



Living on the Spectrum

Autism and Youth in Community

BY ELIZABETH FEIN

Instructor's Guide

How youth on the autism spectrum negotiate the contested meanings of neurodiversity

304 pages | Paper | 9781479889068

Sociology | Disability Studies | American Studies

www.nyupress.org

 NYU PRESS

TABLE OF CONTENTS

Author's Note – 2

Introduction – 4

Chapter 1 – 6

Chapter 2 – 8

Chapter 3 – 10

Chapter 4 – 12

Chapter 5 – 14

Chapter 6 – 16

Chapter 7 – 18

Chapter 8 – 20

Chapter 9: Conclusion – 22

AUTHOR'S NOTE

How to use this book and guide for your course

Autism is a deeply contested condition. To some, it is a devastating disease; to others, it is a fundamental and valued aspect of the self. Young people who are coming of age with an autism spectrum diagnosis have to reconcile these seemingly irreconcilable oppositions within their own developing identities. I wrote this book because I wanted to understand how they managed to do that.

Taking place in a variety of communities—from summer camps and science fiction conventions to research labs, schools and conferences—the book observes how youth with these diagnoses, their family members, and the professionals who work with them negotiate the meanings of autism in the places where they live, learn, work, play, and love. It describes the medical models of autism that surround them, how those models developed, and the kinds of assumptions these models make about people: that the healthy self is sharply bounded, self-contained and separate from its environment. Then it shows how young people on the spectrum are looking beyond medicine for ways of reconciling the conflicts of their contested condition, identifying with an alternative shared mythology of mutant, hybrid anti-heroes drawn from video games, anime, fantasy literature and other speculative fictions. In doing so, they are pioneering new and more inclusive understandings of what makes us who we are.

I imagine this book might be relevant for many different kinds of classes. I've focused this Instructor's Guide on the three I can envision most easily: **classes on research methods** (particularly qualitative methods and ethnography), **classes on the social study of neuroscience** (sociology/anthropology of neuroscience, neuroscience and identity, critical neuroscience, psychiatric/medical anthropology, etc.), and classes on **working clinically with people on the autism spectrum** (for psychologists, speech and language pathologists, occupational therapists, other health professionals, etc.).

Those who are using this book to teach **research methods** might want to focus on the Introduction and chapters 1, 2, 6 and 8.

For those who are teaching the **social study of neuroscience**, I recommend working with the entire book, since it lays out an argument on this topic, but if you don't have time or space to do that, you could focus on chapters 2, 3, 4 and/or 5.

For those who are focused on **working clinically with people on the autism spectrum**, I recommend the Introduction and chapters 1, 6, 8 and 9; those working with young adults might take a look at 4, while those working with families might look at 7.

For those who are just looking for a few chapters to assign on some of the **controversies surrounding autism** and its meanings and interpretations, I'd

recommend the Introduction along with chapters 7 and 8 – Chapters 4 and 5 could be relevant as well. Parts of this book would also be appropriate for courses on **speculative media, science fiction and fantasy literature**, particularly those focused on how this material might be applied to other disciplines or its place in contemporary society more broadly. For those courses, I would recommend chapters 1, 8 and 9.

But it's up to you! In the rest of this guide, I'll take you chapter by chapter through the book and its contents. For each chapter, I'll give some suggestions about how you might use the chapter to teach each of these three topics. I've also put together a little 15-minute video that you can use in class to introduce the book; in it, I give some background on the project, describe how I did the research, and outline the overall argument of the book.

Keep in touch! I'm eager to hear how the book is being used, and what you and your students have made of it. And if you teach the book, I'm happy to correspond with you and your students about any questions or comments you have after reading it—email me at feine@duq.edu. If we can find a time that works, I might even be able to stop by for a videochat visit.

INTRODUCTION

The Introduction to *Living on the Spectrum* is available for free download on the NYU Press website, so you can take a look to get a sense of whether you want to read the rest of the book or not. If you are only assigning a chapter or two from the book, you might want to assign the Introduction alongside those chapters for context, since I lay out the entire argument of the book there. I also give a brief history of the many controversies surrounding the autism spectrum, and discuss some important issues like person-first and identity-first language in autism and why I've made the decisions I did about them in this book. I describe the particular methods I used to research the book: ethnographic observation and interviewing in a variety of settings that bring together people with Asperger's Syndrome and related autism spectrum conditions, all in a rural area I call "Brookfield" and the nearby "Park City" on the East Coast of the United States. I talk about what it means to do "clinical ethnography"—immersive participant observation that is carried out by people with clinical training, looking both at and through clinical traditions by taking them up as both analytical tools and objects of study. And I tell the readers a bit about myself: how I first became aware of the autism spectrum through my experiences with a captivating friend, and how my own relationship with autism has shaped the book's focus on questions of attraction, affiliation, and choice.

