

Interview with Jim Sinclair

Michael Ellermann

Jim Sinclair is an autistic professional who specializes in working with autistic people. Jim has a BA in psychology, post-graduate education in developmental and child psychology, and an MSc in rehabilitation counseling, as well as being a Certified Rehabilitation Counselor. He has worked professionally with autistic children, adolescents, and adults, and has provided training seminars for teachers and therapists of autistic people. Jim also has extensive experience in autistic self-advocacy, having pioneered the use of service dogs for autistic people in the late 1980s; co-founded Autism Network International in 1992 and been its coordinator since that time; and produced Autreat, the first annual gathering of its kind designed by and for autistic people, since 1996. Jim's writings have been widely reprinted and translated into many languages. He is a popular and dynamic speaker at autism conferences nationally and internationally.

First, let's talk a bit about words and phrases surrounding autism. You explicitly define yourself as an "autistic" person, as opposed to the commonly used term "person with autism". Can you explain the reason for that?

There are some characteristics that are central to who a person is, and other characteristics that are peripheral. Characteristics such as gender, nationality, cultural identification, and major personality traits are considered central to people's identity, and this is reflected in the language that we use: We don't refer to "people with femaleness," "people who are citizens of Denmark," "people with introversion," "people with athleticism," "people with excitability," etc. We say that someone is a woman or a man, American or Danish or Vietnamese, introverted or athletic or excitable.

If you try to think of someone as just "a person," without acknowledging that person's gender, culture, and other important characteristics, then you aren't seeing the whole person.

On the other hand, you may be a person with a blue shirt today, but if tomorrow you have a white shirt instead, you'll still be the same person. You can have a shirt that's blue, white, yellow, green, or no shirt at all, and you're still the same person—a person with (or a person without) a particular kind of shirt. It doesn't make you who you are. You can know who someone is, as a person, without having to know anything about the person's shirt. Shirts are peripheral, not a defining characteristic of a person.

Being autistic is at least as much a part of someone's unique personhood as is gender, culture, and personality. It's not removable and switchable like clothing. If you could take away the autism, you would have a different person, not the same person at all. It can't be separated from personhood.

But, people argue, autism isn't all there is to a person! Well, that applies to all those other characteristics as well: A woman isn't *just* a woman, there's more to her than that. Being Danish isn't all that makes someone who he is. And an autistic person is more than just autistic—each of us is a unique individual with a lot of different characteristics.

So why is it considered politically correct to say "person with autism"? The rationale is that non-autistic people need to be reminded that autistic people really are people. In fact "person first" language comes from the intellectual disability movement, a group of people who have been very badly dehumanized and treated as non-persons due to their disability. Of course it is important to remember that people are people, regardless of disability.

The problem I see is that by trying to make this point by separating out the disability from the person, you end up actually reinforcing the idea that the disability is so terrible as to be inconsistent with personhood—that the only way to acknowledge that people are human is to separate them from their disabilities. But as I've just explained, in the case of autism which affects so much of every aspect of life, it's impossible to do that. If you look at an autistic person as just "a person," and try to pretend the autism isn't there, then you not only aren't seeing the whole person, you're denying a very important part of that individual's personhood.

Currently autism is often defined from a "deficit model". You have presented a different option, namely a cultural model of autism? Could you elaborate on that?

In the traditional deficit model, autism is defined in terms of deficits—things that are "wrong" with a person. It then follows that the way to support a person who has all these deficits is to try to fix the things that are wrong, and make the person more like a normal person who doesn't have those deficits.

What I mean by a cultural model is not that autism is a culture in the same way that we talk about American or Swedish or Mexican culture. Culture is learned; autism is innate. A baby born in America will grow up to be culturally American if raised in America, and culturally Danish if adopted into a Danish family and raised in Denmark. But if that baby is autistic, he will be autistic no matter where he grows up. (Autistic culture does exist, but it's not what I'm referring to when I talk about a cultural model.) I developed the concept of a cultural model to describe an approach incorporating the values of multiculturalism and cross-cultural counseling: looking at autistic characteristics as differences, part of human diversity, not necessarily things that are wrong and need to be changed.

As a counselor, I have been trained that if a client is different from me because her cultural background is different from mine, I should not assume that her culture is inferior to mine. I should not try to change her to be more like me. I should respect and work with her cultural identity.

In order to do this, if I am not familiar with the client's culture, I should make an effort to learn about it. I should be aware of the customs, values, and world view of that culture. I should be particularly sensitive to how people from that culture communicate, both verbally and nonverbally, and I should accommodate the client's communication preferences. I should be attentive to my own attitudes and perceptions, and alert for possible biases in myself. If I find myself feeling uncomfortable about the client, I should be aware of whether my discomfort stems from my own prejudices about the client's culture, or whether the client really is signaling a serious problem unrelated to culture. If I cannot do these things, then I am not a culturally competent counselor for that client, and I should refer the client to a different counselor.

