Shrink Rap Radio #54, October 14, 2006. Understanding Autism

Dr. David Van Nuys, aka "Dr. Dave" interviews Lorna Catford, Ph.D. (transcribed from www.ShrinkRapRadio.com by Jo Kelly)

Excerpt: "Now people talk about the "autism spectrum", autism spectrum disorders, because there's a wide variety of conditions of certain kinds of impairments that are lumped under the label of autism. Basically autism is seen as being a condition that has impairments in three different areas: in social interaction; in communication, verbal and non-verbal communication; and in imaginative play."

Introduction: That was the voice of my longtime friend, and Sonoma State University psychology department colleague, Dr Lorna Catford, Ph.D. I first got to know Lorna quite a few years ago when she was working on her Master's at Sonoma and she took my class in Myth, Dream, and Symbol. In that class, she became very interested in The Hero's Journey. Later, after getting her Ph.D. at Stanford University, she began co-teaching with Dr. Michael Ray a very popular class on Creativity in the Stanford Business School. During this period she also wrote an excellent book applying the model of the Hero's Journey to everyday life and to the challenges of the business world. Some years back, Lorna returned to Sonoma State to become one of our most talented and energetic teachers. She is, herself, the mother of an autistic child. Out of that painful and challenging experience, she has created an award-winning program that trains and utilizes university undergraduates as in-home helpers for families dealing with autism.

Dr. Dave: I am at Sonoma State University with my longtime colleague Dr Lorna Catford. So Lorna, welcome to Shrink Rap Radio.

Catford: Thanks for inviting me David.

Dr. Dave: After all the different things that we have done together over the years, this is a new fun direction for us to take. And you have had a very diverse career, teaching not only here at Sonoma State but also at Stanford University, where you received your doctorate. So there are many things I'd like to interview you about, because I know you have been involved with a lot of very interesting stuff over the years; but today I think we are going to focus on your work on autism. I know you have developed a program, but before you tell us about that program, let's start with some background info on the disorder itself.

So first of all, how is autism defined these days? Back when I was a student, autism was just like one thing, but I have the impression that's changed.

Catford: Yes, now people talk about the autism spectrum, autism spectrum disorders, because there's a wide variety of conditions of certain kinds of impairments that are lumped under the label of autism. Basically autism is seen as being a condition that has impairments in three different areas: in social interaction; in communication, verbal and non-verbal communication; and in imaginative play.

People with autism – of course it's on a spectrum so there's a range of severity – but often times a child or an adult with autism has difficulty interacting with people, responding the way people normally respond to social cues, often not picking up on emotional cues. Communication – in some people with more severe autism they have no verbal communication.

Dr. Dave: They miss facial cues as well?

Catford: Sometimes, yes. Sometimes they don't even like to look at a person's face. But they can communicate with noises and with movement; you learn to read the communication of somebody who is non-verbal.

The impairments in imaginative play, are that when children with more severe autism are given a toy they often won't play with it in the same way that other children will. They might line toys up, or get involved in spinning the wheels of a car, or wave it around. So there are some stereotyped behaviours that they might have.

Autism actually ranges these days from very severe conditions that are included in the Diagnostic Manual, such as Rett syndrome in girls; childhood disintegrative disorder in boys – which I suspect with the revision of the Diagnostic Manual those will not be considered autism, but they have autistic like behaviours. So those are at the severe end, up through severe moderate autism, up to what some people call high functioning autism, and then something called Asperger's syndrome.

Dr. Dave: Right, I was going to ask you about that, because I actually had contact with a ham radio operator when I was back in ham radio, who let me know that he had Asperger's; and I was always trying to make him laugh and say funny things, and his response was always very flat, and factual. He was very bright, very technically adept.

Catford: Well you know it's interesting: a lot of people with Asperger's get very angry that people think of Asperger's as a disability, and say "don't cure us, we're not sick, we just think differently". A lot of people with Asperger's are very bright and they often become very good at one particular thing that catches their interest. Often, you described your colleague's flat affect.

Dr. Dave: The ham radio operator guy, yes.

Catford: Yes – they often take things very seriously, very literally; so I could see why he might not have related to your joking around.

