Episode 97: Asperger's Syndrome and PDD-NOS Explained

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VOICEOVER
Welcome to Up Close, the research, opinion and analysis podcast from the University of Melbourne, Australia.

ERIC VAN BEMMEL
Hello and welcome to Up Close. I?m Eric van Bemmel. In 1944 Austrian physician Hans Asperger identified a number of children visiting his medical practice characterised by poor non verbal communication skills, physical clumsiness and a general lack of empathy for their peers. Some 50 years later what has come to be labelled Asperger?s syndrome, Asperger?s disorder or simply Asperger?s entered the diagnostic manuals relied upon by psychiatrists and other mental health professionals. Some researchers believe Asperger?s to be under the umbrella of autistic spectrum disorder while others aren?t so sure. Aspies, as individuals with Asperger?s sometimes label themselves typically have difficulties in social interaction, tend to have narrow interests and often exhibit repetitive behaviours. But many are also able to find a life and livelihood in the general population. For a closer look at Asperger?s we?re pleased to have with us in the studio, Professor Margot Prior who?s appeared on past editions of this podcast on the topics of autism and early intervention programs for children. I?ll give you more info on those episodes later. Professor Prior from the School of Behavioural Science at the University of Melbourne is a recognised expert on autism, Asperger?s and related disorders and she?s authored or edited seven books and over 200 articles and chapters on child development. In 2003 Margot edited the book Learning and Behaviour Problems in Asperger?s Syndrome published by the Gilford Press. Professor Prior, welcome once again to Up Close.

MARGOT PRIOR
Thank you, good morning Eric.

ERIC VAN BEMMEL
Now Margot, let?s sort of take it from the beginning. What makes individuals with Asperger?s syndrome different from other people?
MARGOT PRIOR
Well, they present with a rather unique pattern of behaviour in that they have autistic traits and characteristics but because they?re generally of normal or even above normal intelligence and generally they have reasonably good language skills, it?s quite hard for people to go beyond thinking, well they?re rather odd but not knowing really what?s wrong. They are on the spectrum in my view and on the basis of the research around, they are part of the spectrum of autism but they?re at what we call the upper end. So they?re higher functioning, intelligent, less seriously impaired. But nevertheless, having the same pattern of social and communicative problems that you see in autism. So when you see them around with you know, a clear mind so to speak, without prejudice they seem like eccentric, egocentric people, odd. The thing is, they don?t really understand the world. Part of their difficulty is that they don?t understand this very complex world we live in, the people, how people think, how they feel and they don?t understand how to interact with them. So they?re often very isolated as in autism. They find it terribly hard to make friends but unlike classically autistic children they usually really want to make friends, they just don?t know how to go about it. So they?re socially awkward, socially immature. They often lack facial and gestural expressions. So they have a sort of a flat expression and almost always what we call abnormal eye gaze or poor eye contact. Although, most of them do have relatively normal language. And that?s part of the diagnostic criteria. They do have odd ways of speaking. So they have a very pedantic style often. But they?re not good at two way conversations so backwards and forwards as we?re used to doing, that?s very hard for them. Most commonly they will talk at you and they will talk about something which is of particular interest to you without thinking about whether that?s going to be of interest to the person they?re speaking to. There are a range of other language peculiarities. For example, they?re often rather stilted and they speak too loud or they?re poorly modulated. They might have an usual pitch or accent or stress in their language, and some of them imitate other voices. So they?ll take on some other voice that they?ve heard, say on the TV, and they?ll use that voice. So although we say their language is likely to be normal it isn?t really in that you know this is odd.

ERIC VAN BEMMEL
When we speak about poor non verbal skills you mentioned that often times their facial expression is flat, they don?t express themselves facially. That also means that they?re not picking up other people?s facial expressions and the communication that comes from that. Is that right?

