“Two Opposite Ends of the World”: The Management of Uncertainty in an Autism-Only School

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Abstract
How do individuals maintain a sense of efficacy and purpose in the face of high levels of ambiguity and uncertainty? In research on medical uncertainty, sociologists often discuss the strategies health practitioners employ to control uncertainties relating to diagnosis and treatment. Over six months of ethnographic field work at an autism-only therapy school, we observed seventy-five students and forty-seven instructors and formally interviewed ten instructors and four parents. While other studies on medical uncertainty have focused on controls over external circumstances, we demonstrate that another management strategy is for individuals to perform ethical work on themselves in order to adjust how they conduct themselves in uncertain situations. Despite the ambiguity of both the autism diagnosis and the therapeutic method employed at the school, instructors are able to maintain a sense of efficacy and to recognize themselves as “doing floortime” by transforming themselves to become “child directed.”

Keywords
autism, managing uncertainty, therapy, ethical work, medical uncertainty

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How do individuals maintain a sense of efficacy and purpose in the face of high levels of ambiguity and uncertainty? This question has been treated by a voluminous sociological literature, extending from economic and organizational sociology, to the sociology of scientific knowledge and medical sociology (Stark 2009; Vaughan 1996; Wynne 1992). In this paper, we report the results of a 6-month ethnography at an autism-only school, where instructors similarly have to contend with a great degree of ambiguity and uncertainty resulting from the nature of the condition, the therapeutic approach emphasized by the school, and their own lack of preparation. While the sociological literature on the management of uncertainty has focused on strategies by which practitioners locate the sources of uncertainty in external circumstances, over which they then seek to exert control (Ringsberg and Krantz 2006), we seek to contribute to the literature by showing that instructors at the school drew on a different set of procedures meant to cope with highly uncertain situations: instead of transforming their relation to external circumstances, they modify the relationship with their own selves.

Background

As we noted above, the sociological literature on the management of uncertainty is voluminous and we could not possibly survey it all here. Instead, we chose to contrast our findings with the treatment of uncertainty in medical sociology, because of the basic similarity between medical situations and our own ethnographic material. Both involve encounters between professional service providers and clients/patients diagnosed with highly ambiguous and uncertain conditions, and both involve some attempt at treatment. Moreover, whether an intervention is billed as medical or “educational” is not a given, but is an object of struggle with tremendous consequences in terms of legitimacy, authority of the practitioners, insurance coverage, etc. Especially regarding behavioral approaches to autism (see below), there are fierce struggles currently waged in school districts all across the country. We feel it legitimate, therefore, to ignore the boundary work between medical and educational approaches and emphasize their similarities.

Research on the uncertainty experienced by medical students and practitioners was initiated by Renee C. Fox’s (1957) classic argument that medical education was “training for uncertainty.” Medical education inevitably generates high degrees of uncertainty because medical knowledge is by definition limited and full of gaps, yet also vast and continually changing so that students and residents necessarily have an “incomplete or imperfect mastery of available knowledge” (see also Fox 1980: 5). Medical training, therefore, seeks to socialize trainees so that they manage the limitations of medicine
and of their own knowledge by projecting an attitude of objective expertise and detached concern. In short, residents learn to live with uncertainty and to be skeptical about the promises of medicine (Fox 1957; Timmermans and Angell 2001). Later authors, however, challenged Fox’s argument and emphasized the extent to which medical training involved learning to control and reduce uncertainty, thereby developing the opposite attitude of dogmatism and overconfidence (Atkinson 1984; Light 1979; Katz 1984). To cope with uncertainties relating to diagnosis and treatment, practitioners refer to previous experience, focus on techniques (Light 1979), evaluate or consult evidence-based medical research (Timmermans and Angell 2001), and develop scripts and routines (Ringsberg and Krantz 2006).

In this article, we would like to return, in a sense, to Fox’s original insight, by proposing that in situations of high ambiguity and uncertainty, individuals can maintain a sense of control and efficacy by locating the source of difficulty inside themselves and working to modify the relationship they have with themselves. In other words, if sociologists after Fox have emphasized the interpretive or bridging work (Timmermans and Buchbinder 2010) individuals perform to reduce/manage uncertainty, we emphasize the ethical work individuals perform on themselves and their relationship with others to adjust to uncertain situations. Instead of resisting uncertainty or even accepting it as an irreducible limit (as in the detached attitude), ethical work is conducted to render the self compatible with a circumstance of pervasive uncertainty.