For those teaching this book in a **research methods course**, you might want to explore questions like:

- What does it mean to say this book is a "clinical ethnography"? How might clinical training shape ethnographic research? What bodies of knowledge and training do you bring to your own research practice, and how does it shape what you see and do?
- What kinds of decisions does the author describe having to make in the research and writing process? How might you handle these decisions in your own projects?
- What relationships in your own life have shaped your development as a scholar, your choice of research questions, and your approach to those questions? What effect have these relationships had on your scholarly work?

For those teaching this book in a course on the **social study of neuroscience**, you might want to explore questions like:

- What does this chapter suggest is lacking in much current scholarship on the neurosciences and their impact on individuals and society? Do these observations resonate with your own reactions to other material we have read?
- How does the author propose to use Ian Hacking's theories about "the looping

effect of human kinds” and what does the book propose to add to these theories?

- Think about another study we have read in this course that considers neuroscience in social context. How, if at all, did that study account for “the ways in which patterned neurodevelopmental variation shapes social, cultural, and biopolitical processes?”

For those teaching this book in a course on **working clinically with people on the autism spectrum**, you might want to explore questions like:

- Fein invites us to consider autism as something that happens between a person and their social world, rather than as something that is located within individual bodies. If you were to think of autism in that way, what (if anything) might change about the way you did you work?
- Following Stuart Murray, the chapter argues that many discussions of autism focus on absence rather than presence. The book will go on to describe some ways that people affected by autism are resisting representations of autism as absence and asserting their own presence. In your own work and your own training, where have you heard autism described through language of absence? Where have you seen autism treated as presence? What difference, if any, have you seen this make for how autism and people affected by autism are treated?

CHAPTER 1

The Summer of Adventure

This chapter tells the story of my first summer of ethnographic participant observation, as a camp counselor at a day camp for teens on the autism spectrum run by a community of live-action roleplaying gamers. In live-action roleplaying games, the players are all assigned characters and goals and collaboratively improvise a storyline within a set of pre-existing constraints. They are not unlike ethnography: you learn about a world by immersing yourself in that world while helping in some small way to create it, through the experiences you have and the relationships you build with other characters. So this chapter is also an account of how I approached the project methodologically, describing my own arrival at my field site and my negotiation of various roles. It gives some backstory about the world in which I found myself immersed: about how a neurodiverse network of educators and artists in Brookfield developed new approaches to autism, culture, and community, and about the rise and fall of the programs they designed. The chapter provides an introduction to some of the major theories about autism and cognition, and reinterprets those observations through a cultural lens, exploring affinities between the cognitive characteristics associated with autism spectrum conditions and the cultural practices of the live-action roleplaying gamers. In order to understand why teens on the autism spectrum were so powerfully drawn to these games (despite the significant challenges they posed!) we need to think about autism in a new way: not merely as a set of individual deficits or limitations, nor as a set of individual weaknesses and strengths, but as a collaborative and co-constitutive relationship between cognition and culture.

For those teaching this book in a **research methods course**, you might want to explore questions like:

- This chapter asks how and why live-action roleplaying games, which pose particular challenges for youth on the autism spectrum, became a place where these youth could thrive. What kind of data does Fein use to address this question? How does she go about collecting it? Do you find the evidence convincing? Why or why not?
- Fein argues, in this chapter, that the meanings and manifestations of autism and other such neurodevelopmental differences are inextricable from the norms, demands, and practices of the worlds in which these differences develop. How does she, as a clinical ethnographer, make that argument? How might a different research method make this argument in a different way?

For those teaching this book in a course on the **social study of neuroscience**, you might want to explore questions like:

- The Journeyfolk are described here as a distinct culture, with their own set of

norms, expectations, and practices. The characteristics associated with autism take on new—and often, though not always, less stigmatized—meanings within that culture. How does autism manifest and how is it conceptualized among the particular practices and priorities of the Journeyfolk? Why do they interpret and experience autism in the way they do?