MARGOT PRIOR
Exactly, yes. One of the things we say about them is they don?t understand what?s in other people?s minds and they don?t really have a grasp of feelings. And so they?re not really tuning into the people they?re trying to relate to and so it?s not surprising that they have trouble making good interactions and relationships.

ERIC VAN BEMMEL
But it would be wrong to say that they?re devoid of feelings themselves, they certainly...
MARGOT PRIOR
Absolutely not. The problem is understanding really, what a feeling is, what it’s about and how to deal with it.

ERIC VAN BEMMEL
Now, Asperger’s syndrome first appeared in an article, I should say it made its first appearance in the literature, scientific literature in 1944 in the German language and only in 1981 did we see it in the English language and its first appearance in the Diagnostic and Statistical Manual of Mental Disorders, the DSM which is sort of the bible of diagnosis from any psychiatrists and other mental health people, that was only 1994. It’s been labelled and sort of put out there recently even though the phenomenon of course has probably existed as long as humans have. Now, there’s talk of, in the next DSM in 2012 or beyond to remove the label Asperger’s syndrome. Why’s that?

MARGOT PRIOR
Well, when Asperger first wrote about this disorder he called it a personality disorder. It was very interesting because we had Leo Kanner in America at about the same time talking about autism and Hans Asperger in Austria talking about Asperger’s syndrome. And the two concepts really didn’t meet at that time. Partly perhaps because of the label personality disorder. Well, over the years as we’ve learnt more and more we’ve realised that it is part of the same spectrum of disorders. So I think that’s why there’s discussion about changing the way it’s classified shall I say, in the next DSM5, it will be. That’s part of moving towards a notion of disorders not being clear boxes that people fit into but like a continuum from the mildest to the most severe. That’s not just for the autism spectrum, that’s supposed to be happening across a range of other disorders. I mean, it applies also for example to ADHD, Attention Deficit Hyperactivity Disorder where we try to put children into boxes. They’ve got it or they haven’t. But in fact like autism, it’s something that varies from mild to severe.

ERIC VAN BEMMEL
In my preparation for this interview I was reading about Asperger’s syndrome and some people compare it to high functioning autism and others say it may not be the same. That sort of touches on what you were saying about it perhaps being under this umbrella, in the spectrum of autism.

MARGOT PRIOR
Yes, well because of its relative newness which you referred to, many people thought that Asperger’s syndrome was something different, not part of autism. Or if so, in some other kind of class. But there’s been a great deal of research since we started to pay attention to Asperger’s syndrome and what that research has added up to is saying that look, it is a continuum, you can’t find real reliable differences between children who have a diagnosis of high functioning autism and children who have a diagnosis of Asperger’s syndrome. Certainly, I’m convinced that those two labels are talking about the same kinds of people and while there may be some lingering beliefs that they’re different I think all the evidence is against that.
ERIC VAN BEMMEL
What do we know about the causes or origins of Asperger’s syndrome?

MARGOT PRIOR
Well, as with autism, we really don’t know what the causes are. Certainly it’s the case that heritability is high. You do see cases of autistic like syndromes or patterns within families there is quite a lot of evidence for what we call traits or subclinical signs of Asperger’s syndrome in first degree relatives. Especially fathers, in my clinical experience. In fact some people claim that as many as 40 to 50 per cent of families have another member with Asperger like subclinical characteristics. So there is genetic research and there are some possible candidate genes but no clear picture yet.

ERIC VAN BEMMEL
I understand with classic autism that the prevalence tends to be one in 150 or one in 100. What are the figures for Asperger’s syndrome?

MARGOT PRIOR
Well, it’s very difficult to ascertain because the figure of one in 150 approximately covers all autism spectrum disorders within which you get classic autism, Asperger’s syndrome and Pervasive Developmental Disorder. When you try to find sub percentages if you like, within that, it’s much more difficult. So I don’t think we really know what proportion of that one in 150 would come into the Asperger’s category. It does depend a bit on the diagnostic criteria that you use. So you will get some variation.

