In our Words: Sixty years of the National Autistic Society and the story of autism in the UK

Oral History Interview with Dawn Mills. June 2024

Trigger warning: The following item references information relating to mental health.

00:00:00 Oscar Hilder

I am Oscar Hilder interviewing Dawn Mills for the National Autistic Society's *In our Words* project.

The date is Thursday the 27th of June 2024. So, Dawn, can you please confirm your name, how it is spelled?

00:00:15 Dawn Mills

Dawn, D A W N, Mills, MI double LS.

00:00:20 Oscar Hilder

Lovely, thank you.

Take us back to the moment your journey with the National Autistic Society began. What inspired or motivated you to get involved with the charity?

00:00:30 Dawn Mills

I've got two journeys here; one is me as an autistic person and the role that the National Autistic Society has... in me, finding my truth at the end of the day. And then there's a story about my involvement with the campaigns as an autistic person who knows she's autistic and wants to contribute something.

It's easy for me to see now how my life has been marked by my autism in many, many respects my whole life. But a lot of those things are very positive. The one impact for me had been the most tremendous medical and body phobias. And I had sought therapy a number of times for this. In the early days, certainly as I was hitting my 30s, I'd had a whole battery of really traumatic experiences in medical contexts that other people didn't seem to think I should be traumatised by and was experiencing anxiety levels that were just astronomical. And I think I realised that, one of these days - and I'm getting to that age now because I'm nearly 60 - it was going to be a case of this is life or death. If you can't get over the threshold to a doctor's and you can't get through medical procedures, you're going to end up dying of something that you need not die of.

So, in my 30s, I think, was probably the first time I tried something like CBT [Cognitive Behavioural Therapy]. It really had no impact at all. It was almost as though… there was… in my experience couldn't really be my experience… is what I was… nobody fell out with anybody but… but it wasn't doing me, it wasn't doing me any good. It didn't do me any harm at that point, but it wasn't doing me any good.

I got a little bit older, I had a number of digestive problems, urm, that triggered all these anxieties again, it was getting very distressing, and I had some psychology at that point. And again, didn't do me any harm, but it didn't do me any good. And to be honest, I was always very confused by the process. I just never saw the relationship to what I was experiencing in a medical context… just nothing made sense.

If we fast forward to my 50s, kind of, the worst scenario happened for me. They were going to have to extract some teeth and do it under a general anaesthetic and that coincided with my involvement with the mental health teams.

Err… I was still trying at this point to crack the problem, and they had been… knocking me back for some time. They'd say: "But you've tried this stuff before. It doesn't help" and I'm thinking: "What? You can't just leave somebody in that position." If I had a problem with my foot and nobody understood what the problem was, they'd say so. But it's just kind of: "go away, little girl", and I'm thinking: "but this could… this is really serious. This has me in a very desperate state". But it was unfortunate that, when they extracted what I thought was going to be one wisdom tooth, they took half a dozen. I can understand in retrospect that what I was experiencing was an extreme sensory trauma. It was like I was trying to run away from my face. The whole time I couldn't abide the sensations within my own mouth. It… and it seemed to me throughout… I mean, I did go into a cycle of what I now understand to be meltdown, shut down meltdown, shut down, meltdown, shutdown.

And they just didn't… they weren't listening. They seriously were not listening. I think things went wrong at my first assessment with them. They were looking at it through a lens of what they are taught to deal with, trauma and personality disorders, I think…

And I could tell from this assessment letter, they hadn't listened at all. They weren't listening throughout. I… and I can see now, I was repeatedly trying to describe to them an experience other than they were looking for. From the outset, it seemed to me, even before they extracted the teeth, they sent a coordinator around and it seemed to me they weren't getting it and I can see now from my notes what they were looking for. They were looking for probable feelings of unworthiness, self-loathing, shame, none of which I feel.