- While he is not diagnosed with Asperger’s Syndrome, camp counselor Patrick nonetheless describes the Aspie campers as “my tribe”. How is he drawing on neuroscientific concepts to articulate this sense of kinship, and how is he adapting, changing, and adding to them as he considers the difference between chilling over beers and playing “Magic: The Gathering”? How might thinking about teens with Asperger’s as Patrick’s “tribe” shift the way we think and talk about diagnosis and identity?

For those teaching this book in a course on **working clinically with people on the autism spectrum**, you might want to explore questions like:

- Live-action roleplaying games can provide unique and valuable social opportunities for youth on the spectrum. What is it about LARP’s that allows them to provide these kinds of opportunities? What other kinds of shared activities can you imagine (or have you observed) working in this way?
- The chapter describes the development of a much-loved community for youth on the autism spectrum. It also describes many obstacles that participants faced in sustaining that community, from the individual to the interpersonal to the structural. What are some of the difficulties they encountered? Have you seen these problems in communities you’ve worked with? How do you think these kinds of challenges could be effectively addressed?

CHAPTER 2

Searching for a Place

Chapter 2 picks up the story where Chapter 1 leaves off: with the closing of the Unity Center, and the struggle of the students who planned to enroll in school there (and the ethnographer who planned to study it) to find a new place and a new path forward. It introduces Beck and Beck-Gernsheim’s concept of “institutionalized individualism”—the idea that large-scale institutional systems both standardize and separate our lives, compelling us to think of ourselves as decontextualized individuals even as much of our life possibilities are determined by complex bureaucratic structures—and argues that this phenomenon worsens the social disabilities displayed by students on the autism spectrum. Through ethnographic observation of two classrooms for youth on the spectrum, and a close look at one family’s long search for an appropriate school placement, the chapter chronicles the inventive way youth on the spectrum build a sense of community and stability amidst their own experiences of fragmentation, discontinuity, and dysregulation.

For those teaching this book in a **research methods course**, you might want to explore questions like:

- The chapter starts with the author describing the closure of the site where she had planned to conduct fieldwork. Ethnographers frequently need to deal with unexpected changes in plan. How might you design a research question that can be flexible and responsive to these sorts of developments, while still providing guidance and consistency to your project?
- Rather than being set within a singularly located field site, this chapter analyzes the absence of a consistent sense of place, following students through a variety of school settings and describing their disrupted educational trajectories. How might we use ethnographic fieldwork to investigate the experience of losing or lacking a place? What challenges does this author face in doing so? What is included in this account, and what (and who) do you think might be left out?

For those teaching this book in a course on the **social study of neuroscience**, you might want to explore questions like:

- What are students in this chapter learning about their brains, their identities, and the relationship between? What is it about the institutional structures they inhabit—their schools and school systems, their experiences with testing and assessment, their Individualized Education Plans, et cetera—that teaches them this?
- This chapter describes a community that brings together people who share certain cognitive, affective, and interpretive tendencies, giving rise to a particular

cultural style that influences the uptake and implementation of neuroscientific knowledge. The characteristics of autism itself—and the “broader autism phenotype” shared by many who surround them—contributes to the amplification of particular discourses over others. What does this observation add to Ian Hacking’s concept of “the looping effect of human kinds?”

For those teaching this book in a course on **working clinically with people on the autism spectrum**, you might want to explore questions like:

- This chapter describes a wide variety of students facing a wide variety of challenges, all of whom have found themselves grouped under the broadening umbrella of the autism spectrum disorder diagnosis. What, if anything, would you say these students have in common? If you were working in a school program like ASPEN or Valley View, how might you address the diverse needs of its students?
- Drawing on Ochs and Solomon’s concept of “proximal relevance”, this chapter describes a form of bantering humor in the autism-specific classrooms that is based on taking systems of related concepts apart and putting them back together in new and unexpected ways. The teasing can simultaneously be both adversarial and also a means of bonding among the students. What role does humor play in communities where you’ve worked? If you were working in a group like this, how might you manage this kind of teasing?

