

AN INSTRUCTOR'S GUIDE

UNIQUELY

HUMAN

A DIFFERENT WAY
OF SEEING AUTISM

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WITH TOM FIELDS-MEYER



As noted in **UNIQUELY HUMAN**, autism is a passionate affair. The culture of autism has a long history of divisive issues: How should autism should be defined and diagnosed? How can we better understand and provide support to autistic individuals? This guide aims to encourage thoughtful discussion and reflection about many subjects raised in **UNIQUELY HUMAN**. It is designed to be used as a guide for instructors in classes, and for reading groups. We hope the guide will inspire respectful consideration and productive discussion of a variety of perspectives.

INTRODUCTION

1. Dr. Prizant respects an individual's personal choice to use or to be referred to with "person-first language" (e.g. "an individual with autism"), that identifies one's autism as one aspect of that person, or "identity-first language" (e.g., "an autistic individual"), which communicates that autism is an essential and inseparable part of the person. However, the choice of terminology still remains a controversial issue in the autism community.

Taking the perspective of a person with autism, which do you prefer? (a) using person-first language, (b) using autistic as a personal descriptor, (c) no strong opinion. Why? [Facilitator note: For larger groups, ask how many fall into each of the categories].

Do you think a professional, caregiver, or family member would have a different preference? Why?

Have readers take the stand opposite of their preference for the use of "person-first language," or for using autistic as a descriptor of a person. Debate the two contrasting positions.

2. There are many ways to reveal or share a person's diagnosis of autism with parents, family members, teachers, or even a potential employer.

Have you observed a diagnosis being shared in a manner that you believe is not helpful, that engenders fear and anxiety, and that does not communicate a hopeful perspective? Describe that experience.

Have you observed a diagnosis being shared in a manner that is helpful and supports a hopeful perspective? Describe that perspective.

If you have experienced both, identify some critical differences between the two approaches.

3. Can you think of a person you have known who probably was on the spectrum, but lacked a diagnosis (or had not disclosed it)? How did other people react to this person? What was their perception of this person? If a diagnosis was given or revealed, did it change other people's reactions or perceptions?

CHAPTER 1

ASK “WHY?”

1. Dr. Prizant writes that “Difficulty staying well regulated emotionally and physiologically should be a core, defining feature of autism.”

Do you agree or disagree? Construct an argument for your position with examples from your own experiences.

2. Discuss the similarities and differences between people with autism and neurotypical people in reference to:
 - a) Factors or triggers that cause dysregulation
 - b) Signals of dysregulation that may be observed in a person
 - c) Strategies that a person may use in attempting to cope with dysregulation
3. The author contends that the behavior of other people may be a primary source of dysregulation. Have you ever observed this phenomenon? Are there similarities to how other people might serve as the source of dysregulation for neurotypical individuals?

CHAPTER 2

LISTEN

1. Historically, professionals have referred to language characteristics of people with autism as deviant, irrelevant, bizarre, and noncommunicative. These characterizations were often first noted in the clinical and research literature, while parents and those close to people with autism often found meaning in their language. Why do you think this dichotomy existed for so many years—and still does to some extent?
2. The author’s study of echolalia took into consideration many factors previously not examined. What were some of these factors and how did that contribute to changing our understanding of echolalia?
3. Dr. Prizant writes that one foundation of building trust is for partners to listen carefully and assume that what may appear

unconventional or nonsensical may actually be an attempt to communicate. From the perspective of a person with autism, why do you believe this is so essential? What are some of the challenges in taking this approach?

CHAPTER 3

ENTHUSIASMS

1. Using the terms “enthusiasm” or “passion” instead of “obsession” is emblematic of a shift in attitudes about interests of people with autism. How does this shift affect approaches to supporting academic and vocational success for people with autism?
2. How do specific interests relate to the unique learning style and learning strengths of people with autism? Is an intense focus on an area of interest always desirable or helpful?
3. How might parents or teachers use interests in a beneficial manner, such as supporting relationships with peers and active participation in family activities?