And it went from bad to worse then. I am afraid of doctors. They had made…an appointment with a psychologist. The… it hadn't been clear in the letter what (the appointment) was for. And as soon as I went in, I turned up, thinking it was the first of psychology appointments, a little bit anxious but I'm otherwise quite pleased.
And, in 5 minutes flat, on realising I was with a psychiatrist, erm… I hit the nail on the head. I said: “Am I here for you to give me drugs?”. He said: “Yes”. I left and I was so upset. And I look back over the whole horrendous experience now and can see they were trying to treat a personality disorder in someone who did not have one.

Moreover, they weren't listening to the sensory experiences. There's an awful lot that went on there…. that I can see just would have been difficult for any autistic person who'd been there for any reason. I've known I'm dyslexic since, you know, I was 18 or so and I can remember at the outset saying: “I'll answer anything you want, but can we deal with one point at a time? Can I be allowed to follow that line of thought to its conclusion and then ask me the probing questions?”. Because I found therapy just did this business, it was going round in circles, not really achieving anything, and I think: “This isn’t going anywhere, I can't make any connections out of this.” But that was never listened to. Every, every point that I was trying to follow through was always interrupted…so even though I'd asked for that, I didn't get it and that there was so much to that.

The one that sticks with me the most would be a point where I… I do know something about attachment disorders and stuff because I work for a virtual school. And this had puzzled me in my relationship to my mother and I remember telling the therapist: “Well, my mother recently said something quite strange to me, she said to me that as a baby, I didn't particularly want to be hugged. I didn't want to be handled. I seemed to be happier, left to my own devices.” It's just so simple to look at that now, that was the behaviour of a perfectly normal autistic baby, and my mother had respected my wishes and not handled me more than I actually wanted. She'd actually done the right thing.

There were lots of other instances where she (the therapist) is asking me to tap into the sensory world, asking questions, and I'm trying to, you know, I didn't have a ready answer for her. I needed a lot more thinking time, lots of very nonspecific questions. I remember she began one session saying: “So, what were your thoughts of last week?” And I just went…. speechless, gulping, goldfish moment I call them, where we just don't say anything at all. Power of speech leaves you, and it's because you're processing so much back there. I had a million and one thoughts, which one did she want? It was too vague, too vast. A lot of probes to the sensory stuff when I just go: “I can't name it”. The worst, I think, where she pushed, pushed, pushed about what I was feeling in my body… and it has always been the case that a lot of sensations that I feel within my own body are very, very alarming to me. They push up the anxiety, they push up that sensation of panic. And I can understand now it does that because I can't interpret them. It’s all very scary, I can't put a label on them, I can't identify what they are. I have horrible problems trying to explain to a doctor what is wrong with me or what I think might be wrong with me or my pain level. And because I was struggling with that, I'm being uncooperative. And she pushed it so far, one day I melted down in there. I was, to be fair, getting pretty frustrated with the services because they were not listening, so, of course, they washed their hands of me. And we're in the middle of a pandemic and things are getting worse.

There were more interactions with doctors that did not go well. My medical anxieties were just reaching a point where I just didn't want to be on the planet anymore, at all. I just could not cope…couldn't cope. But there was something still in me, I think, that wanted to… something in me was still fighting. And it was at that point I… engaged a private counsellor and at that point still not having realised that I could be autistic, I went for somebody who specialised in phobias. And I started to research myself. There had to be an explanation for this…’cause all I'm getting from mental health services was just nothing. Nobody was offering any explanations at all and I tested just about everything. I even went through all the personality disorders, actually, all the quizzes, from the reputable sites and none of that was matching my emotional landscape at all or my personality in any which way. And I was about to give up and that's when I just… by accident, there'd been all these links coming up to the National Autistic Society and of course, I'm not autistic. I'd even said that in therapy when they were saying, you know: “Can't you see that such and such a person feels X?” and I'm saying: “Of course I can, I’m not autistic” …Yeah right, Dawn! [laughs]