This argument is based on the findings of a six-month ethnography and interviews with instructors at an autism private school. The school we have chosen to study maximizes the degree of ambiguity and uncertainty associated with the treatment of emergent illnesses (Dumit 2006): newly delineated behavioral syndromes lacking a clear biomarker and organized in a spectrum ranging from the severe to the near-normal. The job of instructors is to provide specialized therapeutic treatment and education to developmentally disabled students, using a “child-directed” approach. As we will show, instructors enter the school without prior training in the treatment program used at the school. Moreover, the students’ diagnoses of autism spectrum disorder (ASD) as well as the treatment program present the newcomers with multiple sources of uncertainty. We have found, however, that the intolerable pain of uncertainty experienced by medical students, as described by Fox (1980), is absent at the school despite the pervasiveness of ambiguity. In their interviews with us, instructors emphasized the process of personal transformation they underwent to adapt to the child-directed pedagogy practiced at the school and to cultivate in themselves the requisite personal qualities of patience, openness to the unexpected, flexibility, and willingness to be led. These qualities
provide them with a “feel” for the right pedagogic action or a pedagogic “habitus” (Bourdieu 2000) and thus reduce the inextricable uncertainties that pervade their work environment. Moreover, instructors told “conversion narratives” (Greil and Rudy 1983) in which they reinterpreted their past experiences as leading up to this personal transformation, and in which they depicted a fundamental compatibility achieved between their selves and the values emphasized by the treatment program. Instructors contrasted these values and qualities with the “forced” and “unnatural” practices of the behavioral approach for autism treatment prevalent outside the school. Their “feel” for the correct pedagogic action was thus enhanced by this opposition to a therapeutic model that approximates, in many respects, the format of standardized, evidence-based treatment.

In what follows, we first discuss our research methods. Second, we describe our field site and the three primary sources of uncertainty experienced by instructors—disorder diagnosis, treatment program, and instructors’ lack of experience. Third, we draw on our observations and interviews to analyze (1) the stories instructors tell about how they arrived at the school, (2) case vignettes that exemplify how instructors account for their pedagogic choices, and (3) the contrast instructors draw between the relational and behavioral models. Finally, we conclude with a discussion of the implications of our findings and a brief note on how our work is applicable to sociological studies about the growing field of complementary and alternative medicine (CAM).

## Methods

During six months of fieldwork at the private school—henceforward “Uptown School”—one of the authors observed twelve classrooms, seventy-five students, and forty-seven instructors. Over this time, six head teachers, three teacher’s assistants, one transition facilitator, and four parents were formally interviewed off site.

The study was approved by the Institutional Review Boards of Columbia University and Uptown School. After gaining authorization from the Uptown School administration, instructors were recruited through a schoolwide distribution of participation forms, which allowed them to either opt out or indicate interest in observations and/or interviews. To ensure anonymity, instructors dropped completed participation forms in a sealed box, to which only the researchers had access. Participation forms sent home with students allowed parents/guardians to give consent that their children would be observed or to opt out. The forms also allowed parents to consent to be interviewed or to opt out. These forms were collected by the school and returned
to the researchers. None of the instructors asked to opt out of the study. Only one parent opted his/her child out of the study, so the classroom including this student was not observed. From the remaining eligible classrooms—classrooms with consent from all instructors and parents—we sampled twelve classrooms to represent the full range of developmental stages and age groups.

Visits to the field site involved unobtrusive participant observation and informal instructor interviews. The researcher’s participation in classroom activities typically entailed assistance in the general oversight of students’ work and, on one occasion, the teaching of a money-counting curriculum when the classroom was temporarily understaffed. The researcher, however, was not trained in the treatment program and acted essentially as a classroom aide. While a fully representative sample of Uptown’s staff was difficult to obtain for formal interviews, informal interviews during classroom observations supplemented and supported interview data. Data collected at the field site were initially hand recorded; later, field notes were typed up in an electronic text document by one of the researchers.

