementary to one another, that each of them explains some of the phenomena of autism and no one theory explains all of the phenomena, how does your theory relate to that, where does it fit into that picture?

### **Wendy**

When we think of the current cognitive theories of autism, then it is pretty wise and plausible, understandable to think of all of those theories as each one having some relevance to the world of autism, and they certainly do. Whether it's theory of mind, whether its central coherence theory, whether its executive dysfunctional theory, it doesn't matter, the cognitive theories all have something to say and quite rightly, about aspects of what autism is. I think where SAACA, (Single Attention and Associated Cognition in Autism), where this theory differs is that it actually it seems to take up the slack from those other theories from where they leave off. It seems to fill in the gaps and the holes, from the research it seems to cover more of what autism really is which will have a big impact on how people are educated, how educators work with those of us who are autistic. It's a bit like in the old days they talked about being dyslexic or having a reading disorder as you were naughty and you were difficult. I think if people still see autism as lack of empathy, then that's misguided, they are going to work with children in a different way. If they see autism as an attention issue, I would hope they'll work with children who are autistic in a much more positive way. I can see it revolutionising education and how we work with kids, adults and teenagers on the autistic spectrum very differently that the other theories are all based on deficit whereas SAACA homes in on ability. They are very very different from one another, so they are complementary. I am not rubbishing the other theories in any way, I think that they have been very useful in pointing us in ways to work with those of us on the spectrum, but I think they are inadequate and times hopefully are changing and people are focussing a lot more, even those who brought us the theories of central coherence for example, are focussing in on-one lady says that she wished she called it not 'weak central coherence' but 'strong central coherence', and I agree with her, I think that we should be focussing in on strength, not deficit.

### **Ilona**

Well that brings us naturally to the question of where you think the next big advances will be in understanding autism and in helping people on the spectrum.

### **Wendy**

Well I really hope the next big advances in autism will be focused on using skills for employment issues. Technology is a world that is expanding in the 21<sup>st</sup> 22<sup>nd</sup> Century scene, and there has never been a better time to be autistic. I think that a lot of us are very much at home in the world of technology, we are very good at it and this will

be a natural place for many people on the spectrum. Academia is a natural place for people on the spectrum. It's been said that Universities are sheltered workshops, dare I say, for those of us on the spectrum. We naturally fit into situations where we have to focus in on, whether its history, geography, technology, you know areas the arts, science; these are all realms that we thrive in, rather than the social world where we might feel lost. Instead of pushing social I think there should be a shift in the way that society is thinking. And we are all being told we should be more at home in a group than we are on our own, and you know that just isn't always true and I think people are scared to stand up and say, well actually I like just reading a book by myself rather than going to the pub or something like this. We need to stand up and be accounted for I think when it comes to these things. So I would see advances taking us much more into not feeling bad about being on computers and seeing the computer as isolating, but rather in autism as seeing that is actually connecting, and people are connecting over the internet in ways that are quite difficult for us to do in person .So yep that's what I would be hoping; that we are focussing in on the positive elements of where autism could lead us rather than the deficits.

## DIFFABILITY NOT DISORDER

**Ilona**

Wendy, you are known to consider that autism is a 'diffability' not a disorder. Can you elaborate on that view?

**Wendy**

I'm much happier and more at home in thinking about autism as a diffability- as being differently abled rather than disordered; disordered conjures up very negative impressions of broken, of out of order, of not functioning not working, and I don't believe that to be accurate. I know I am not very good at being organised, but then I know a lot of people who are not autistic who are not very good at being organised. I know I have a number of difficulties, and yes I am disabled in a world that says I have to be a certain way, but I don't feel disabled at home, where I organise my life to be a way that I can work with and I think a difference of ability should be where our focus is rather than not working, rather than being disordered. That is how I see and feel about the actual terminology.

**Ilona**

What would you say to those parents who are very keen to promote the idea that their children have a disorder?