And when I accidentally clicked on that link, the first thing that came up was the description of the meltdown and the shutdown and I thought: “That's what I'm experiencing”. Recognised it immediately and I was still scratch…. I was just stunned, still scratching my head… And I thought: “How can that be possible? I'm a linguist. I am a communicator. What communication deficit have I got? I've got friends. It's not that I, you know, I'm… I'm an asocial creature” but, when I looked at the childhood indicators, I thought: “Oh God. That's me.” [laughs] Everything from all the eating peculiarities and difficulties I had as a child to the lack of coordination, I can't ride a bike. I can't drive a car because… I thought it was just dyslexia. All the school bullying because I never really seemed to fit in. The fact that I just don't get jokes very often. And I thought: “OK, I could be, I could be” and it was at that point that I self-referred to the National Autistic Society's Lorna Wing Centre.

00:13:17 Oscar Hilder

I just wanted to ask a few elaboration points. So, just talking about your research that you did and, in particular, your research into autism on the National Autistic Society's website, what was your knowledge of autism like at the time and also before that throughout everything that you've been... that you've discussed so far?

00:13:37 Dawn Mills

That's a really interesting point, isn't it, looking back? I mean, I suppose... if you don't know you're autistic, you know what the rest of the general population knows, and I'd grown up in that generation that has made the new discoveries. Dr Wing made that connection between classic autism and Asperger's in the course of my lifetime. I mean, I'd have been in the Sixth Form college at the time.

So, I've grown up with various documentaries appearing on the television from time to time that I've taken an interest in, and it mostly featured nonspeaking kids who didn't appear to show any affection toward their parents. They're viewed as these poor victims that have no emotions. You know, they're talking about these therapies for them that you now understand to be these behavioural therapies that are actually very, very damaging to autistic people. And I'm thinking: "Poor things, to be born without your emotions". Doh!

So yeah, I mean, I would... like anybody else, I'd have had Sheldon or, you know, *Rain Man* or... in my head on one hand and these kids on the other, certainly didn't think that that could be me. So, it's been an eye opener for me to realise and I...but I think there's something important...a lady called Jane McNeice says, she wrote a book called the Umbrella Picker, but in other context, she said the three conditions that are needed for somebody to enter the realisation that they are autistic. One is a really good self-awareness and the other is a real quest to understand what their problems are and why they're experiencing them. And... I think I'd had those two in place for many, many years. But the third condition is the information needs to be there in order to be found, otherwise you will be forever wandering in these circles and that is what the National Autistic Society provided for me, it was the last of those conditions.

All of a sudden, the information was there and it was so rapid. I mean, those neurons were firing within minutes of realising, at minimum, I had a major sensory processing issue and that, you know, I could very well be autistic as well. I'm thinking: "hang on a minute. All those medical traumas, when it seemed I was faced with so much cruelty from doctors, is because I was experiencing those procedures and that environment and that communication process in a way that other people do not and they come across the way that they are because they don't understand what I am experiencing. No cruelty was intended and the trauma could not be avoided because neither one of us knew what we didn't know. It's… I suddenly understand this is entirely about the sensory processing and any trauma experience is consequent to that. And it was, it was just the most massive relief because… therein lay the potential of a solution where I'd become so hopeless I had never been able to see a solution to this and, all of a sudden, what if… if I can understand it and they can understand it, then, somehow, we're going to make it better between us, we're going to give me an easier ride.

00:17:18 Oscar Hilder

So, on the note of how you would… you were describing in particular this, it was the sort of realisation about sensory issues that made you realise you were autistic. Was there anything on the National Autistic Society's website that, really any sort of individual stories or pieces of information or anything like that that really made you think this condition is exactly what I have been experiencing all my life, it's these experiences that I relate to.

00:17:45 Dawn Mills

Yeah, there was an awful lot there and it kind of falls into two categories really. One is the community forum and the other is the information and guidance that they've got there, which led me on to look at an awful lot of other research pieces out there and I slowly educated myself from this wobbly phase of “Oh my God, this could be me!”, to familiarising myself with the likes of Dr Milton.