Interviews were semistructured and conducted in-person. Ten instructors and four parents were each interviewed for about an hour. Instructors and parents were interviewed off the field site at various locations of their choice. All interviews were audio recorded and transcribed by one of the researchers. Only the researchers had access to the data collected during the course of this study. Both researchers read all the field notes and the transcribed interviews and collaborated in their analysis. The analysis involved identifying recurrent themes, then attempting to connect several themes together into a more general concept. Once a concept was developed, both researchers reread the field notes and interviews to identify more instances that could be illuminated by it. In this way, the researchers were able to focus attention on how instructors managed the inherent ambiguity in their work.

Setting and Sources of Uncertainty

Uptown School, established in 2006, is located in a dense metropolitan area and serves children with developmental disabilities between the ages of four and nineteen. The students at Uptown range widely in terms of the severity of their disability and their level of functioning. In total, at the time of our observation, there were fourteen classrooms, fourteen head teachers, and forty-six teacher’s assistants for 105 students. Of the ten head instructors observed, nine were female and one was male. Of the thirty-eight teacher’s assistants observed (including the teacher’s assistant that was promoted to head instructor during our observations), twenty-six were female and twelve were male.
As one can see, the vast majority of Uptown staff were women. At the same time, autism specifically and developmental disorders more generally are more prevalent among males. The ratio of four affected males to one female is often cited for autism, but it is merely an average of different studies. As a rule, the lower the IQ or the more severe the disorder, the lower the gender ratio (it can be as low as 1.2:1), while in high-functioning autism or Asperger’s disorder it could be as high as 16 boys to 1 girl (Fombonne 2003). It should be clear from the outset, therefore, that the educational intervention we describe in this article—specifically, as we shall see, the values and ethical work involved in being “child-directed”—is gendered work. Not only do female instructors perform care work traditionally associated with the women’s sphere in the sexual division of labor (Padavic and Reskin 2002) but much of this work involves teaching boys, in particular, to communicate and relate to others in appropriate ways. Most importantly, we will show that the staff at Uptown manages ambiguity and uncertainty by cultivating in themselves the qualities of patience, forbearance, adaptability, “relatedness” and willingness to be led. The capacity to do so draws upon attitudes and values learned in female gender socialization, and is “emotional labor” associated with “deep acting” of female gender performance (Hochschild 1983, 1990).

At Uptown, instructors face multiple challenges due to uncertainties deriving from (1) the diagnoses given to the students, (2) the treatment program, and (3) the instructors’ lack of prior experience.

1. The first source of uncertainty is the students’ diagnoses. All the students are diagnosed with some variety of Autism Spectrum Disorder (ASD)—including autism, Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS), and Asperger’s Syndrome. ASD is a group of related neurological disorders of unknown etiology, encompassing a very broad diagnostic profile (American Psychiatric Association 2000; Centers for Disease Control and Prevention 2012; Waterhouse, Fein, and Nichols 2007). The DSM-IV diagnostic criteria require the presence of six symptoms out of a possible twelve in three broad areas of social interaction, communication, and stereotyped patterns of behavior (American Psychiatric Association 2000). Consequently, disorder manifestation varies enormously from case to case. The population of children at the school was indeed highly heterogeneous. This means that the diagnostic label provided instructors and therapists with relatively little information about the specific problems, needs, and prognosis of any individual child. At one extreme are nonverbal children (some use Picture Exchange Communication System with prompting) who engage in self-stimulatory behaviors,
appear inattentive, require regular support, and lack control over their movements. On the other side are highly verbal children and adolescents who possess critical thinking skills, and high self-sufficiency, and the whole range of intermediate disabilities in between.