Dr. Dave: In this particular guy's case, he might lack what would ordinarily pass for tact, (laughs) being able to gauge somebody else's response. Because I had earned my "black belt" of ham radio, if you will, by becoming an Extra class ham radio operator; there are five levels of licensing and you have to know Morse code at 20 words a minute, and a lot of technical information. And he was candid enough to tell me that I was the dumbest Extra class operator he had ever met.

Catford: On the other hand, you can say that he didn't play social games.

Dr. Dave: Yes.

Catford: He was very direct and honest, which I've found in a number of people with autism and Asperger's diagnosis. And of course, here I am describing a diagnosis, but every individual is so unique and so different that I want to give that caveat.

Dr. Dave: Sure; that's always a problem I guess with all diagnoses really.

A lot of people will have the image of Dustin Hoffman in "Rainman", in their mind. How accurate a representation is that of autism, in general?

Catford: I'd say that's very rare. Yes, there are people who don't communicate and are so fabulous at something that it's astronomically amazing; but I don't think that is a really accurate representation.

Dr. Dave: That "idiot savant" phenomenon is pretty rare.

Catford: Yes.

Dr. Dave: OK so what's the current view about the causes of autism? Or given the spectrum that you're talking about, maybe it doesn't even make sense to talk about causes; or maybe there are multiple causes, or different causes for different syndromes. I don't know, you tell me.

Catford: Well there's a huge debate about the causes.

Dr. Dave: Oh, goodie (laughs).

Catford: Yes, it's all very hot and heavy. The one I think that has the most heat, is the notion that thimerosal, which is a mercury based preservative in vaccinations, is a cause of autism. There have been studies pro and con, many of each. Some showing that when children have a vaccination with this agent in it, almost immediately they lose verbal skills; they start losing eye contact, start picking up stereotypic behaviours, and it can be traced almost to the day to when they got the shot. There have been epidemiological studies saying yes, look, and showing correlations. There have been counter studies saying no, there isn't a statistically significant correlation.

There have been theories put forth that the causes are genetic, there has been searching for the genes that accompany a predisposition for autism.

Heavy metals: that theory has been around for a while, and it's interesting that when Kanner identified the first – I've forgotten how many it was – 14 kids with autism and coined the term to describe severe autism, most of those kids' families worked in the agriculture business and a lot of the fertilisers had mercury and metals in them.

Dr. Dave: That would have been about what time?

Catford: 1943.

Dr. Dave: OK.

Catford: Or just before; I think 1943 or 44 was when he wrote his dissertation about these kids.

Dr. Dave: And that was the beginning of the use of the concept of autism?

Catford: Yes.

Dr. Dave: And what vaccinations are we talking about; measles, mumps?

Catford: Measles, mumps; actually it's even in flu shots.

Dr. Dave: Oh (laughs) I was going to enquire about those today.

Catford: Yes, they are making thimerosal-free flu shots, and anyone who is concerned can ask for a thimerosal-free vaccination. I understand that those have been hung up, they are slow on getting those out to the market, but they are there.

There are other theories as well: there recently has been some thought that older fathers may have a higher number of kids with autism. It's been linked to an immune system deficiency; perhaps allergies; different brain structures; I was reading this morning about some neurotransmitters being implicated. So I think there is still a search for the cause.

Dr. Dave: Yes, maybe because it is a spectrum, maybe we are really looking at a variety of different disorders.

Catford: Oh I am thinking it might be.

One thing that I want to say that is not considered a cause, and it was considered a cause when I was in my undergraduate studies, which is the notion of "refrigerator mothers".

Dr. Dave: I knew that was going to come up.

Catford: You knew I was going to say that? Yes, Bruno Bettelheim, and even Kanner talked about very cold mothers being associated with autism; and the cure was to separate the kids from their families, and give them intensive therapy. That idea is long since dead.

Dr. Dave: Good, I'm glad to hear it. Now another one of the paradoxes though, is that the statistics I've heard seem to be suggesting that autism is on the increase. Why would that be? Is it that the disorder is on the increase, or is it just that we recognise it better through new diagnostic techniques, or the expansion of the category?

Catford: Well you are hitting on a lot of these hot and heavy issues.