But yeah, amongst those first descriptors I looked at it was a lot of the playground experiences. An awful lot that… I just thought: “Oh well, I'm me, I'm quirky.” My friends will all apply the word quirky to me: “you're weird, but we love you.” There was, there was an awful lot there, but it was a platform for deeper research. When you dig around the videos, there's quite a lot there that's very useful. Various people involved in research who looked at different aspects, whether it's autistic communication or autistic social experiences.

And I was, you know, slowly realising this was all so me, not just the sensory.
I mean, if I give you an example from the communication. My mother always… and bearing in mind I'm a linguist… my mother tells a very weird story about how I learned to speak. All mothers remember your first words and she said I would be in my cot staring at people's mouths as they were talking to me. And I think I've got a memory of it, of her saying: “come on, you can do it.” And I would just copy the lip movements. Soundlessly. I was just copying the lip movements over and over and over again. And I wouldn't say anything but the minute my mum left the room, I'd be talking to the animals on my wallpaper, and my voice was clear. Every word that I said there, there was no toddler,

clumsy first attempts, every word was bang on, perfect, the first time I said it. But I would not say it, until it was perfect.

Now I've studied child language acquisition and I know that's not the pattern of normal language acquisition. I know that babies babble. I know that babies get it wrong. I know that they build up their grammar slowly. I know that their motivator is the interaction with the adults around them, mine wasn't. It was an imperative to get this perfect and I was saying nothing to anybody, until my words were perfect. She then says I spoke little, but I spoke when I had something significant to say.

So, that's an example there where it's been a combination of looking at the research with the National Autistic Society's websites as a platform to go off in my own direction. And the forum, where I've been able to talk to other autistic people and say: “well, this this this was me” and for them to say: “well, yes, this was me” or mine was a bit different but you can see there are parallels in other ways. So, I'm recognising the experience and for the first time in my life, hearing other people echo my experience and then I'm reading the research that gives me satisfactory explanation.

I probably could go on to talk about the social as well. Certainly my first day at school, I was so eager, I was so keen. I thought they were going to teach me to read and write day one at school. My Aunt had promised me that's what would happen and I can remember walking into the classroom and there's a couple of guys running around the centre of the room. There are no desks, there were tables, kids have got play dough and I'm thinking: “what, where's my little desk with the lifty-up lid and the teacher at the blackboard?” The children were playing, there were a couple of kids with a dressing-up box and I just stood and stared, I didn't understand what they were doing. And it's only now, looking back, I can see that was a neurotypical kids play, and to me I just didn't get it. Play time, teachers usher you out the door and I'm saying: “but it's cold out there, I don't want to go out." "You have to go out.” So, I just stood on the doorstep, it didn't occur to me to play. I just didn't understand it.

And again, I’m finding platforms for that from the National Autistic Society website. I'm seeing some description of it there. I’m finding links that lead me to dig deeper and I'm hearing other autistic people articulate my experience. And I think that community actually was the big lifesaver for me between the point of realisation and my assessment. Just to hear… and about the medical, many other autistic people were saying: “but I've got XYZ problem communicating with medical professionals, in sitting in that waiting room….” and so on and so forth. And… just, there were other people like me out there and… and that just… it just lifted me and gave me hope, it really did.

00:22:53 Oscar Hilder

Thank you. Going on then, you previously mentioned of course you self-referred to the Lorna Wing Centre for Autism in Bromley. So, are you able to tell me what the self-referral process was like and you know, who was it that you met? What did they say to you or did you talk about? All of those sorts of things….

00:23:11 Dawn Mills

It was a lot quicker than the NHS. I mean, I'd approached the National Autistic Society because I needed somebody who really knew what they were talking about, and I can't imagine anybody questioning their verdict, really. That was reason number one, reason number two was the astronomical wait lists for the NHS. So, those were my two reasons, I needed it to be quicker than that and I really needed somebody who knew what they were talking about. I just really couldn't face coming out with an unclear verdict.