2. The second source of uncertainty stems from the unconventional treatment program, which makes it hard to pinpoint instructors’ responsibilities. The Developmental Individual-difference Relationship-based/Floortime (DIR/Floortime) or, as we will refer to it here, the “relational model,” was developed by psychiatrist Stanley Greenspan in the 1970s and first introduced in his 1979 book *Intelligence and Adaptation: An Integration of Psychoanalytic and Piagetian Developmental Psychology*. It prescribes a child-directed approach to teaching, which embraces each student’s “unique” learning style (Greenspan 1979; The Greenspan Floortime Approach 2013; Greenspan and Wieder 2006; ICDL 2010). As instructors are expected to take cues from and be led by students, the model offers broad principles but does not give specific directions. Unsurprisingly, the lack of direction leaves instructors improvising on the basis of their own understanding of the model. While most of our interviewees did not express themselves so forcefully, the quote below captures the general experience of confusion instructors had upon entering Uptown:

I had no idea . . . even going in, I mean, I—they tell us like, “read *Engaging Autism* by Greenspan.” I remember, I picked up the book and I started reading it and I had no idea, I was just lost. I was like, “what is this?” . . . It was like pointless reading because I had no idea, and then I came here and like the same thing, I was lost, I was like, “I don’t know what to do, I don’t get it.” (Carol, Head Teacher)

Although the relational model does not explicitly give instructions on how to work with students, there are three main components to the model that shape pedagogic action. The first is a nine-stage developmental scale on which students’ condition-related behaviors can be plotted to determine their developmental “stage” and, in theory, assess their progress. In practice, it is difficult to use the scale for evaluation since stages are differentiated by vague qualitative measures that lack clear achievement markers. The second component of the relational model is the idea that each child has a “unique” learning process (Greenspan and Wieder 2006; ICDL 2010). This emphasis on individuality (which is of course true for all of special education in the United States, but is especially pronounced at Uptown) makes it difficult to provide the staff with
detailed descriptions on how to perform the model, as each child’s set of goals and academic programs are tailored case-by-case. The individualized program require instructors to be highly cognizant of each student’s needs—whether such needs are overtly communicated or not—through every aspect of education. Instructors learn a general attitude, an ethos, a “feel” for how to engage with the child’s uniqueness:

I think it’s almost an innate thing—you have to, I guess, pick up on it, but you need to learn and do it, I don’t know, simultaneously to really grasp it? (Carol)

The third component of the model is its “relational” character, which means the teacher works to foster the capacity for interpersonal relationship in the student, and that this is done by the teacher herself being “related,” that is, by example, prompting, and by taking cues from the student in interaction. It is something that the instructor must embody to eventually demand of the child as well. Obviously, it is very hard to evaluate or measure relatedness. The only way to get a handle on what it may mean in a practical setting is precisely by learning painfully, through ad hominem criticism, what it is not, when one’s errors are pointed out by peers.

I’ve seen some bad [child-directed interaction] and I can pick it out. . . . Sometimes I’ve seen some things that had some video footage and I was like, “wow, that was bad,” and I can be like, “you know what? We definitely shouldn’t have done that,” maybe not like, “we should have done this,” but like, “we could have done this, this, or this,” and like not to say that that would be the right thing but it would definitely be a better thing. (Carol)

Thus, Uptown’s pedagogy presents multiple layers of uncertainty: how to evaluate effectiveness and progress, how to tailor each intervention to the individual child, and what it means to be child-directed.

3. The third source of uncertainty is attributable to Uptown instructors’ lack of exposure to the relational model prior to joining the school. As can be seen in Table 1, none of the interviewed instructors were trained in the relational model before employment. All received on-site training mainly in the form of hands-on coaching from a relational model specialist and videos of Greenspan at work with children. Coming to the school without much knowledge about the relational model no doubt increased the uncertainty faced by instructors.

In the face of a difficult and ambiguous condition such as autism, equipped with a fairly loose approach learned on the job, how were instructors able to
maintain a sense of the rationality and efficacy of programming necessary for daily pedagogic and therapeutic work? We argue that despite being vague and ill defined, the relational model did require instructors—if they were to adapt—to modify the relationship they have with themselves, to perform ethical work on themselves, to turn themselves into instruments that gauge and foster relatedness in their students. It was this sense of personal transformation, the capacity to feel inwardly its effects that provided instructors with a feel for the right action—bolstered by the contrast with the “wrong” attitude and action of the behavioral model—and made external uncertainty less relevant.

Table 1. Career Trajectories of Interviewed Teachers and Teacher’s Assistants at the School.