CHAPTER 3

Innocent Machines

In Chapter 2, we saw how youth on the autism spectrum come to identify with their own neuropsychological classifications; they discover that how they learn determines a lot about who they are within the school system that constitutes much of their social lives and identities. Chapter 3 explores what they learn about themselves, by analyzing a commonly drawn distinction between students classified with developmental disabilities and students classified as having emotional, behavioral or psychiatric problems that fall under the domain of mental health. The students with “brain developmental things” are often depicted as innocent, rule-bound, mechanistic, and estranged from sociality, while those with mental health conditions are treated as morally culpable, relationally engaged, and messily human. While this depiction of learners on the autism spectrum as appealingly technoscientific wins them scarce educational resources, it silences the moral meaning of their irrepressibly social lives.

For those teaching this book in a **research methods course**, you might want to explore questions like:

- This chapter can be used as an example of how to extract implicit cultural models using both interviews and ethnographic observation. At the beginning of this chapter, the author works closely with a lengthy excerpt from an interview with a teacher, in order to illustrate and analyze a broader set of shared beliefs about students on the autism spectrum and how they differ from students with mental health concerns. How does she do so? What kinds of moments does she focus on most closely and why?

For those teaching this book in a course on the **social study of neuroscience**, you might want to explore questions like:

- How is Fein’s definition of “brainhood” similar to, and how does it differ from, other representations of the brain-as-self that we have encountered in this class?
- This chapter describes moments when students in the Asperger syndrome classrooms are perceived as both enacting and exemplifying neuroscience, in a way that allows their differences to be depicted as value-producing while downplaying the moral significance of their choices and actions. Does this resonate with other representations of neuroscience you have encountered in this class or elsewhere? What might be some of the consequences of this process for the circulation, uptake and impact of neuroscientific knowledge?

For those teaching this book in a course on **working clinically with people on the autism spectrum**, you might want to explore questions like:

- This chapter describes a very common way of talking about people on the autism spectrum: as if their social transgressions invariably lack intentional meaning. Have you observed this as well? What, according to this chapter, are some of the problems with interpreting people on the spectrum in this way? What's missing from that way of interpreting them, and why does it matter?

CHAPTER 4

Hardwired

In Chapter 4, the book shifts to the urban area I call Park City, and the challenges faced by youth on the autism spectrum as they move into adulthood. Drawing on observations and interviews among participants in a network of support groups run by and for adults on the spectrum, this chapter draws connections between the psychological and the political. I argue that a “neurostructural” model of the autistic self as a fixed and interconnected system, often developed and deployed in these meetings, serves as a form of resistance to the demands for flexibility, fluidity and adaptability found in contemporary “neurochemical” and “neuromolecular” forms of biopolitical governance.

For those teaching this book in a **research methods course**, you might want to explore questions like:

- How do you create memorable characters in an ethnographic narrative? This chapter describes the lives of people who have experienced a great deal of social vulnerability and who report feeling quite sensitive to the judgments of others. What decisions has the author made here about how to represent them and their stories? How can you imagine they might react to reading about themselves in this text? If you were writing up this material, what might you do in a similar way and what might you do differently?

For those teaching this book in a course on the **social study of neuroscience**, you might want to explore questions like:

- This chapter compares a number of common metaphors for the brain and its relationship to self and sociopolitical identity, ending with the evocation of “microplasticity” and its potentially toxic consequences. Consider teaching this chapter alongside some of Nikolas Rose’s work on the neurochemical self, Joelle Abi-Rached and Nikolas Rose’s work on the neuromolecular gaze, and some work on neural plasticity by Tobias Rees, Victoria Pitts-Taylor, and/or Catherine Malabou. What are some of the personal and political implications of these “brainhoods”?
- What does it mean to adopt a “neurostructural” model of the self? Have you seen the “neurostructural self”—linked to developmental disability rather than psychiatric disorder, and associated with assertions of fixity over fluidity and flux—articulated elsewhere? To what purpose, and with what consequences?

For those teaching this book in a course on **working clinically with people on the autism spectrum**, you might want to explore questions like:

- Young adults on the autism spectrum face a wide range of challenges as they transition from the relative structure and support of high school to the pressures of adulthood and independent living. What are some of the difficulties reported by people on the spectrum in this chapter? What helps them? What kinds of interventions (ranging from individual supports to the formation of groups to shifts in public policy) do you think might make this transition easier to navigate?
- Many of the speakers in this chapter draw a sharp distinction between autism and mental illness, depicting autism as an innate and fundamental aspect of the self and mental illness as something external and unwanted. Do you agree? Why or why not?