So, I filled in all the paperwork. The wait was a little longer at the time because of the pandemic, but it was well worth it. It was a matter of months rather than the years on the NHS. The staff were very, very good and very, very helpful. The paperwork I spent a lot of time on. I gave as much information as I possibly could, rounded up all sorts of things, from teenage diaries to old school reports. And my mother was still with us, and I was able to say the questions in front of her and get a really comprehensive response to send off to them.

On the day, of course, I needed to travel down to London and one of my good friends came with me and the process was a lot easier than I thought actually. They do go out of their way to put you at ease, even consideration to the sensory environment and all the rest of it. I could tell from the get-go I was really being listened to and I think, for the first time ever, I felt that I was listened to. In fact, a couple of the questions surprised me even after all of my research. It was Dr Sarah Lister Brook who diagnosed me, and I can remember, she said: “And do you get tired?” and I went: “Uh, yeah!” And I'd never considered that. I can't count the times I have been into GP surgeries saying: “but I am beyond exhausted”. Burnout, I was in burnout. Even then, pennies were dropping for me.

So yes, I found it quite a caring and comprehensive process. When they gave me the diagnosis, I didn't know what to say really, I was…thank you is too small a word. I really felt vindicated, validated, hopeful for the first time in a long time, I think, and I don't think it's an understatement to say that National Autistic Society literally saved my life.

00:26:05 Oscar Hilder

So, you've talked about the sense of relief that you felt with the diagnosis, the sense that everything in your life, you know, it was... you suddenly understood why it was happening, there was a proper reason for it. Do you feel any differently about the fact you're autistic today compared to when you first received the diagnosis those years ago or are your attitudes towards it largely similar?

00:26:30 Dawn Mills

Well clearly, I have a way deeper understanding, I know this isn't about *Rain Man*. [laughter] However, as far as that reflects on my view of self, it's nothing but positive really... I am also, not just a bit, but a lot dyslexic. And I had some very switched-on teachers who twigged that one when I was in my late teens and I had a diagnosis that was in the vanguard then, actually, because we thought it was mostly a bloke’s thing, when I was 18. So I'm used to... I've been through the process before, if you like, on a much more minor scale. Of looking at it and saying: “Ok, well, what are the barriers, what are the strategies that can I find around the barriers and what are its strengths? And let's celebrate those.”

So, I didn't really... I know some autistic people have, when they've been surprised by a diagnosis, said: “No, no, no, this can't be me” (and) who felt quite angry. For me, it was entirely positive. It was, kind of, just wow! This is an explanation for... this is my theory of everything, but I think I... I was quite lucky and I realised quite quickly that this was not only describing the tough stuff, like the medical phobias. It was also describing all of the best bits of me, all the things I've always liked best about myself and all of my strengths and my talents. As well, my obsession with crocheted socks and wanted to get the most perfect pair for instance! Well, hey, who doesn't want? Who doesn't want special interests like that? It's that's, that's fun. The sheer determination to achieve things in the face of adversity. I've got a degree in modern languages, despite the fact that I am dyslexic.

So yeah, I was just embracing it all from the get-go, I think. And the deeper I get, the happier I feel about being autistic and it's... it comes as a surprise, you know it's there, but it comes as a surprise when people assume that you won't (feel happy about being autistic). It's a lot easier to deal with now because they're trying to understand. I am just so grateful that I was born autistic, I don't want to be any other way, I really don't. All I want is the world to understand me when I have to walk into a hospital, really.

00:28:53 Oscar Hilder

Lastly, about the... on the note of your personal experiences side, going back to what you said at the beginning about there being two sides to the first question. Based off of your experience, what advice would you give to undiagnosed autistic individuals who are possibly in a similar situation to you, they're doing their own research, they're confused as to what's actually cause for many of the problems that they're facing in their life, what sort of advice or information would you give them?

