Episode 18: Autism Spectrum Disorder: An Updated Look

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VOICEOVER
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SIAN PRIOR
Hello and welcome to Up Close, coming to you from Melbourne University, Australia. I'm Sian Prior. Today we want to take a look at one of the most baffling forms of developmental disability, one which has no known cause and no known cure, but whose prevalence has been steeply increasing in recent decades. I'm talking about autism or more specifically autism spectrum disorder, because the condition ranges from being so mild that it's hardly noticeable to the lay person, to being so severe that the autistic child is extremely dependent for care and support. So why is autism spectrum disorder on the increase and what are the very latest developments in diagnosis and treatment. Professor Margot Prior is one of the world's leading experts in the field and is currently based at the Department of Psychology in the school of Behavioural Science, here at the University of Melbourne, Australia. Professor Prior has been a lecturer, clinician and researcher in the field of Family and Child Development for more than 30 years. She's written and or edited 7 books and published over 170 scientific papers and chapters in her various areas of expertise in child development and clinical psychology including autism. Professor Prior is our guest today in Melbourne University Up Close, she also happens to be related to me. Margot, welcome.

MARGOT PRIOR
Thank you Sian.

SIAN PRIOR
Now before we talk about this apparent massive increase in the number of children diagnosed with Autism Spectrum Disorder, can we go back and briefly explain what it is and what makes autistic children different from other children.
MARGOT PRIOR
Well we describe it as a lifelong neuro-developmental disorder, so it obviously it involves brain development in some way that we don't quite understand. And these are children who, whilst they often look extremely beautiful, which is quite puzzling, they are indeed very handicapped. And the way we try to summarise what we know about the problems is to think about a triad of impairments. So, that triad which as you said varies in severity includes social functioning, so probably the majority of these children are very withdrawn. They live in their own world, they have very little interest in interacting with people or in what's around them. And there's no reciprocal social interaction. The second part of the triad involves communication impairments. And again, these vary from children who are mute, who never actually speak, children who have poor comprehension, may have a few words, children can speak but often what they say is really idiosyncratic and bizarre and again non-reciprocal. But then at the other end, the high-functioning end you have children who !V with whom you can converse although again it's a bit one-sided, but they're perfectly articulate and often extremely interesting.

SIAN PRIOR
When you say bizarre, what's an example? What things might a child with autism say to you that would sound so strange?

MARGOT PRIOR
Well, I can remember talking to a young lad years ago who had a great preoccupation with the Hopi Indian Alphabet. And that's what he talked about and was of absolutely no use to him in his daily life, but that was his interest and that's what he wanted to talk about. So, a very bizarre interest and very bizarre conversations. The third part of the triad is a resistance to change, a lot of repetition, inflexible obsessive behaviour and so these children have a lot of difficulty if things aren't absolutely predictable. And in terms of preoccupations, well I just mentioned one with the Hopi Indian alphabet, but I can also remember a really low functioning boy who pretty much spent most of his life stacking chairs, that was his total preoccupation.

SIAN PRIOR
So, tell us about this reported increase in the prevalence of autism. I believe one recent British study has reported a ten-fold increase in diagnosis since autism was first recorded. Can that be right?

MARGOT PRIOR
Well, I don't think we know if the prevalence has really increased. We certainly know that we are identifying lots more of these children. And in part, it may be because we're much more conscious of the high-functioning end. So, whilst I think we !V we haven't changed a lot in terms of the severely handicapped children, we are now pulling our children who might have been thought odd or eccentric or different and nobody really understood them. These days they're often being called autistic or given another title which is Asperger's Syndrome which really refers to the high
function end. Almost everybody's reporting an increase. And almost everybody is finding that increase at that upper end that I was talking about.

SIAN PRIOR
So can you give us an estimate, Margot, of how many infants are born with autism spectrum disorder?

MARGOT PRIOR
Well the estimates vary, used to be about four in ten thousand. It's now moved to something like about one in 170. So, you know that's a huge increase. And really, if this is true, it makes autism one of the most common childhood disorders that we have and that's a real revolution compared with the way we used to think of it as a very rare disorder.