CHAPTER 5

The Pathogen and the Package

Chapter 5 is an exploration of autism science that juxtaposes fieldwork at research labs and conferences with interviews with autistic self-advocates whose identities have been profoundly shaped by such neuroscientific knowledge production. The chapter argues that a paradigm shift in psychiatric research—what I refer to as the neurodevelopmental turn—is producing new kinds of diagnostic entities, of which the contemporary “autism spectrum” is perhaps the most visible. These new neurodevelopmental conditions are multivalent (they contain both valued and unwanted elements, packaged up together), identitarian (they are profoundly connected to our most fundamental human capacities, the things that make us who we are), and worlded (they are intimately bound up in our social, sensory, and aesthetic connections to the world around us). But they function within a medical infrastructure still organized around the detection and elimination of pathogen-like disease states, often depicted as antithetical to and separable from the self. Through a process I call divided medicalization, two versions of autism are produced – autism as a pathogen and autism as a whole package of multivalent traits. In this time of paradigm shift, autism-the-package is often viewed through the lens of autism-the-pathogen, with potentially threatening consequences.

For those teaching this book in a **research methods course**, you might want to explore questions like:

- What are some of the challenges and opportunities of using ethnographic research to study science? What different kinds of science get done in this chapter, and how are they connected? Is ethnography a science?

For those teaching this book in a course on the **social study of neuroscience**, you might want to explore questions like:

- This chapter describes a paradigm shift in psychiatric diagnosis, a “neurodevelopmental turn” with profound implications for how disorders are conceptualized and treated. What are the characteristics and consequences of this neurodevelopmental turn? What is its historical context? Have we seen evidence of this turn in anything else we’ve read?
- Consider teaching this chapter alongside a chapter or two from Annemarie Mol’s *The Body Multiple: Ontology in Medical Practice*. Mol illustrates how multiple versions of diseases are produced within multidisciplinary medical settings, and then (often awkwardly, often consequentially) made to cohere. To what extent is the “divided medicalization” of autism an example of the kind of multiplicity Mol describes? What are some of the consequences of this process?

For those teaching this book in a course on **working clinically with people on the autism spectrum**, you might want to explore questions like:

- Lana, an autistic young adult, asserts in this chapter the importance of listening to people on the autism spectrum themselves about what's best for them. Why is this important? What are some of the challenges that might make this difficult, and how might you address those challenges in your own work? Were you convinced by Lana's controversial claim that she could relate to a child who is very young, nonverbal, and significantly affected by autism, even if their lives were very different, because of the ways in which their brains are similar? Why or why not?

CHAPTER 6

The Division of a Syndrome

This was the first chapter I wrote for this book, and it's still one of my favorites. I think parts of it are very funny. If you're only going to teach one chapter out of this book, this one works fairly well as a standalone little ethnography of the medicalization of sociality and some of the weirdness that causes. It focuses on a group of psychologists and psychologists-in-training at a clinic for Asperger's syndrome located within the psychiatry department of a medical school. They are grappling with an irony: the medical center, focused on containing and eliminating disease, is an inhospitable environment for the kinds of playful social activities that are most healing for their kid patients. A case study of divided medicalization in action, the chapter shows how social, aesthetic, and identitarian elements of Asperger's syndrome were at first invited into and then gradually banished from the clinic. What's left behind is a hollowed-out representation of social disorders as problems to be addressed through work with individuals.

For those teaching this book in a **research methods course**, you might want to explore questions like:

- How can ethnographic observations and interviews be effectively integrated? How would this chapter be different if the author had only conducted interviews, or only done ethnographic observation without interviewing? What is each able to accomplish here, and how do they fit together?

For those teaching this book in a course on the **social study of neuroscience**, you might want to explore questions like:

- What is the difference between the “package” model and the “pathogen” model of autism? How do they co-exist at the Hayes Center? What happens in moments when they cannot be made to cohere?
- This chapter describes a process of expansion and constriction: medical practice is expanded to include aesthetics, pleasure, and sociality, and then reduced back to a focus on unwanted individual impairments. Applying the concept of “divided medicalization” here, what might be some of the consequences of this process? How might medical practice be different at the end of this process than it was before? How might our understanding of self and social life be different? What has changed?