00:29:21 Dawn Mills

It's difficult to say. I think they need exactly what's on the National Autistic Society website. You can't advise somebody who... who's looking for answers but hasn't yet encountered it... actually thinking about it, this is a place of professionals, isn't it? This is where people like the mental health services come into it, potentially GPs and social workers as well, people who might be dealing with people who are struggling and they don't know why they're struggling and it isn't until the point where somebody puts the information in front of you that the penny drops. Not everyone is going to want to go down 'Doctor Google' route, they're looking to those professionals: "Please professional, tell me what's wrong with me. Why can't I handle these things like everybody else can?" It's got to come from them, I got lucky. I dropped on the right place and I know other people have followed a similar path. They found that information from a credible site, such as the National Autistic Society provides. To me, this is about education of the professionals, they've got to find us.

What I am happy about is the number of later diagnosed women in particular, who are now writing like billy-o. There are a lot of autobiographies out there. I've read a number of them, some of them by well-known people - Christine McGuinness, I understand, has also worked for the National Autistic Society - and what they do is invaluable. There will be people struggling out there, just happen to pick up a book and think: "oh boy, you're describing me" and will find their answers. It's about finding the lost girls now. Yes, it's difficult to answer that question in other terms really. It's the professionals. It has to come from professionals.

00:31:19 Oscar Hilder

You've made a very good point there about, of course, late diagnosed autistic woman and we're going to get on to that point in just a moment, especially with your involvement with many of the National Autistic society's campaigns around women and girls with autism.

But before I get onto that, just one final question on this matter is, obviously you would recommend the National Autistic Society as a place for information and also a diagnosis. Can you think of anything, possibly things you've been involved with, possibly things you haven't, any particular part of the National Autistic Society's websites, its projects, its fundraisers, its staff, anything in particular that you would recommend as a place to get information or a diagnosis?

00:31:58 Dawn Mills

For people who've known that they are autistic all of their life, the community forum is a good place to talk about your problems or share a joke with other autistic people. That might be exactly what they need for that social interaction. Could be you're looking for a particular service and there is a directory there that might point you to something in, in that area. For somebody like me, the need was much greater because you come at it knowing nothing and you have everything to learn, so you're going to spend a lot of time digging around those pages and following all those links. And in that respect, it provides a valuable service. I think the campaigning and the push at governments beyond that is probably one of the most important things that the National Autistic Society does. You've got to keep it on the political agenda and we've got far too many people in inpatient units who should not be there as autistic people and we've got to keep pushing that. The will has to come from government there to pump out the resources. We need legislative changes: we need for it to no longer be possible to section somebody on the basis purely of their autism, so that campaigning is, is so vital.

But those three things together (information, social interaction, campaigning) are what would make the change… so at some level it's about the individuals, what can the individual find in terms of information, what can the individual find in terms of camaraderie, but it's about how we're going to change society as well.

00:33:30 Oscar Hilder

So that's basically all of the questions I have to ask about your personal experiences. So, I'd like to move on now, if it's alright with you, of course, to the other side of your involvement with the National Autistic Society. In particular, can you tell me about the *Now I Know* campaign and its aims and methods?

00:33:48 Dawn Mills

Yes, I sort of landed into that one. I can remember a questionnaire coming up on the forum and I answered it, it was actually about use of the community and off the back of that I had an invitation to do a little interview and it's in response to something I said then and it was: “Well, I've always known who I am, but now I know why I am”.

I was so happy to be asked to be involved with that and I can only give you an emotional response to it actually. I think I've just been through so much pain to get to the point where I was at. And I had the growing realisation that I was not alone, that so many other women had travelled such a similar journey. I just had this… I just had to do whatever it was that I needed to do to make a contribution, however small, to ensuring that other women weren't going to go through this. And I just didn't want to see anybody else have to walk the path I've walked and I think the better we can make services aware of what the presentation of autism can be in women and the better aware that we can make the public so that autistic women can find themselves, the further we're going to get along the path towards those improvements, so we don't have autistic women walking through the doors of mental health services to be put in the wrong box.