<table>
<thead>
<tr>
<th>Teacher</th>
<th>Undergraduate Major</th>
<th>Graduate Studies</th>
<th>Job before Joining School</th>
<th>How Joined the School</th>
<th>Worked with Autism before Joining the School</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nicole (HT)</td>
<td>General and Special Education Psychology</td>
<td>Special Education Psychology</td>
<td>Milieu therapist</td>
<td>Accidental. Was looking for an ABA</td>
<td>No</td>
</tr>
<tr>
<td>Tina (HT)</td>
<td>Psychology</td>
<td></td>
<td>Special education teacher</td>
<td>N/A</td>
<td>Yes</td>
</tr>
<tr>
<td>Helena (HT)</td>
<td>Childhood and Special Education</td>
<td></td>
<td>Sales and customer service</td>
<td>First job offer after graduation</td>
<td>No</td>
</tr>
<tr>
<td>Monique (HT)</td>
<td>Elementary Education and English Language Psychology</td>
<td>Special Education</td>
<td>Obama campaign</td>
<td>School hired her because she spoke Russian</td>
<td>No</td>
</tr>
<tr>
<td>Carol (HT)</td>
<td>Psychology</td>
<td>Special and General Education</td>
<td>ABA Instructor</td>
<td>No longer wanted to work with 0–3 years old children</td>
<td>Yes</td>
</tr>
<tr>
<td>Leslie (HT)</td>
<td>History and Secondary Education</td>
<td>Childhood and Special Education</td>
<td></td>
<td>N/A</td>
<td>Yes</td>
</tr>
<tr>
<td>Brenda (TF)</td>
<td>Psychology and Secondary Education</td>
<td>School Counseling</td>
<td>Paraprofessional</td>
<td>Contracted through the Board of Education</td>
<td>Yes</td>
</tr>
<tr>
<td>Margaret (TA)</td>
<td>Religious Studies</td>
<td></td>
<td>Aide at a community home for people with special needs</td>
<td>Contracted through the Board of Education</td>
<td>No</td>
</tr>
<tr>
<td>Jaleh (TA)</td>
<td>Speech Pathology</td>
<td></td>
<td>Student</td>
<td>Researched schools for autism</td>
<td>No</td>
</tr>
<tr>
<td>Vivian (TA)</td>
<td>History and Education</td>
<td>Behavior Disorder</td>
<td>General education teacher</td>
<td>Heard of school’s reputation</td>
<td>Yes</td>
</tr>
</tbody>
</table>

Note: HT = head teacher; TF = transition facilitator; TA = teacher’s assistant.
a. Paraprofessionals are contracted through the Board of Education to provide students with instructional services under the general supervision of a certified teacher.
b. Promoted to head teacher in the second half of our observation.
Managing Uncertainty by Learning to Be “Child Directed”

In this section, we use our data to make three points. First, we analyze the stories instructors tell about how they arrived at Uptown and demonstrate that they are similar to religious conversion narratives, where the new converts reinterpret their past experiences in light of the new worldview they acquired. Second, we present a series of vignettes demonstrating that, despite the vagueness of the relational model, instructors are able to draw on the opposition between “child directed” and “adult directed” to derive a feel for the correct pedagogic action. This feel or pedagogic habitus, we argue, is anchored in the work that instructors perform on themselves to cultivate the qualities of patience, flexibility, openness, and willingness to be led that are necessary for being child directed. Finally, we demonstrate that instructors draw upon the opposition between the relational and behavioral models as a resource in explicating and justifying the pedagogic value of being “child directed.” Put differently, they manage the uncertainty surrounding the relational model not by knowing that they are doing the right thing but by knowing that they are not doing the “wrong” thing.

Finding Uptown: Narratives of Arrival and Conversion

As noted earlier, none of the instructors had worked with the relational model prior to arrival. Most were unaware of it before they were hired and did not embark on their job search intentionally seeking a school practicing this model. As shown in Table 1, most Uptown instructors found their way to the school serendipitously; a few teachers were originally contracted through the Board of Education, others discovered Uptown while searching for an Applied Behavior Analysis (ABA) position, and one head teacher responded to Uptown’s need for a Russian speaker. Nonetheless, in interviews, instructors framed the story of their arrival as the result of natural compatibility with the relational model. They portrayed themselves as either possessing the requisite qualities of child-directedness prior to employment or having a latent desire to cultivate such qualities.