**Wendy**

I think for some families it is more comfortable, perhaps, less complicated perhaps, to promote the idea of autism as a disorder because then they can be seeking a cure, then they can be perhaps drawing on medical support and they don't have to accept that they have a child that has this kind of mental disadvantage in a world that says we all have to multi task. Some children who are autistic also have an intellectual disability, also have epilepsy, also have a number of complex needs, not just their autism. And yet, unfortunately, families can lump everything together and just see it as the product of autism. Autism doesn't just automatically make you an epileptic, it doesn't automatically give you an intellectual disability; they are separate things that obviously can co-occur but you can be a neurologically typical person or normal person and have epilepsy, you can be a normal person and have a intellectual disability, and yet we don't see this push to get rid of normal, lets cure the 'NTs'\* then we will get rid of their epilepsy. I think sometimes families get things muddled and confused because there isn't the support out there to help them unravel and there isn't the support that says it's ok to live with autism the way that your child is. And there isn't the mainstream acceptance, unfortunately, of these kinds of dramatic differences. Autism is one of the most difficult disabilities to get a handle on more difficult, some of the research would say, some of the research by people like Vicki Bitsika, more difficult than Downs Syndrome, more difficult than any other disability actually, because of the way that our heads work, there isn't that reciprocity of interaction that people would like from one another, so getting on the same wavelength as your autistic child and accepting their differences and their interests and working with their interests, goes against the grain of current societal thinking, so it's harder.

**Ilona**

So what would be your advice to neurotypical people who are trying their best to understand autism and to help people on the spectrum?

**Wendy**

Trying to give advice to neurotypical people who might be working with those of us on the autistic spectrum or living with us, loving us, I hope, is hard because we are all

so different. I guess I would say please accept us with our disability, our differences, accepting of who we are as people needs to be foundational to working with who we are. Then I would say, build on our strengths work with our abilities and our interests; and that's hard because sometimes we have some very odd interests but I would encourage people to try to find a way to work with our interests and not take it away. Then I would say, that you could open doors with that interest for a very positive future. I love the story of the young lass in America, who was a girl who would just pick bits of fluff up from the carpet; she didn't seem to have any real ability. And eventually because of her love for cutting things up, her family got her working in sheltered workshop where she would cut up old t-shirts from second hand shops and make industrial cloths. Eventually that sheltered workshop closed and her parents were able-they must have had a bit of money-they bought the equipment and set their daughter up at home still making bundles of industrial cloths for various companies and she was able to earn a living that way. One day on a shopping expedition out to the second hand shops to buy various t-shirts and things for her to cut up, she found a t-shirt that she particularly liked and refused to cut it up, refused to take it off even. The slogan on the back of that t-shirt was something like, I can't remember exactly, but was something like, 'Please accept me for who I am'. And the parents had not an inkling that their daughter could read, they were quite shocked but they were convinced by her response to this particular t-shirt that she could read and she continues to cut up material and she continues to make cloths, she is happy and she is doing very well and may be as parents sometimes we need to accept that washing cars, cutting up bundles of cloth, doing things that might seem quite menial. If this is what makes our kids happy, then this is what we need to do, if it's studying engineering that that is what they need to do. We are all so different, but we should be starting of with acceptance and then working our way to working with interests, I believe, in autism.

\*'Neurotypicals'

## VIEWS ABOUT THE OU

### **Ilona**

Now you studied psychology with the Open University, what did you gain from that experience?

### **Wendy**

I studied psychology with the Open University, which to me was a brilliant experience, not only because I could study off campus, because studying on campus I found very difficult, I found it difficult trying to comprehend lectures, write notes etc with a group of lots of people. Studying off campus, distance education, meant that I could study at my own pace, it meant that I had time to take in the material. I found all the support that I needed - there were people always available to check in with. I found the tutorial groups that I become part of very very helpful and of course the residential times I could let the tutor or the lecturer know that I was autistic. I had somebody come in to the lectures with me as my support person. The whole experience for me was very useful very accommodating.

### **Ilona**

So you are a fan of distance education?