ERIC VAN BEMMEL
Given its relative subtlety compared to say classic autism, is it possible that it’s under-diagnosed?

MARGOT PRIOR
I think highly possible that it’s under-diagnosed. One of the phenomena of the last five years has been how many more children are getting that diagnosis. So the figure will be changing all the time. Researchers and clinicians think that it’s under-diagnosed particularly for girls. Because girls much less often are presented at clinics for assessment and we think it’s possibly because girls cope better with the social difficulties, they cover up. They’re not so completely flabbergasted by how to cope with being with a crowd of other people.

ERIC VAN BEMMEL
So Margot, are there other mental or physical conditions that often accompany Asperger’s?

MARGOT PRIOR
Well, as you said in the introduction there’s the issue of clumsiness. It has been considered sometimes that clumsiness was inevitable in Asperger’s syndrome. But I think research has shown that some young people with Asperger’s are clumsy but
not all. So it's associated but not inevitable. But there are also some other childhood disorders which frequently accompany Asperger's syndrome and sometimes are the first diagnosis before the Asperger's is recognised. They are first of all ADHD which I referred to before, Attention Deficit Hyperactivity Disorder. So they do have some of those symptoms of agitation, overactivity, problems with attention and concentration and that often is associated with particular problems in school, of course, because the combination of those two is pretty hard to deal with.

ERIC VAN BEMMEL
I want to touch on school in some detail in a moment. Let me just mention that you're listening to Up Close coming to you from the University of Melbourne, Australia. I'm Eric van Bemmel and in this episode we're looking Asperger's syndrome with Professor Margot Prior of the School of Behavioural Science. So Margot, are there any other associated problems or to use the technical term, co-morbidities with Asperger's syndrome?

MARGOT PRIOR
Yes, there are. A proportion of these young people will have what we call conduct disorder or problems with managing themselves, aggression, sometimes violence you know, lashing out. They can be easily lead into delinquent behaviour because of their lack of understanding of the social world. So that can be a problem. In older people you do find a number of cases getting into real trouble with the law. So that's one other co-morbidity. As these children grow older and realise that they are different and they're not able to do some of the things that other people can do; and they can't join in, particularly towards adolescent they can become depressed and that is of course another serious issue for them which needs help. Depression of course goes along with anxiety. And we do notice that lots of people with Asperger's syndrome suffer a lot from anxiety and that's considered to be relevant to another really stand out characteristic of Asperger's syndrome which is this need for sameness, for routines, for rituals, for rules and regulations around things. They're very important and we think that gives them a sense of security. Now, if you talk to them about their special interests and preoccupations which is you know, quite a major characteristic, they'll say to you well you know, it keeps me safe, it's something that is about me and about my things and I can just focus on that, that's my interest and then I'm not so worried by all of this blooming, buzzing confusion around me. So they do have these very special interests like in dinosaurs or cars. I had a young chap once who was an expert in American war history and so he would talk at you endlessly about American war history and there just wasn't anything he didn't know about that topic. So that's another very strong characteristic. It's important to mention it because it is quite hard for people to deal with that, hard to teach young people with Asperger's syndrome that you know, not everybody's interested in American war history for example. But it does serve to help with dampening down those feelings of anxiety.

ERIC VAN BEMMEL
For children with Asperger's in and out of school, are there any special situations that they encounter or you know, how do the schools I should say, deal with
Asperger students?

MARGOT PRIOR
School is a great challenge for both the children and for the teachers. Socially it’s very challenging. They’re children who are misunderstood, they’re awkward, they have inappropriate behaviour, they have personal space issues, they can be very isolated or sometimes very aggressive. They are subject to bullying and they will tell you that they easily get overloaded with so much going on. So they don’t cope well with school and they certainly need special help.

ERIC VAN BEMMEL
That suggests that these children are being put into normal mainstream schools for the most part.