The apparent contradiction between this framing and the instructors’ lack of prior knowledge about the relational model can be resolved by examining more closely instructors’ trajectories before they arrived at Uptown. As Table 1 indicates, almost all interviewed instructors have been educated in disciplines—special education, psychology, behavior disorder, speech pathology—where they were likely to have acquired at least scholastic knowledge of the existing approaches to treating ASD and the differences between them.
Thus, while they may have not heard of the specific relational model practiced at the school before, instructors were likely aware of the wider space of available therapies/methods for treating autism, and the prevailing opposition in it between relational and behavioral methods (Eyal et al. 2010). This opposition served as an interpretative resource for instructors to make sense of their arrival at Uptown. Becoming child directed is thus a process not unlike conversion, at least in the more secular and flexible sense of the concept elaborated by Greil and Rudy (1983). As in other conversion narratives, instructors reinterpret their past experiences in light of the worldview they acquired at the school. Whether they told a story of accidently stumbling upon it, or they depicted themselves as “seekers” for whom the school provided an answer to long-felt dissatisfaction, the instructors’ narrative was one of recognition: they recognized themselves, their self-image, in the mirror provided by the relational model.10

Typically, instructors’ first exposure to different autism therapies has happened in an academic setting—in a course or a practicum. While the instructors did not study the relational model specifically, some traced the trajectory that led them to Uptown to an initial negative experience with, or reaction to, behavioral approaches taught in college. The early discomfort they felt regarding the behavioral model of educational intervention appears in the instructors’ accounts as a point of departure for their process of conversion to the relational model and is analogous to the narrative of the religious “seeker” who describes conversion to the new faith as finding the answer to a deeply felt existential tension (Lofland and Stark 1965). One teacher’s assistant recalled an event that was a turning point in her trajectory. While in college, she observed a clinician working with a child with autism—presumably as part of practical training—and her uneasiness with what she saw prompted her to embark on a search that led her to Uptown:

But then there was a part of the session where he was sitting down and the therapist took a desk and locked him against a wall with the desk and I was just horrified. I’m like, “whoa, there has to be something or another way to help these kids; another therapeutic way instead of locking them behind a desk,” so I started Googling all different kinds of schools and Uptown came up. (Jaleh, Teacher Assistant)

The opposition in the wider space of autism therapies, of which instructors become aware through their experiences navigating it, forms the background and basis for what they depict as a deeply personal choice. This opposition is articulated by means of various analogies, as we shall see below, but it is couched primarily at the level of the proper relationship between instructor and student, as well as the relationship to oneself.
And when I first went in the school what set it apart from all other schools was—the school had such energy. . . . It just looked like a really supportive, friendly, happy energetic environment. And like, I have a lot of energy—I thought I would be a great fit there. (Helena, Head Teacher)

Some instructors, therefore, narrated how they arrived at Uptown differently from the “seekers.” In their story, who they were—their self-image—dictated their preference for the relational model as a natural, uncomplicated choice, devoid of the drama of crisis and resolution. We must remain agnostic as to which came first, the instructor’s self-image or the choice to work at Uptown, yet we note, as can be seen in Table 1, that only two of the teaching assistants indicated in their answers that they actively researched and selected Uptown because of its approach, while for most instructors the opposite story is probably no less plausible: how they arrived at Uptown was fairly accidental, but they learned to identify with the relational model in the course of working there and as part of reinterpreting their past. Conversion, whether to religious cults or self-help groups, often entails this process whereby the convert reinterprets the past in light of the present worldview, creating a coherent self who was “destined” to arrive at the true faith (Greil and Rudy 1983, 6).