SIAN PRIOR
So basically, by describing this as a spectrum disorder it widens the catchment in a way.

MARGOT PRIOR
That's absolutely right. And with that widening of the catchment comes changes in diagnostic criteria. So I think we're in a phase !V I mean these things vary, but I think we're in a phase now where the diagnostic criteria are relatively generous. But it's also true that these days we know so much more about autism. So, you know we've seen Rain Man, and we see stories in the paper, and autism is out there much more on the agenda. So that means that people are very much more aware of these very odd children and so they're more likely to get attention and that may also influence the prevalence.

SIAN PRIOR
At the beginning of our conversation I talked about this as quite a baffling mysterious disorder. What does the latest research tell us about the causes of autism spectrum disorder?

MARGOT PRIOR
Well despite squillions of dollars being spent on trying to find predominantly a biological cause, 'cause that's what we think is the case, we still don't know. We really can't say. And almost anything you can think of, physiologically, biologically, biochemistry, etc, has been looked at. I think the strongest evidence that we've got in the last few years has been about genetic effects, so that there is certainly a risk for families with an autistic child to have somebody, another child or a relative with if not autism, then some kind of related problem which might be Asperger's Syndrome or communication problems, learning difficulties etc. So we certainly have got quite a bit of evidence about a genetic influence. That said, we can't really say what the genes are or how they're operating. We can say that there's probably multiple genes which you would expect in such a complex disorder, but we still seem to have a way to go.

SIAN PRIOR
I'm Sian Prior and my guest today in Melbourne University Up Close is Professor
Margot Prior, one of the world's leading experts in Autism Spectrum Disorder. Professor Prior is from the Department of Psychology here at the University of Melbourne, Australia. Margot there've been some extraordinary cases of people with so-called high-functioning autism who've been able to describe their experiences very vividly and given us great insights into their world and how it differs from you know the world for !V for most of us. You've worked with a woman called Wendy for example who's written about her condition. Can you tell us a bit about Wendy and what !V what we've learnt from her?

MARGOT PRIOR
Well Wendy's an extraordinary woman. She's now !V she must be around about 50, she was actually born in Britain but has been in Australia for most of her life. She's extremely interesting, not only because of her own personality and her capacities and I should say that she's certainly at the high end of the spectrum, but because she grew up in a time when we hardly knew anything about autism, and so she suffered enormously from that lack of understanding. She had a terrible time at school, bullying, misunderstanding, and as she grew up and her behaviour became increasingly obviously bizarre, she went from pillar to post, never really finding a diagnosis. I would say that in some cases she was actually mistreated by the medical profession, ignorance of course, but very hard for Wendy. Anyway Wendy has triumphed. She has been married, got a family, she's done degrees at the University, I think she's currently doing her PhD, she goes all over the world talking about autism, what it's been like for her, how to deal with it. She writes wonderful poetry about it. Wendy's an absolute star whose history really illustrates the history of autism and what is possible if you're able, persistent and you get enough support which she !V these days she does.

SIAN PRIOR
And so what kind of features of the disorder has she been able to describe that have given us insight.

MARGOT PRIOR
Well, I think one of her greatest contributions is that she's able to tell us about the mind of a person with autism, how they understand or misunderstand what's happening around about them, how they are very literal and so things that you say which you know we would understand, they take very literally.

SIAN PRIOR
So, for example, you and I might use metaphors or irony or sarcasm and say things that we don't literally mean in our conversation. For someone like Wendy that would be baffling?

MARGOT PRIOR
Absolutely baffling, even subtle nuances in language are very baffling. She's also able to tell us about how they process information, for example in school or through learning and how difficult that is for them. Another issue about autism which Wendy has highlighted but everybody is very conscious of is there's a collection of sensory
abnormalities which seem to characterise the disorder, so some people are very hypersensitive to sounds or visual stimuli and that again makes their world very confusing. And with her gifts for writing Wendy's been able to describe that in a very vivid way so that we can get some insight into the heads of people with this disorder.