For those teaching this book in a course on **working clinically with people on the autism spectrum**, you might want to explore questions like:

- The practitioners in this chapter found lots of creative ways to bring kids (and young adults) on the autism spectrum together to have fun and share activities with each other. Why do you think they chose the kinds of activities they did? Why might a drama group or an Exploring the City group be useful for youth on the autism spectrum? What other kinds of activities might be effective in similar ways?
- Have you ever tried to develop an activity-based group for people on the autism spectrum? How did it differ from other kinds of clinical interventions? Did you ever wonder, as the practitioners in this chapter did, how these activities fit with your identity as a health care provider? What is health care, and what does it mean to be healthy?

CHAPTER 7

The Dilemma of Cure

While I was researching this book, my interviews often covered a wide range of topics. But with each interviewee, at some point, I asked some variant on the same set of questions:

How would the world be different without Asperger's/autism?

How would you/your child/your students/your patients be different?

What do you think would change if you could make it go away somehow?

And what was often the most difficult question:

If you could, would you?

This chapter looks at how they answered, dwelling in the fraught ethical and relational ambivalences engendered by questions of prevention and cure. As Alice, a special ed teacher, points out in this chapter, when asking these questions, “you’re talking sort of fundamentally about *what is a person*, you know?” The intractable quality of ethical debates about cure, I came to understand through these conversations, is grounded in an unsustainable model of the self as defined entirely by its internal traits and characteristics.

For those teaching this book in a **research methods course**, you might want to explore questions like:

- How might you handle difficult questions in an interview? In this chapter, interviewees often struggle with conflicting and painful emotions as they respond to interview questions. What are some of the benefits and drawbacks of asking interviewees to discuss subjects about which they feel powerfully conflicted? What are the ethical implications of doing so? How might you do so respectfully?

For those teaching this book in a course on the **social study of neuroscience**, you might want to explore questions like:

- This chapter argues that conflicts over curing or preventing neurodevelopmental disabilities are grounded in a particular understanding of the self: as determined entirely by internal traits, fundamentally separate from its broader social context. How might construing the self in a different way—as more relational, more permeable, and/or more continuous with the physical and social ecologies in which we live—change our understandings of neurodevelopmental disability? How might it change debates over prevention and cure?

For those teaching this book in a course on **working clinically with people on the autism spectrum**, you might want to explore questions like:

- This chapter depicts several complicated family relationships. As Lyndon, a college student on the spectrum, points out, it's often difficult for families of youth on the spectrum to balance concern for their child's long-term well-being with respect for their developing autonomy. How might you support a family who is dealing with these challenges?
- This chapter points out that resources devoted to improving lives affected by autism are often allocated towards changing individuals rather than changing social relationships and meeting needs for social support. In your own work, where do you feel like your efforts are most often directed—towards individuals, toward broader social structures, or toward the relationship between? Would you like anything about that balance to be different, and if so, how might you change it?

CHAPTER 8

The Sword in the Soul

This chapter focuses on the experiences of the youth of Brookfield themselves. Autism, to them, feels both intimate and alien, brings both cherished strengths and terrifying vulnerability, and constitutes their sense of self while also profoundly disrupting it. Neither of the prevailing medical models of autism—autism as a destructive pathogen and autism as a value-neutral form of neurogenetic hardwiring—can capture the ways in which these aspects of experience co-exist. By playfully reinventing their autobiographies through roleplaying games, anime, and other popular culture, however, they generate new ways of coming to terms with the complexities of their condition. In the process, they are pioneering new understandings of what makes us who we are.

For those teaching this book in a **research methods course**, you might want to explore questions like:

- The research on which this book is based began as a study of a medical diagnosis. Yet in this end, this chapter argues that we often need to look outside of medical settings, discourses and methods to understand the lived experience of such conditions. How will you set up your research project so that it is limited enough in its questions to be feasible and focused, yet still open to unexpected surprises? How might you balance the need to organize your study around a particular phenomenon with the understanding that this phenomenon might manifest in places you don't expect?
- This chapter, more than any other in the book, focuses closely on the opinions, thoughts, and beliefs of teenagers on the autism spectrum. What are some of the challenges of conducting research with teenagers? What are some of the challenges of conducting research with people managing social, cognitive, and/or communication disabilities? How might you adjust your own ways of listening, attending, and questioning in order to hear their perspectives?