CHAPTER 4

TRUST, FEAR, AND CONTROL

1. Dr. Prizant contends that autism can be understood as a “disability of trust.” How is this perspective different from more traditional definitions and descriptions of autism? Does this “trust” perspective provide any additional insight into how best to understand and support people with ASD?
2. Ros Blackburn, a woman with autism, has stated “Because I find it so difficult to read the behavior of other people, what they do often comes across as very sudden and threatening to me.” What are the implications of this insight for how we must behave, and when necessary, change our style of social interaction?
3. “Controlling behavior” has been described as an undesirable pattern observed in autism, however, Dr. Prizant contends that it is a natural response to fear and anxiety. Describe types of

“controlling behavior” in persons with autism that are similar to what you have observed in neurotypicals. Discuss a few strategies to help a person feel less of a need to be in control.

CHAPTER 5

EMOTIONAL MEMORY

1. How does the concept of “emotional memory” help us to better understand reactions of people with autism that are confusing to us? How might extreme reactions be similar to challenges related to PTSD (Post-traumatic Stress Disorder)?
2. People with autism often possess a relatively strong rote memory. What are the potential benefits as well as the potential challenges of this learning style? Based on your experience with persons who have a similar pattern of abilities, share some examples of how you have capitalized on the potential benefits or have dealt with the challenges.
3. Give some examples of how you, or others you have observed, attempt to replace negative emotional memories with positive emotional memories. Provide examples of strategies that have worked, as well as some that have not.

CHAPTER 6

SOCIAL UNDERSTANDING

1. It has been said that people with autism, due to their neurological differences, have limitations in social intuition. What does this concept mean to you? What are the implications of understanding and supporting people who may have such limitations?
2. With a deeper appreciation of the challenges of social understanding, reframe/challenge the following descriptions of people with autism, and provide more accurate descriptions:
They are rude and too direct. They only talk about their interests and don't shift to topics of interest to you. They ask too many questions, and often the same ones over and over.

3. Emotional expression can be a real challenge for many people with ASD. Early descriptions claimed that people with autism didn't experience emotions like neurotypical persons. What aspects of emotional understanding and emotional expression seem to be particularly difficult, and why do you think that is so? Discuss misguided versus more reasonable ways to help emotional understanding and expression.

CHAPTER 7

WHAT IT TAKES TO “GET IT”

1. Without referring to **UNIQUELY HUMAN**, discuss three qualities of people you have observed who have the ability to “connect” with persons with autism, and give at least two specific examples of those qualities in action. Discuss how the qualities you identify align with, or are different from, those listed in Chapter 7.
2. What kinds of support would “It-like” people benefit from to help them to “get it”? Give specific examples of when you have seen “it-like” people evolve into “got it” people. If this evolution has happened to you, please describe what has been most helpful.
3. Role playing: Break down into pairs, with one person having autism and the other person being a teacher or therapist. Identify an activity you are engaged in, with the teacher/therapist engaging in “It-less behavior” for five minutes. Each participant should then discuss how they felt in the activity. Reverse roles with the teacher/therapist engaging in “got it” behavior. Each participant should then discuss how they felt in the activity.

CHAPTER 8

WISDOM FROM THE CIRCLE

1. Parents often find themselves between “a rock and a hard place,” as their parental instincts move them to request, and if necessary, push for the best teachers and supports for their child. However, if they push too hard, or in a way that is off-

putting to others, they risk damaging relationships with those whom they need to rely on to care for their child.

Select one pair of participants, and role-play, with one being a teacher or administrator and the other participant being a parent. In this first role-play the parent should have a style that is more “aggressive” than “appropriately assertive” when requesting a change in his/her child’s program.

Discuss as a group a way to change the dynamic for it to be more successful. Then in a second role-play, demonstrate a style that is more “appropriately assertive” than “aggressive.” Participants should then reflect on their feelings and comfort level during the simulations.

2. Discuss all the challenges that parents potentially face in public, when they have a child who engages in behavior that is difficult for other people to understand. What is the range of feelings that a parent might experience? What strategies would you suggest for parents to use in dealing with difficult public situations? You can also set this up as a role-play with one participant being the parent, a second being the child/person with autism, and two to three others being on-lookers who react in less than helpful ways.
3. Discuss five helpful things that professionals can do to support families on their journey of raising a family member with autism.

CHAPTER 9

THE REAL EXPERTS

1. As Bob Dylan sang, “The times they are a changin’.” For decades, neurotypicals have had to guess about the experience of people with autism. People with autism now say “Nothing about us without us” (the motto of the Autistic Self Advocacy Network), as they have become important voices in establishing disability policy and in expressing their opinions about different treatment approaches. Discuss three significant areas of change that have come about due to this movement.