SIAN PRIOR
Well we can provide a link to Wendy's website here on Melbourne University Up Close, so those of our listeners who are interested can find out more about Wendy and her experiences. So, you've talked about the!V you know the problems of ignorance of the community, about the disorder, the problems of bullying of children with Autism Spectrum Disorder. What are the greatest challenges for the families of the children and adults who have Autism Spectrum Disorder?

MARGOT PRIOR
It has to be emphasised that autism really is a huge burden. If I think about all the childhood disorders that I know about this is probably the most challenging. And of course as you know I said earlier it's a life long disorder, even if it's relatively mild. So for parents things like how can I make the most of what potential my child has, how can I access diagnosis, assessment, intervention, schooling, later on employment, something to do, somewhere to be, how I can manage the challenging behaviour because many of these children have enormously challenging behaviours !V aggression, screaming, over reactivity, hyperactivity, anxiety, they often go with the condition, and things like the repetitive behaviour like the chair stacking for example, that was a huge problem to manage. And so when you get that kind of repetitive behaviour, resistance to change, inflexibility, it makes for great challenges in managing those kinds of behaviours. And if you talk to parents, they will often tell you about all sorts of things they can manage, but that repetitive obsessive behaviour which really interferes with the child's capacity to learn, and to socialise is a great challenge. So it is really very hard for parents and finding support and respite and expert advice and care is still a real problem in this country.

SIAN PRIOR
And what does the latest research tell us about the most effective forms of intervention and treatment for this disorder?

MARGOT PRIOR
Well, with Jackie Roberts, a colleague in Sydney we've just done a review of the literature trying to be able to say, these are the most effective treatments. In fact that's proved to be very difficult because there's so little evidence. So, in order to make judgements about efficacy of treatment, you know you need randomised control trials which can give you data showing what happens when you apply this kind of treatment. And there are so few of those that it's very hard to make any conclusions which will hold out. So, what we've done is we've focused on early intervention because that's really a key, key issue for families, you have to get started early, and what we've done is we've extracted the principles of good intervention. Rather than saying well program A is better than program B and we can't, you know, rank them or even give them you know four or five stars, we're
saying that there are particular principles that you need to look for if you're looking for a program for your child. And they include things like the intervention needs to be early -

SIAN PRIOR
How early?

MARGOT PRIOR
Well these days we're talking about early intervention for infants, but certainly two to three years of age at the latest. So, it needs to be early, needs to be intensive, so that means like every day, minimum of 20 hours a week but preferably more, depending of course on the severity of the condition, the kinds of teaching, training, intervention that you do are most successful if they're focused on behaviour and on education. The programs also need to take into account the specific needs for autism, so to have particular content matched to the particular handicaps of the children. These children need a lot of structure, a lot of predictability, organization, regulatory, consistent management and specific objectives. So it has to be highly organised, highly organised and supportive teaching environment.

SIAN PRIOR
Well this might bring us back to a very early point we were discussing about prevalence and diagnosis. Presumably, the earlier you attempt to diagnose the greater room there is for error and misdiagnosis. I mean how at what age can you really be certain that you have pinned this thing?

MARGOT PRIOR
Very good question. I think the answer to that is that we have improved in our diagnostic methods. We do have studies, international studies which show that you can pretty well reliably diagnose by two, so that if you diagnose at two and then look at two and a half, three, four, most of the time you'll have it right. Not every time, but most of the time. And new research is showing that we can even pick up these children earlier than two. Studies particularly in the US and in Britain are showing that between 12, 18, under 24 months, we can pick out the children who are shall we say, at risk, so you mightn't give a confident 'this is it' type of diagnosis, but you can say this child's at risk and we need to do something about it. And in most cases it looks as if you're going to be right.