Dr. Dave: Oh good. (laughter)

Catford: One of them is the cause, and thimerosal in particular. The other one is the ideas about why it is on the increase: it is true that in 1994 the Psychological Diagnostic Manual expanded the category for autism, the autism spectrum, and did include more items and it become more in focus. So there was a rise starting shortly after 1994.

However if you think about when you were a child, or when I was a child, the number of children that we came across who had symptoms that looked like autism, versus the number of children now: there really are more. And one of the questions is: why.

Some people say that the reason there is an increase, is because children who previously would have been diagnosed with mental retardation or some sort of learning disabilities are now being labelled autistic. There might be some truth to that; however the state of California – which probably leads the nation in documenting diagnoses including autism – there are statistics from the Mind Institute in Sacramento at UC Davis, that along with the rise in autism, the mental retardation rates have remained on the same, almost level, just slightly rising projection. And if in fact children that previously were labelled mentally retarded were now being labelled autistic, you would see a drop in the mental retardation diagnoses accompanying the rise in autism; and we don't see that.

Dr. Dave: Interesting. OK, well what sorts of treatment are available today for autistic people? I am remembering years back, Dr. Lovaas – I have forgotten his first name.

Catford: Ivar.

Dr. Dave: Ivar Lovaas, that's right; he was kind of notorious years ago. He was at UCLA – maybe he still is – but he had a rather radical behavioural approach, in which he not only used M&Ms, but he put kids on an electrified grid as I recall.

Catford: Well today the Lovaas method is quite humane. Probably one of the main treatments is applied behavioural analysis, which has a lot of evidence suggesting that it works very well, which is much more based on positive responses.

You reward the child with hugs; maybe M&Ms; with tickling very often, because they like it and it gives the social connection too. And you shape behaviour, and you teach children appropriate behaviours that way.

In the school system there is a lot of emphasis on wanting to use evidence based strategies. There is ABA, there are some other behavioural ones, discrete trial teaching.

Dr. Dave: Wait, what's ABA?

Catford: Applied Behavioural Analysis.

Dr. Dave: Oh, thank you.

Catford: Discrete trial teaching, where you break what you are doing down into very specific steps, and you keep data on what's happening, and you respond to the specific small steps. And pivotal response training.

However, what are also coming in, and the evidence is being gathered for these: are more socially oriented treatments, and sensory integration techniques. Floor time: Stanley Greenspan's model of floor time involves playing with the kid. I have seen many parents use PECS, the Picture Exchange Communication System, where non verbal kids use pictures when they want things; and they have them catalogued so they can get them. A child who wants a drink, instead of just making a noise, or grabbing your hand and dragging you towards the refrigerator, would go and get the picture of the glass of lemonade or whatever it might be, and take you to the refrigerator with it.

So there are social approaches, there are visual approaches. Making visual schedules – so that the child can see what's coming up in the day – can help with dealing with transitions; because a lot of people with autism don't do well with transitions from one activity to the next. They need a lot of warning; they need to have a sense of what is going to happen when.

Dr. Dave: They get kind of stuck and attached to the routine that they are in.

Catford: Yes, so they need to know what they are doing, what's coming up, and also with any task they are doing: how will they know when it's over and it's time to move on; giving them nice warnings.

Dr. Dave: And I hear you that saying multiple sensory inputs are important too, not just auditory but also visual.

Catford: Auditory, visual, tactile; sometimes with young children, this is where occupational therapists come in, and also early intervention

programs. There is a lot of tactile: of moving, swinging, which stimulates brain development and awareness of where the body is, and is fun; a lot of physical approaches when the children are younger.

There is another approach that I know many people find very useful, which is that of social stories. Which is where stories are made up: "when I get up in the morning, I walk through to mummy and daddy's room, then I go into the bathroom and get my toothbrush, then I put the toothpaste on the toothbrush and brush my teeth." Or you can make up a social story about getting on the school bus, or going to the store; and you can illustrate it, and these are stories about how to behave.

Dr. Dave: Would you say "I", would you use I or would it be about the little bunny, and the little bunny goes to the store?

Catford: No, it wouldn't be about the little bunny.

Dr. Dave: It would not.

Catford: "This is what we do when we go to the store". It's first person.

Dr. Dave: Because they would be too concrete if you said the little bunny.

Catford: Exactly, right; like your ham radio friend.

Dr. Dave: (laughs) Right.