2. Identify three significant “take-aways” that you have learned from people with autism, either from their writings, lectures, or your personal contacts.
3. The neurodiversity movement has emerged, in large part, due to self-advocates seeing themselves as different, and not deficient. However, this position is not without controversy. Break into debate teams to debate the pros versus the possible cons of the neurodiversity movement.

CHAPTER 10

THE LONG VIEW

1. Discuss the potential benefits of a developmental “longview” perspective of the experience of autism. Discuss from the perspective of a professional, as well as from the perspective of a family member.
2. Give a number of examples of how a professional or service provider may “join” a family on their journey. Include in this discussion specific strategies to develop a trusting relationship with parents and other family members.
3. Parents and family members may evolve through stages from first understanding that a child is not developing typically through all the transitions in the school years and into adulthood. Discuss some of the stages that you have observed and families you have known, and how we may be respectful and understanding of where a family is on their journey.

CHAPTER 11

ENERGIZE THE SPIRIT

1. Discuss the types of activities that you have observed that result in a great deal of positive emotion being expressed by people with autism that fosters engagement and participation.
2. Have a debate around the issues of supporting happiness and positive emotion as opposed to teaching functional life skills. Are these really diametrically opposed positions, or is there

a middle ground that can be reached, and if so, give some examples.

3. Discuss the role of the arts in helping to “energize the spirit” of people with autism (and for all people). Provide specific examples of innovative activities for children and people with autism that are now being tested and implemented with positive results.

CHAPTER 12

THE BIG QUESTIONS

1. In addition to the questions and responses in this chapter, develop six additional questions and come up with reasonable and research supported responses to these questions. Do this by breaking down into discussion groups, with each group developing two to three questions, and appropriate responses.

ABOUT THE AUTHORS

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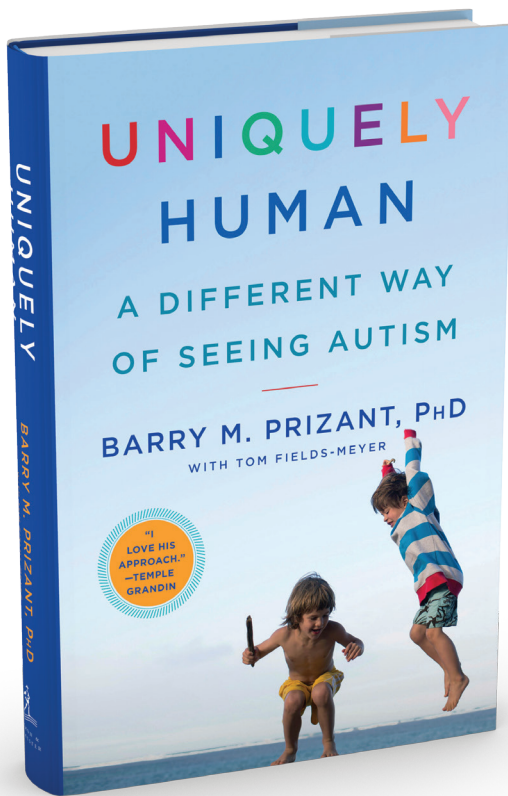
is one of the world's leading authorities on autism, with more than forty years' experience as a scholar, researcher, and international consultant for individuals with autism and their families.

Dr. Prizant is an adjunct professor at Brown University and coauthor of *The SCERTS Model: A Comprehensive Educational Approach*, now being implemented in more than a dozen countries. He has published more than 120 articles and chapters in scholarly journals and seminal volumes on autism, other developmental disabilities, and child and human development.



TOM FIELDS-MEYER is the author of the critically acclaimed memoir *Following Ezra: What One Father Learned About Gummy, Otters, Autism, and Love from His Extraordinary Son*, a finalist for the National Jewish Book Award.

A former senior writer for *People*, he lives in Los Angeles, where he teaches in the UCLA Extension Writers' Program. His work has appeared in *The New York Times Magazine*, *The Wall Street Journal*, the *Los Angeles Times*, and *The Washington Post*.



Essential reading for any parent, teacher, therapist, or caregiver of a person with autism.

UNIQUELY HUMAN

is a groundbreaking book on autism, by one of the world's leading experts, who portrays autism not as a tragic disability, but as a unique way of being human.

Available in hardcover and ebook, wherever books are sold.

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