This is the approach that I urge therapists, educators, and other professionals—and really society as a whole—to adopt with autistic people: Respect autism as part of a person's unique individuality; become educated about what autism is and about common characteristics of autistic people; be especially attentive to autistic communication needs; self-monitor for biases and prejudices; and refer clients to more qualified professionals if they aren't able to apply these elements of cross-cultural sensitivity.

You have dealt a lot with the concept of autistic identity. Unsurprisingly, many autistic people do develop a low sense of self-esteem as a consequence of being defined by others as deviants. What are your thoughts on this?

As you said, when people are constantly being treated as if they're defective, criticized for their natural behavior, and taught that they only earn approval and respect by pretending to be something they're not, they're likely to develop a low sense of self-esteem. Another contributor to low self-esteem is being overprotected and "taken care of" too much, which gives the message that we are incapable of doing things for ourselves. It often becomes a self-fulfilling prophecy because when autistic people aren't given opportunities to learn and try new things, we end up truly being less capable, simply because of the lack of opportunity to develop our abilities.

How can parents and professionals relate to autistic persons in a manner that supports a positive identity development?

The cultural model, as I've discussed, provides a framework for relating to autistic people (and any other people who are "different" in some way) in a manner that conveys respect and supports healthy self-esteem. Parents and professionals should also work on their own attitudes, so that they approach autistic people with an expectation of ability, instead of a presumption of inability.

But no matter how accepting and supportive neurotypical people are, if autistic people are isolated from other autistic people, they are at risk for difficulties with self-esteem and positive identity. There are some benefits that only peers—meaning other autistic people—can provide. So if an autistic person is not already in contact with an Autistic community, it can be very helpful for parents or professionals to offer to help the autistic person make such contacts. I have seen amazing things happen when autistic people find each other for the first time. One person told me, "I'm going home a different person than I was when I came here." This person later wrote in an article for the ANI newsletter, "I believe all persons with Autism need the opportunity to become friends with other Autistic people. Without this contact we feel alien to this world. We feel lonely.

Feeling like an alien is a slow death. It's sadness, self-hate, it's continuously striving to be someone we're not. It's waking up each day and functioning in falsehood." [French K. (1993) My personal holiday. Our Voice, the newsletter of Autism Network International, 1,(3).]

What can autistic people offer parents and professionals in this context, in terms of learning about the way autistic people communicate and relate to each other?

There is a great deal that parents and professionals can learn from autistic people, but the responsibility is on the parents and professionals to learn. It isn't the responsibility of children to educate their parents. It isn't the responsibility of students to educate their teachers. It isn't the responsibility of clients to educate their therapists. And it isn't the responsibility of autistic people to educate non-autistic people about autism.

Some of us are willing to work as educators. Some of us are qualified to do so, meaning we're knowledgeable about more than just our own personal stories. Non-autistic parents and professionals can seek out autistic professionals and educated, informed autistic lay people who are willing to teach them.

If you are in any kind of profession that involves working with people, you should be a skilled observer of people. If you are a caring and committed parent, you should be attentive to children and interested in learning about them. You should be willing and able to learn from your observations and interactions. You should seek out opportunities to spend time with autistic people—as many different autistic people as possible, so you get a sense of the great diversity among us, as well as the things we have in common.

But you should not approach autistic people with the expectation that we're here just to be resources for you. Many autistic people are already overextended just trying to manage our own lives. If you're the one who's supposed to be helping us, it isn't reasonable to expect us to do more work to teach you. Autistic people who become professionals may choose to spend our time and our energy working directly with other autistic people, who have so very few professionals who can understand and communicate with them. It isn't right to demand that we take time away from working for our peers in order to educate you.

I am rather passionate on this point because over the years I have seen so much exploitation of autistic people by parents and professionals who want to learn about autism. Their desire to learn is a good thing. Their desire to learn about autism directly from autistic people, instead of learning only what non-autistic people are saying about autistic people, is very good. I strongly encourage non-autistic people to learn about autism from autistic people. The problem is *how* people sometimes go about trying to learn. Here are some things that parents and professionals should *not* ever do:

Do not ask autistic people personal questions about their lives, unless the purpose is for you, in some helping role, to be able to assist the autistic person, or unless you are in a personal relationship with the autistic person in which you are sharing as much personal information about yourself as you are asking the autistic person to share about himself. If you are asking someone else to share personal information about himself, only for the purpose of educating you and without reciprocal sharing on your part, this is what I have often referred to as a "self-narrating zoo exhibit." It can easily become demeaning and exploitative.

If an autistic person is willing to answer personal questions and share her life story, do not overgeneralize and assume that what this one person reports about her own life is true for all autistic people. People do this a lot, and it causes misunderstandings and difficulties when they encounter other autistic people who don't meet their preconceptions.