MARGOT PRIOR
They are, because most of them are intelligent they are going into mainstream schools. It’s a real challenge for their teachers too, to understand these seemingly normal children who are intelligent enough to talk and cope with what’s going on but inside they’re often in turmoil. And the teachers don’t really understand the way that they think and how they struggle to communicate. They’re very literal, people with Asperger’s are very literal. So things like jokes and sarcasm are a complete mystery to them. For example, there’s a little boy that I heard about to whom the teacher said, look if you don’t catch up with your work you’re going to be snowed under. Then she wondered why he kept anxiously looking up at the sky. Another one, little story about a boy in the library who was told to keep his voice down so he continued to speak just as loudly but from a crouching position. Yes.

ERIC VAN BEMMEL
Very good.

MARGOT PRIOR
So that’s an example of the kind of you know, mismatch between the capacity of Asperger children to cope with our, the traditions of some of our language and their innate literalness.

ERIC VAN BEMMEL
Now Margot, I suppose it’s worth asking, are there pharmaceutical approaches to behavioural issues with Asperger’s syndrome?

MARGOT PRIOR
Well, as for autism there really is no way to remove the problems for children with Asperger’s syndrome. Sometimes drugs can be helpful for some children for example, with dealing with aggression or sleep problems or agitation or for those who are very anxious. Sometimes people try anti-anxiety drugs. So for some children it can be helpful but it’s not really the best way to go. First of all we don’t really like drugging kids and secondly if you can get good behaviour management and learning and teaching strategies in place and the families and the schools
particularly cooperate well then it’s better to work things out that way.

ERIC VAN BEMMEL
We’re speaking about Asperger’s syndrome today on Up Close brought to you by the University of Melbourne, Australia. Our guest today is Professor Margot Prior of the School of Behavioural Science. I’m Eric van Bemmel. And moving onto adults with Asperger’s syndrome, it’s not uncommon for adults to get a late diagnosis and often times when the children are being assessed, is that correct?

MARGOT PRIOR
Yes, that is correct. In fact it’s been happening more and more over the years as people began to understand something about Asperger’s syndrome and present themselves for a diagnosis in adulthood and they come in and describe a story often of you know, classic Asperger’s syndrome and they’re so relieved to get a diagnosis because all their lives they’ve known they were different and odd and they’ve worried that maybe they were mad or they had something wrong with their brain. They knew all was not well but not why. So sometimes in adulthood, getting a diagnosis and getting some understanding of what you’re like and why you’re like that has been very helpful.

ERIC VAN BEMMEL
This is the benefit of a label.

MARGOT PRIOR
That’s right. It is the benefit of a label. It’s understanding a knowledge and that empowers you then to go and seek out more information, to be in touch with other people with this difficulty, you know there are a number of clubs and groups, especially on the internet, of people, you mentioned, Aspies who have kind of joined together in mutual support.

ERIC VAN BEMMELO
Of course, those people don’t wish to be pathologised or to be seen as abnormal and that’s one of the reasons why they perhaps move together and there’s a pride movement. Because many of them can function quite well in society.

MARGOT PRIOR
That’s right. Many of them are doing extremely well. I mean, across the spectrum of Asperger’s if you like, you know, you get variation from professors of mathematics to people who are doing quite menial jobs but it fits with their interests and their capacities and you know, they’re leading semi independent lives in employment or higher education. So there’s a lot of variation in where they go with their career. Often those special interest or circumscribed interests we call them, that I was mentioning before, that’s often a pathway into employment for example, with computers or special knowledge about cars, for example.

ERIC VAN BEMMEL
There seems to be a media image of these people as having special gifts for
example, in maths. But is that actually the case?

MARGOT PRIOR
I think that's an exaggerated picture. Some of them are very gifted, no doubt about that. But I think if you looked at the proportion of people who are gifted in Asperger's it wouldn't differ from the proportion of people who are gifted in the non Asperger's population. But because of their other differences shall we say, this often stands out as being something they can really excel at even though they're struggling with other areas of their life.