For those teaching this book in a course on the **social study of neuroscience**, you might want to explore questions like:

- After spending most of the book contrasting the view of autism as a hardwired neurogenetic package with the view of autism as a pathogen-like disease, Fein pivots in this chapter to talking about the ways in which these models are similar. What do both of these models share? What are they both missing?
- How are the narratives of “mutant antiheroes” used by the Brookfield teens similar to these medical narratives about autism spectrum conditions? How are they different? What are these teens accomplishing by drawing on speculative fiction in

order to re-tell their autobiographies? How does the form as well as the content of these myths help to instantiate a different model of the self?

For those teaching this book in a course on **working clinically with people on the autism spectrum**, you might want to explore questions like:

- Different kinds of stories, and the different forms of media through which they manifest, reflect different understandings of the self, emotion, and social relationships. And these stories, with their embedded assumptions, shape the way we suffer and heal from distress. How do the stories of possession, mutation and hybridity told by the Brookfield teens help them manage the challenges of their condition? You might want to teach this chapter alongside some of Laurence Kirmayer's work on culture, narrative, and mental health, or other scholarship on culture-specific "idioms of distress".

CHAPTER 9: CONCLUSION

Bowling Together

A few years after I concluded the initial phase of my research, I returned to Brookfield to see how the youth I'd known as teenagers were faring as young adults. Informed by their observations, I end the book with some recommendations, suggesting that interventions on the social disorder associated with neurodevelopmental difference should attend not only to individual bounded bodies but also to the strengthening of interpersonal social connections. I discuss a number of shared social spaces that were meaningful to the participants in my research—a bowling league run by and for adults on the autism spectrum, a “Repair Café” where broken things are rebuilt rather than thrown away, a fencing club where youth develop and follow a code of honor, and a science fiction convention where attendees come together to dream of the stars—and I look at what made these spaces worth fighting to sustain. Drawing on James Gee's concept of “affinity spaces”, I argue that communities organized around shared super-ordinate goals, rather than around the personal acquisition of decontextualized “social skills,” can be an effective way of mitigating the loneliness and isolation that too often surrounds neurodevelopmental difference.

For those teaching this book in a **research methods course**, you might want to explore questions like:

- How can qualitative and ethnographic research be used to support clinical and/or policy recommendations? The Conclusion ends with suggestions about how to build, maintain and support social spaces where people on the autism spectrum can thrive. What are some of the strengths of this kind of research for developing and/or supporting particular kinds of interventions? What are some of the potential limitations? How might these strengths be maximized, and these limitations addressed?

For those teaching this book in a course on the **social study of neuroscience**, you might want to explore questions like:

- Throughout the book and especially in this concluding chapter, the relationship between “local” and “global” is used to simultaneously evoke both a neurocognitive information processing style and a broader set of sociopolitical relations. How do these levels relate to one another? How do these sets of relations play out in the lives of Brookfield youth like Darren?
- What do programs like Superflex teach kids about their brain, their society, and the relationship between? What kinds of assumptions are embedded in its mythology, plotlines, and characters? A great deal of the Superflex curriculum is available online, at socialthinking.com—you might want to assign some of this

material, along with other programs teaching kids about social cognition and self-regulation like the Alert Program (*How Does Your Engine Run?*) alongside this chapter for a deeper dive into the narratively and metaphorically rich world of “self-regulation” curricula.

For those teaching this book in a course on **working clinically with people on the autism spectrum**, you might want to explore questions like:

- Looking at the social spaces that were most meaningful to youth on the autism spectrum in this book—spaces that they created, communities that they strove to sustain—what kinds of characteristics do they have in common? Can you think of any social spaces that you know of that share some of these characteristics? What have you observed in your own work and life about the kinds of situations where people on the autism spectrum are more likely to thrive?
- What are some of the concerns raised in this chapter about social skills groups often offered to youth on the spectrum? Do you share these concerns? For those who have read Chapter 6: Think back to the groups run through the Asperger Center. How are they similar to the kinds of groups critiqued in this chapter, and how are they different? For those who have read Chapter 8: What are the similarities and differences between Nightblade and Superflex, and why do they matter?