If an autistic person is willing to answer personal questions and share his life story, be very careful about the person's dignity and privacy, even if the person himself doesn't seem to mind. If a person has been rejected and devalued all his life, and then suddenly finds that a lot of people want to listen to his story and ask him for advice, this can be very exciting and seductive, just like any kind of "celebrity." People can get caught up in getting all this attention and approval, and allow themselves to be exploited. People can also come to believe themselves to be autism "experts" solely on the basis of their own personal experience, and make broad pronouncements about autism that really don't apply to most autistic people.

Another negative aspect of relying on personal stories is that parents and professionals can lose sight of the fact that autistic people have

our own lives and our own priorities, and start treating us as if we are "free natural resources" for them to take at will. Autistic people who agree to present at conferences have found ourselves pursued by eager audience members beyond the time that we've offered to speak. Some autistic conference presenters have had people follow them to their hotel rooms and demand personal consultations. One person even had someone follow her into the toilet and continue asking her questions while she was trying to pee! I have another autistic friend who was participating in an online mailing list while she was a university student trying to complete her degree. At some point she realized she needed to spend less time writing emails responding to parents' questions, so she could focus on her studies and not flunk out of school. Some parents told her that she did not have the right to make this choice. They said that their need for her to answer their questions, which they hoped would help them with their children, took precedence over her own need to pass her courses and pursue her life goals.

Even though it can be very interesting and appealing to listen to personal stories about individual autistic lives, it's necessary to guard against improper uses of people and their stories.

What sorts of problems do autistic people experience when it comes to belonging, fitting in and being part of society?

I think the really critical differences between autistic people and neurotypical people have to do with social participation. Autistic people do not "fit in." The details are different for different autistic individuals. Neurotypical humans have instinctive desires to belong and fit into a group, and instinctive skills for doing that. Of course different cultures have different social norms, and different social contexts call for different kinds of behavior within the same culture. But neurotypical people have an innate ability to notice and imitate and learn these things.

Autistic people may have less desire to belong and fit in. Some of us don't care at all about these things. It simply never occurs to us to pay attention to them, or if we do happen to notice other people's social behavior as interesting phenomena, it doesn't occur to us that we should do the same things. There's no motivation to fit in.

Some of us have some degree of interest in fitting in, but it's less important to us than it is to typical people. Other things are more important.

And then there are autistic people who desperately wish to fit in, but don't know how. No matter how carefully they study other people and try to imitate them, they stand out and are recognized as being odd and out of step. Also, this kind of constant desperate effort to fit in, and repeated failures to do so, lead to a lot of anxiety, emotional exhaustion, depression, and low self-esteem.

I think traditional approaches to social skills instruction for autistic people only exacerbate these problems. For autistic people who are not interested in belonging, being pressured to change ourselves, to conform to something we don't care about, makes the whole concept of being "social" into something aversive. People may become fearful, resentful, or angry about such experiences, and instead of being merely uninterested in being part of society, may become actively avoidant.

For autistic people who are very interested in belonging, teaching us to perform imperfect imitations of neurotypical behavior may appear to be successful on the surface, but underneath people are still experiencing all that anxiety and exhaustion and depression and self-hatred. In my experience, the more "successful" an autistic person has become at emulating NT social skills, the more anxious and insecure that person is inside. Long-term effects on mental health can be devastating.

I've developed a functional approach to social skills, which I find much more meaningful and accessible for autistic people. In my workshops on this topic I teach both autistic and neurotypical people to evaluate social skills in terms of logical functions of behavior, personal boundaries, rights and responsibilities. In these terms, autistic social skills can be every bit as adaptive for autistic people as NT social skills are for NT people. People can find ways to "belong" and to participate in society without ever needing to "fit in."

What are your thoughts about the opportunities for developing dignified relationships between professionals and autistic people - what are in your experience some of the significant success factors?

I notice that this question seems to assume that “professionals” and “autistic people” constitute separate and non-overlapping categories. That illustrates the problem: the attitude that autistic people, across the board, are incapable and in need of help and guidance from non-autistic people.

The best solution I’ve seen is for non-autistic professionals to experience the “reverse inclusion” of attending autistic-run, Autistic-community events such as Autreat and Autscope. When they find themselves in the minority, feeling disoriented and confused because they don’t understand the majority of people around them, and they need to work harder to communicate than they’re used to, but at the same time they see autistic people all around them who are enjoying themselves and reveling in an environment that accommodates their needs, this can have a profound effect on attitudes and perceptions. If they have the courage to come back again and again, and spend enough time immersed in Autistic community and culture, they may be able to form relationships with autistic people that are based in mutual respect and equality. They may become allies to the Autistic community. We have some wonderful allies who are part of the Autreat community.

It also helps that more autistic people are accessing higher education and are becoming professionals ourselves. I think autistic professionals are able to understand, accept, and respect autistic students and clients in ways that neurotypical professionals have difficulty achieving. And if neurotypical professionals are able to overcome their cognitive dissonance and relate to an autistic professional as their peer—which, in my experience, can be very challenging for professionals who are used to thinking of autistic people only as children or clients in need of their guidance and supervision—if they are able to learn to relate to an autistic fellow professional as an equal, this may influence the way they perceive their own autistic clients or students.