ERIC VAN BEMMEL
Something you've written about, and I read this in your 2003 book, was around the issue of should a diagnosis be kept confidential. Whom do you tell? Do you want to comment on that one?

MARGOT PRIOR
Yes, that is a real question for parents and for, especially when you get to adolescence and adulthood, when you can decide for yourself about this kind of thing. I think, on the positive side parents are often greatly relieved, as are individuals, by getting a diagnosis because it adds to their understanding and their knowledge and it settles a lot of the doubts and worries that they've had for a long time. So there's a lot of positives about this. But some people reject the diagnosis, some people want to keep it hidden or they just want it kept to a small group of close others, shall we say families and friends. There are some disadvantages for example, if it's widely known in a school and a child gets teased and called names, that's hard. On balance, I think the experts would say it is better to communicate the fact that you do have something called Asperger's syndrome which has these particular characteristics because then it can lead to the development of good support strategies and more understanding about why this person is like that.

ERIC VAN BEMMEL
I just want to finally move to, well it's a rather unwieldy term, PDDNOS, Pervasive Development Disorder Not Otherwise Specified. It's a term, PDDNOS, that I've seen often accompanying articles on Asperger's. Why is it important, why is it associated?

MARGOT PRIOR
Well, that's a very good question. As you know the whole category of autism spectrum disorders comes under an umbrella label which is Pervasive Developmental Disorder. Now, if you haven't got an autism diagnosis or you haven't got an Asperger's syndrome diagnosis but you look rather like that, especially like an Asperger's syndrome diagnosis but somewhat milder so that you don't meet criteria, official criteria for diagnosis, you will often get this diagnosis PDD, Pervasive Developmental Disorder, NOS Not Otherwise Specified, which most of us believe is a very unsatisfactory way to categorise people but it's just acknowledgement that we really don't know quite what this is about. These are children with a similar pattern of dysfunction but better cognitive, social and
communication skills and maybe not so intense preoccupations. Some say PDDNOS is more common than autism but this can vary with the definition. PDDNOS is something which is a bit of a moveable feast. So some Asperger’s syndrome people may move into a PDDNOS category and vice versa. So it’s a mixed bunch.

ERIC VAN BEMMEL
A bit of a catch all phrase.

MARGOT PRIOR
Yes. That’s right.

ERIC VAN BEMMEL
Quite deliberately vague.

MARGOT PRIOR
Like a residual category really. Not very satisfactory. It just says, look you’re somewhere on the spectrum there but you really don’t meet criteria for a full diagnosis. But the array of impairments are the same and they still need help and support and that’s a sad thing about PDDNOS because they don’t have an autism label, they often miss out on services. It’s always been a real dilemma in psychiatry and psychology, what do you do about labels, how valid are they, how reliable are they, where do they take you? And of course, we’d all like to see progress in the genetics field because that might give us some biological markers which are more concrete.

ERIC VAN BEMMEL
Well Margot, we’ll leave it there. Thanks very much for joining us today on Up Close.

MARGOT PRIOR
Thank you, Eric.

ERIC VAN BEMMEL
I’m Eric van Bemmel and my guest today has been Professor Margot Prior from the School of Behavioural Science, here at the University of Melbourne, Australia. For interested listeners Professor Prior can be heard speaking about autism and early intervention programs on episodes 18 and 86 of this podcast. These episodes and all others can be found on our website. Relevant links, full transcript and more information on this episode can also be found on our website at upclose.unimelb.edu.au. We also invite you to leave your comments or feedback on this or any episode of Up Close. Simply click on the add new comment link at the bottom of the episode page. Up Close is brought to you by Marketing and Communications of the University of Melbourne, Australia. This program was produced by Kelvin Param and myself, Eric van Bemmel. Audio engineering by Ben Loveridge. Up Close is created by Eric van Bemmel and Kelvin Param. Until next time, thanks for joining us. Goodbye.