00:35:19 Oscar Hilder

Can you tell me…just elaborate a little bit further about the sort of… the methods that the *Now I Know* campaign is using and if possible, can you elaborate also on what involvement you've had in developing these methods and overseeing them and all of that sort of stuff?

00:35:34 Dawn Mills

I haven't developed those methods. I've gone with them, let's say, but I found… I found the process quite easy to go through. I liked the fact that the photographer was herself one of the participants. I think she brought something out of all of us that perhaps, a non autistic eye would not have… would not have seen. I found the team very easy to deal with. The process was very smooth, I knew what to expect at each point, and I liked, I like the way the videos were used and distributed.

00:36:14 Oscar Hilder

Great, thank you. So, you've talked a bit about what your involvement in the campaign has meant for you personally. Can you, do you have any sort of particular aims for the campaign that you would like to see? Like on a personal level because obviously with all of the different people involved, there's lots of different ideas of which way it should go and all of that sort of stuff. Do you have any particular ideas yourself of where the campaign should be going and what you what you think its aims should be?

00:36:45 Dawn Mills

I'm a trainer too, this may be why I focus there. I know that a lot of changes begin with training and retraining and retraining and staying on the top of it. I'd like, I'd like to see this move from, I think, something that's there for the public to recognise themselves or recognise their work colleague or recognise their family member or their friend and understand them for some...to become a tool that can be used by the professionals to augment their awareness and understanding and to pick apart some of the issues, across all the domains. For me, it's very focused on general health, it's about services for autistic people, for me. The National Autistic Society does a lot of campaigning anyway, but if that... if this can be used to beef that up, the one thing I have in mind, well, with education I...my boss, who was a teacher of many years' experience, when I first said to him: “I think I found my answer.” I expected him to not really get it, but he said: “Oh Dawn, we all miss the girls. We always spot the lads in the classroom. We always miss the girls at the back of the room shutting down.” So, it's across all of those services. It's about, you know, can teachers better recognise it? Can social workers better recognise it? And, in particular, the medical profession and mental health services - can they recognise a female presentation of autism when they see it? And trans and non-binary people, as well, tend to have that presentation and very often package up whatever their issues are into something else, other than autism, as well. So, it's about giving the tool I think.

00:38:41 Oscar Hilder

On that note, what would you like to see going forward for better representation of autistic woman and non-binary individuals? What sort of things- you know, could be in any part of society- do you think is needed in order for these individuals to, you know, probably become visible not just in the eyes of, you know, psychology, but also within the eyes of the general public as well?

00:39:02 Dawn Mills

‘Nothing about us without us!’ it's a cliche, but it's absolutely true and our voices need to be there at every level, I think.

I am involved at the moment with an organisation called *Grapevine* and another called *Curators of change,* in addition, and they are getting involved with NHS partnerships and County Councils together to look at their autism strategies and the implementation of their strategies and how that translates into something concrete. It's a process called ‘Co-production’ and I think that's what needs to happen basically.

We need to be ‘co-producing’ the services that we use. So, we need to be in there with the recruitment of social workers, we need to be in there with the recruitment of medical professionals, we need to be in there with the commissioning and we need to be feeding them the constant feedback of what it's like to go and use their local library, for example, as an autistic person. Or to go and use whatever, we need to be there, constantly providing that feedback, constantly involved in the decision-making processes, constantly involved in the design. And that's where I think we need quite a lot of what we call ‘experts by experience’ to be there in those committee rooms, to be involved in those processes and outside of that actually, as councils make links with businesses and services, we need to be in at that level as well, I think it's the answer for the improvement bottom up, having those discussions with people around us, but the two need to go in tandem. You need an organisation like the National Autistic Society to be pumping it out to government and then you need at a more local level to have autistic people in there building those structures bottom up.

00:40:56 Oscar Hilder

Getting to the conclusion now… so, on a more general note, in your opinion, how has the public perception and awareness of autism changed in recent years?

