

“We Thought You’d Never Ask”: Voices of People with Autism

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What do we think about when we hear “autism”? Is there another story?





How we got
started...

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DSM???

(Where are the voices of people on the spectrum?; Attention to abilities and strengths?)

The DSM

AUTISM

- Qualitative impairment in social interaction
- Qualitative impairment in communication
- Restricted repetitive and stereotyped patterns of behavior, interests, and activities

What story are we telling about autism? Is it accurate? Useful? Who is telling the story?



How we got started...



Didn't recognize the people we knew in the descriptions of autism (e.g., lacking empathy, no theory of mind)

...it is incorrect to say autistic people are cold and indifferent to those around them or, as conventional wisdom once had it, **lack the high-level trait known as empathy**. Last December, when Pam Barrett felt overwhelmed and dissolved into tears, it was Danny, the most deeply autistic of her children, who rushed to her side and rocked her back and forth in his arms. [C. Wallis--
TIME Magazine]



Theory of Mind?

Here is one example of my grandson's intelligence:

His mother told him that a male sea horse is the one who is pregnant. She asked: "Isn't it strange?"

His reaction was: "If a sea horse would have seen you when you were pregnant, he would find it weird."



How we got started...



We were seeing practices that didn't seem to match the experiences and needs of people with autism

For example:

- Overemphasis on eye contact
- A curriculum focused on “task completion”
- Focus on “extinguishing obsessions”



The movie



What we
learned...



LESSON #1

“Nothing about us without us”

We need to find ways to listen to students (including those without reliable communication).

- Talk to families & LISTEN
- Help students teach (movie, presentation, brochure, handout)



LESSON #2

We have been wrong.

We must raise expectations.

- Teach to a learner's potential, not to his chronological age, IQ score, or expressive communication level
- “Least dangerous assumption”
(Anne Donnellan)

“Intelligence is too complex to be captured with a single number.”

-A. Binet

Binet was afraid that IQ would prejudice teachers and parents, and that people would tend to view it as fixed and prematurely give up on kids who score low early on.



LESSON #3

We **MUST** be tentative.

We **DON'T** know more than we **DO** know.

- It is OK to say “I don’t know.”
- We must all see ourselves as learners.