Catford: Yes, then it's a story about a bunny. But if it's what we do, "when we go to the store, we hold mummy's hand as we go down the toy aisle"

Dr. Dave: OK good. How long have you been interested in autism, and what was it that got you interested?

Catford: Well I actually started working with kids with autism in a psychiatric hospital in Scotland in 1971. You may not know that. (laughs)

Dr. Dave: No didn't know that. That would have been before you and I met.

Catford: Yes, yes it was. And that was fascinating to me, and it was part of an internship that I was doing as part of my training. Then thirteen years ago our second daughter was born – we were going to have the ideal family

with two perfect kids, etc – and then out of left field, our daughter ended up being diagnosed with Rett syndrome, which is one of the autism plus diagnoses, at the bad end of the spectrum.

Dr. Dave: Yes I knew she was severely disabled but I didn't know that it fell within the autism spectrum.

Catford: Well it does – some people have diagnosed her with autism, plus cerebral palsy, plus epilepsy, plus GI issues, plus, plus plus – but basically Rett syndrome covers that.

Anyway, since our daughter was born, we became involved in the special needs community; started a support group for families of children with special needs. Also, totally unrelated to this, I became the internship supervisor at Sonoma State, for the undergraduate psychology students.

Well in recent years, more and more parents would call me up and say, "help! Do you have a student who can do an internship working with my child with autism." And there were so many of these, that I thought we really need to do something.

Dr. Dave: And you started a program out of that, which I believe is called CATS; what does that stand for? And tell us about that program.

Catford: Alright; it's the Collaborative Autism Training and Support program. It's a collaboration between North Bay Regional Center, and Sonoma State University. North Bay Regional Center is a state agency, one of I think 21 in the state, that provides services to individuals with autism and other developmental disabilities. It's a two year program, we got a two year grant, to fund a program that would provide students to work with children in their homes – children on the autism spectrum, in their homes.

Dr. Dave: University students?

Catford: Yes, to provide university students to work with children with autism in their homes. The students would take a course, training them to work with kids with autism. The parents would supervise the students fairly heavily at the beginning of the semester, easing off – so the parents could have some respite – towards the later part of the semester.

Also it's a true collaboration, not just between the regional center and the university, because the course is made up of probably a couple of dozen of

experts on autism in the community who come in and give a series of seminars on the areas of their expertise. These are open to the students, they are open to the members of the community, and the parents.

So, it takes a village to raise a kid; it takes a community to raise these kids, and I'm actually going to be writing up an outline of how to do it, in case other communities are interested in coming up with their own community collaborations to support families of kids with autism.

Dr. Dave: Well your program recently won an award, didn't it?

Catford: Yes.

Dr. Dave: Just briefly, what was that award?

Catford: It was the Outstanding Service Learning Program Award, at Sonoma State University.

Dr. Dave: OK that's great. It does seem outstanding; and I looked at the list of speakers that you have coming in, and I was amazed that there were so many local experts who were knowledgeable about autism, about different aspects and facets.

Catford: Well this is a fabulous community, in terms of awareness and action towards supporting these people.

Dr. Dave: You've got all these university students then, who you've got sort of working in the field, placed with families that have some kind of autism going on. Are there any success stories that you can share with us?

Catford: I hear from families that they couldn't have made it without some of the students. One family in particular says that their student came in, and communicated with their child in a way that no nannies, no tutors were able to do before. Another family has similarly said that the student that worked with their child could connect with the child, communicate with the child in a way that was very meaningful and unusual.

Both of these families, actually many of the families, have continued to hire the students on to work one on one with their children since that time.

Dr. Dave: Oh that's a wonderful success. I wonder if maybe part of it isn't that the students are young themselves, and they bring a lot of energy

and optimism and hope to it, and they haven't become jaded and discouraged.

Catford: I think that's true, and in the course we very much want to get the message across: first of all that the parents are experts; secondly it is a collaborative approach, it's a team. Not only is it the community teaching everybody about autism; but it's the student, the parent, the teachers, the therapist, working together with the student; and in fact in terms of the collaboration the families both times wanted to put together a family network list, so that they could communicate with each other, set up play groups, share information.