00:41:08 Dawn Mills

A little bit. People are aware that there are numerous presentations of autism, I think. Things are moving in the right direction, but you're never quite there enough and with some people there's a misunderstanding as well. That they get… they get a battery of new information, individuals that they become familiar with and then they come to the conclusion, we've all heard it, haven't we?: “But everyone's a little bit autistic.” No, we're not folks. [laughs] Yeah.

I see shifts in people that I know personally as well, and one of my best friends when I told her, her reaction was: “Oh, I don't know, Dawnie, you're one of the most empathetic people I know.” So, she clearly equated autism with lack of empathy, so those barriers are still there to get through.

On the other hand, my other half tells me that I've opened his eyes so much to what autism can look like. So, we're getting there bit by bit, but there is still so much to do and I think we need to be mindful, actually very mindful, with all of these things that we do not create backlash as well: “We're all a little bit autistic, aren't we?” Those are… Those are the things that we've heard before, you know: “We're all a bit autistic”, “It's too easy to get diagnosis", "It's just an excuse for poor behaviour.” We need to be mindful of the potential for misconception when giving a new information. Or a backlash if you like. I've worked as E and D [Equality and Diversity] trainer for many years and for every bit of progress you get moving forward, there's always some... it's not even... it's not even malicious resistance at the end of the day but misunderstanding. We do need to be careful in the message, I think. But yeah, a long way to go, but it is moving.

00:42:57 Oscar Hilder

So, on that note, what role do you think the National Autistic Society has played in this change?

00:43:04 Dawn Mills

Massive, I think. Before the *Now I Know* campaign there was one on navigating the sensory world and I think it's quite a shock for non-autistic people to... suddenly take on board exactly what it is that we are navigating on a day-to-day basis, something as simple as getting on a bus and going to work. So huge in terms of general public awareness and the political usually follows the public I find. When you get a political momentum to want to see some change, then the politicians will get on board. So yes, very significant is what I would say.

00:43:45 Oscar Hilder

Lastly, is there anything else you would like to talk about at all? Just personal experiences, any particular stories, any further opinions you would like to share? It could be anything at all...

00:43:54 Dawn Mills

No, I'm just delighted to have been asked to be involved and one thing seems to be leading to another for me and I'm just so, so grateful, I think of the opportunity to give something back.

I mean, we spent a lot of time talking about me, but I guess my story is the testament to why the work of the National Autistic Society is so vital. I mean, without it I would not have had the information that I needed. Without it, I could not come to my diagnosis. Without it, I would not have encountered other human beings who share the same experiences, and I can see now as a community, that, without it, we aren't going to make a political change, and we aren't going to make a material change within the services that we use. So, I guess that's it for me really, it's just that… delight to be a part of it, I think.

00:44:55 Oscar Hilder

Fantastic! As we conclude this journey through your experiences as a professional working in the field of autism, looking forward, how do you envision society evolving to better embrace and support autistic individuals?

00:45:10 Dawn Mills

I think it goes back to the point I made before about including us at every level. It's difficult to please all of the people all of the time, but no autistic person is ever pleased with their environment without some opportunity to have an input, without those adaptations being made.

I think ideally what I would like to see is a major, major push for training amongst professionals and I would like to see a major push for autistic people involved in building the bricks of society bottom up, so that our voice is there.

The society that I'd like to see is one where we don't have to think particularly in terms of neurotypical people and neurodiverse people… just… people have different needs and you need to design something that's adaptable to whatever people's needs are and that there's more acceptance of individuals as they are. I think the biggest thing for me is I'd like to see more understanding of the strengths of autism and therefore value to the contributions we can make, I think that's largely missing, we've got to drop the deficit model.

00:46:26 Oscar Hilder

Great, so thank you so much for your time, Dawn. Thank you so much for your answers as well, they've been really comprehensive. Thank you so much for everything.

00:46:33 Dawn Mills

No problem. It's been my pleasure, Oscar.