### **Wendy**

I am a fan of distance education especially for those of us who are autistic. I find balancing the roles of being a parent with the kids at home and studying, it was a lot easier, distance ed when I could make my own time to study and you can of course, you can take two years of study and put it into four years if you want to with distance ed which is part-time study, I know you can still do that on campus, but even that kind of thing would have been quite hard for me.

### **Ilona**

In what ways do you think the Open University can be especially helpful to people on the autism spectrum?

### **Wendy**

I think that Open University type courses with distant education can be especially helpful to those of us who are autistic because it enables us to not have to mix with lots other people who might actually take away from our ability to learn. The fact that you can be in a classroom where you have got people clicking pens, turning pages, all the sensory overwhelming stuff that comes from just being with lots of people, closes me down. Whereas distance ed, like the Open University courses, I can study at home, I can set up my study area, I can organise my studies, all the materials are posted out to me, I've got time to process the whole event of distance education in a much better way than I can if I had to go to a typical university

### **Ilona**

As you know we have an undergraduate autism module here at the Open University- it's called 'Understanding the autism spectrum' and on our module we have some students who are themselves are on the autism spectrum and also a substantial number of parents of children on the spectrum. As someone who has been successful in academic study yourself what advice would you like to give our own students on the spectrum, and to parents who are supporting their children with their own studies?

### **Wendy**

One piece of advice for autistic people who are studying an autism module with the Open University is that you might find it confronting. Sometimes in the literature we read about ourselves almost as statistics not people, and I certainly found that very confronting. So I would advise people to attempt to separate their studies from their personal life. See it as a module of study that's written factually rather than taking it too personally. Setting up a study area at home, making time for just studying rather than trying to fit it all together. And I found it invaluable having the support from the disability liaison officer at the university, who would then set me up with somebody that was a person that I could just relate to; a named person I could relate to for support, I found that invaluable. So the two things if you are autistic and you are studying an autism module is that you will find it confronting at times. Reading and talking about personal things to you that other students, see as something that's just in a text book and it's important we try and separate those two things and not take it personally and also to set up a study area and a study time quite specific so this is my time where I sit myself down and have my OU studies happening, rather than trying to integrate it into everything else, it doesn't work. And if you are a parent and trying to support your children who are autistic and you are studying as well, then again you might find some things confronting, understanding that all children are different and that what we read about in the text book won't always apply 100% to every child. Kids are all different and the studies tend to take a general look at things rather than specifics, so some of the things we read about won't be true of our kids and I remember as a parent-I have two boys on the autistic spectrum -thinking my son doesn't experience that and I don't experience that, not everything you read about is true for all people. So separating things, taking away what is relevant for you, leaving the other stuff that you don't need. Dipping in and out of text books you don't have to read everything there is about autism, you need to just dip in and out and take what is just relevant otherwise you will never get through it, it is kind of overwhelming, yes those are the two, three, four things I can think of at this time.

## RESILIENCE

### **Ilona**

One of the things we talk about in the course is resilience, and what is a person with resilience or a family with resilience. Would you say that you are a resilient person?

### **Wendy**

I think of myself as a resilient person. I believe I have a particular personality and disposition which if you tell Wendy she can't; I'll jolly well find a way of showing you that I can. I am not very good at lying down and playing dead. I do get up over and over when I knocked down I will get up again and again and again, so yes I do think that resilience plays a big role in being able to cope and get through things. And of course there are people who don't have such a resilience and will need more support perhaps.

### **Ilona**

Finally Wendy what is your recipe for a happy life?

### **Wendy**

My recipe for a happy life would have to include self acceptance, rather than self loathing, a big helping actually of self acceptance and then you would need to add several spoonfuls of laughter and fun and you would need to mix that together I think with lots of meaningful activity, without meaning I think life is devoid of meaning and therefore devoid of wanting to get on and live, so if you want to be happy in life I think you have to have a recipe that includes acceptance of self, lots of laughter and fun and huge amounts of meaning to one's life.

### **Ilona**

Wendy, this has been a fascinating experience, it's been a real pleasure and a privilege to talk to you, and it will be a tremendous pleasure for our students to hear you. Thank you very much indeed.

### **Wendy**

Thank you.