Also one of the students that I am thinking of who had some amazing successes with the child he was working with last semester, is also now working with the county on their very intensive, early intervention program. Another one is working with adults with autism. Several have gone on to decide that they want to be physical therapists or occupational therapists.

So what is interesting to me is, you said that these students were young and alive: and they get involved in working with these kids and their families, and that's what they want to do with their lives.

Dr. Dave: Yes, so really your program is a win, win, win. It's a win for the parents, it's a win for the kids, and it's a win for the students,

Catford: Yes.

Dr. Dave: It's a win for Sonoma State University, (laughter) it's a win for Dr. Lorna Catford. So that's great.

Some number of people who listen to this program – and I don't know how large the number is – but I think some people are on career tracks where they are majoring in psychology, perhaps are planning to go on. Maybe you can give us a quick thumbnail sketch of what your progress was in terms of becoming a psychologist and doing this work.

Catford: Well it wasn't a straight line.

(laughter)

Dr. Dave: It rarely is.

Catford: Well let me preface it by saying I think there are three things you need to be thinking about as you are looking toward building your career.

One of them is to go with your passion; what do you love and what are you good at, and go for that. Have some clear visions of what that is. You don't need to know what the specifics are, but you need to be aware of your passions and strengths.

The second one is, keep your eyes open for what's out there; what are some career paths that look interesting. Maybe interview people, maybe just see what's around that looks like it would call your name, and find out about it.

The third one is: be open to chance, to fate, to the universe saying come this way.

Dr. Dave: I like all three of those.

Catford: So for me, I started out at the University of Michigan.

Dr. Dave: Yay!

Catford: You went there didn't you?

Dr. Dave: That's where I got my Ph.D.

Catford: OK; I got my B.A. there; very much interested in clinical psychology, consciousness, different ways of thinking. From there, I moved out to California and got my first masters degree, actually at Sonoma State University.

Dr. Dave: And I remember you from that period.

Catford: Yes, you were my professor, lo these many years ago, gosh.

Actually I don't know if you remember this. In your class we had to do a final project, and I put together some music and slides of my artwork and me, to represent the archetypal hero's journey. Do you remember that?

Dr. Dave: I think I do.

(laughter)

Catford: Yes, OK.

Dr. Dave: Of course I do.

Catford: Putting you on the spot here.

Dr. Dave: Of course I do.

Catford: Well that was very important to me. I had been interested in –

Dr. Dave: Well you went on to write a book about the hero's journey, actually.

Catford: Yes it's called The Path of The Everyday Hero – Drawing on the Power of Myth to Meet Life's Most Important Challenges. And it takes the notion of the hero's journey: that we all are called to adventure at certain times in our lives. Leap into the abyss and to the bottomless pit of – oh my goodness how am I going to solve this? And through luck, through strength, through perseverance, through meeting allies, we solve it – and we emerge richer, and deeper, and with something to contribute.

Dr. Dave: And I highly recommend the book.

Now you said you got your first masters at Sonoma State. Was there another one?

Catford: Then I went to Stanford, and I got a masters and a Ph.D. I was interested in different thinking styles, once again, and I got involved in documenting how people making decisions in business don't just use analytical strategies; but they use emotional ones, and intuitive ones, and physical ones as well. And my book in fact is based on that work at Stanford with my partner Michael Ray, and has a lot of ideas for using all those strategies for dealing with life's problems.

And the joke is, that the book was too long, and the publisher said – you know you have to stop writing somewhere. And one of the chapters that didn't get put in the book was dealing with health issues; I mean a lot of other issues relating to having kids with autism, but the one with health issues was taken out. And then my second daughter was born, almost as a way of saying – you left this out of the book, well here!

Dr. Dave: Oh my goodness.

Is there a book that you would recommend on the topic of autism?

Catford: Actually there are a couple that I use in my course. One of them is just called Autism Spectrum Disorders, by a parent called Chantal Sicile-Kira, I believe; very easy to read, good overview.

And then in my course I use that, plus another book, a new book out in 2006, by Pearson, called Students With Autism Spectrum Disorders, by L. J. Hefflin and D. F. Alaimo.

Dr. Dave: OK, well thank you for that detailed breakdown on those book titles; and I want to thank you so much for being my guest here today on Shrink Rap Radio.

Catford: Thank you David, it was wonderful to talk with you.