SIAN PRIOR
I'm Sian Prior and you're listening to Melbourne University Up Close where today we're discussing the latest research developments in autism spectrum disorder with Profession Margot Prior, one of the world's leading experts in the field, based at the Department of Psychology here at the University of Melbourne, Australia. Margot we talked earlier about the challenges facing the families of of children with autism and those children themselves and bullying for example. And another controversial debate in the area of dealing with children with Autism Spectrum Disorder is whether or not they should be encouraged to stay within the mainstream education system which presumably is a place where this kind of bullying goes on. What does the
latest research tell us about whether that's a good idea or not?

MARGOT PRIOR
Well, most parents obviously would prefer their child to be in mainstream, and so, at a principled level, that's good. But what the research shows is that if mainstream schooling is not adequately supported by expertise in autism, then it can be not at all [that] successful. So it's when there isn't adequate support that children become vulnerable to switching off, switching out, being bullied, sitting there all day not doing anything productive, -

SIAN PRIOR
Stacking chairs !V

MARGOT PRIOR
Exactly. Yes. So, support is key. And so if !V if your child's in a mainstream you really need to have an expert who's advising the teachers, helping with the development of a !V an educational plan, coming in to trouble shoot, give advice about management etc. That said, I don't think we have clear evidence about mainstreaming versus anything else. But really the predictors of outcome are not so much whether you're mainstreamed or not, but your level of intelligence and when you develop communicative language. So, if you're one of the children, one of the cases who does have reasonably high-functioning and some language then the outcome is much likely to be better and of course you !V you're better able to cope in mainstream schools. So, that's why I say it's not so much the schooling, but characteristics of the child which affect their capacity to profit from school.

SIAN PRIOR
Would the same theory apply to the employment prospects of people - young adults with autism spectrum disorder, I mean I know for example a former journalism student of mine who was diagnosed with Asperger's Syndrome, happened to have great skills and talents in some areas, mostly related to his passion for sport and sports statistics, and he was finding some work as a sports journalist, as a stats man, but I mean is that a rare case.

MARGOT PRIOR
No I think it's typical of high-functioning young people. And what your young man did is he found a niche, so one of the useful things about specific preoccupations, interests shall we say, obsessions is sometimes they can be useful in finding a niche. So if you can fit the person and their interests to a particular kind of employment then that can work quite well, although it should be said that these young people still need support. So, sympathetic and understanding employers are always going to be necessary.

SIAN PRIOR
Margot what about pharmacological treatment? Are there useful drugs that can help in the treatment and management of children and adults with Autism Spectrum Disorder?
MARGOT PRIOR
Well I'd have to say there are no drugs which really cure or indeed alter the course of autism so far found, and I don't feel very confident that we've made any progress in that department. What we can say is there are a few drugs which may help with symptoms so calm, agitation, perhaps help with aggressive behaviour, perhaps reduce anxiety. So that's a little bit of symptomatic relief for some young people in some cases can be helpful. But on the whole drugs really don't make much of a contribution.

SIAN PRIOR
Are there any major areas of autism research that you think are crying out for further resources, further investigation.

MARGOT PRIOR
Well, I think evaluation of treatment is absolutely. Now this is quite difficult, it's very expensive, it is happening in !V in other countries, not to much extent in Australia, but we are gradually acquiring some data but we've got a long way to go. So I'd put that near the top of my list. We're all hoping for a breakthrough in causes, so I think probably the genetic work is promising and we hope that we're going to make some progress there. Understanding family patterns, not only to do with inheritability of behaviours, but also the ways in which families manage their children which are helpful because we do know that there are differences between families and how effectively they cope. And the most interesting recent research internationally that I've become familiar with is that regarding infants which I mentioned before. So, if we can develop further our capacity to identify the children, younger and younger, intervene earlier and earlier. I think that's really, really promising and that !V that's where we should be putting lots of resources.

SIAN PRIOR
Well many thanks for joining us today Margot and filling us in on all the latest research developments on Autism Spectrum Disorder.

MARGOT PRIOR
That's my pleasure.

SIAN PRIOR
I'm Sian Prior and my guest today has been Professor Margot Prior who's currently based at the Department of Psychology in the School of Behavioural Science here at the University of Melbourne, Australia.

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