Finally, some instructors tell a slightly different story, somewhat analogous to the “sinner” conversion narrative. In this story, the convert describes an “eye opening moment” that made them realize the error of their past ways. Carol, who joined Uptown after previously working at a behavioral school, describes her gradual realization of the problems with the model. She did not leave her previous job or join Uptown because of unhappiness with the behavioral model, yet she learned to reassess her previous experiences and came to lament the ineffectiveness of her former work and depict herself as having been converted:

But I am not walking around with clickers all day! Yeah, it’s a big change, but I feel like . . . it’s just so much more natural, and the way I feel like it is here, it’s not so much about the kids learning the names of these things or whatever, it’s what they are going to do with it—when I think back that was the biggest switch, and I think that’s one of the hardest things to realize, is like: “you know what? This kid can tell me it’s a goat, but when I take this kid to the zoo is he going to know that’s a goat?” And that was the eye opener for me. (Carol)

What all these narratives have in common, regardless how they were sequenced and plotted, is that their core is a relation of recognition. As Greil and Rudy (1983, 245) put it, conversion always involves “coming to see oneself and the world as one’s reference group sees one.” The relational model is not simply a therapy that one can pick or drop at will. It is a mirror where the
instructor’s self-image is reflected. The preference for the relational model is depicted as an existential choice between completely different worlds and radically divergent selves. It conjures an irreconcilable opposition between two pedagogical forms of life—behavioral and relational—without a middle ground. Thus, what may have originally been accidental preferences shaped by academic studies become understood as destinies, as profound confirmation of who one is as a person and educator. Because the relational model provides very little explicit instruction on how to conduct lessons, this self-image is perhaps the most important pedagogic tool at the disposal of instructors, a sense for the right pedagogic action because it comports with the previous choices that have brought them to this place and have shaped the story they tell about themselves.

“Doing Floortime”: Feeling for the Correct Pedagogic Action

Without a clear set of rules defining what it would mean to follow the relational model, how do instructors make everyday pedagogical decisions while maintaining a sense that their decisions conform to a general model? We found that instructors typically evaluate their actions as conforming to the relational model if they can account for them as being child directed as opposed to adult directed. This opposition serves as a practical “feel” for the correct pedagogic action. At this level, the relational model functions as an ethical program that takes as its object, its “ethical substance” (Foucault 1984, 25–28), the relationship between instructors and students, as well as between instructors and themselves. To be child directed means that instructors must cultivate in themselves qualities such as patience, flexibility, openness, and willingness to be led. Instructors must overcome their natural tendency to direct the child, and instead shape themselves into this exquisitely sensitive device that can capture, reflect, and amplify the students’ faltering and idiosyncratic attempts at communication so they form a genuine relationship.

Our method in the foregoing will be to present a vignette, an everyday classroom scene we observed, and that we judge to be illustrative of the type of pedagogic actions and choices that characterize being child directed. We follow each vignette with what instructors told us in interviews to demonstrate the extent to which they account for their actions using the idiom of child-directedness.

Case 1: “dumpling or snack?”

In a class composed of 7–11 years old kids, Student A’s (with a diagnosis of high-functioning ASD) parents had asked Head Teacher Holly
to keep track of what he eats in school. During lunchtime, Holly encourages him to eat the dumplings that his parents had packed, but he evades her and wanders around the room. Holly uses a small dry erase board to write: “dumpling or snack?” She shows him the choices she wrote on the board and he fetches a picture book with anthropomorphized fruits and vegetables. Holly responds, “dumpling or snack? Do you want to read first?” She opens the book and the two of them look at the pictures and discuss images that pique Student A’s interests. After finishing the book, Holly redirects Student A to the board and asks again, “dumpling or snack?” He selects “snack” and they go prepare oatmeal for him to eat.

Even though Holly wanted her student to eat his lunch, she agreed to read the book with him and to return to the matter of lunch later (without much success). We observed similar sequences throughout the school day. In being child-directed, instructors are expected to follow and facilitate the students’ preferred activities and interests, suspending their own lesson plans. This willingness to be led constitutes a core personal experience in the process by which teachers become socialized to Uptown and come to recognize themselves as practicing the relational model.

The first day I was there, a kid ran out of the classroom and the principal was following me . . . and I was like “oh my god, what do I do? I need to get this kid back to the classroom.” And he was definitely just like “No, if he wants to be out there and he wants to play this game, you can play this game with him as long as you want. . . .” “Wow, like it really is all about the kid.” (Nicole, Head Teacher)

What value do instructors see in the “child-directed” pedagogy? Educational interventions and therapies, however technically or scientifically justified, are typically infused with certain moral values and organized around a moral narrative. The relational model, as practiced by the Uptown instructors, is guided by a moral narrative of “discovery,” of drawing the child outside the isolation represented by autism and into a world of relations with others. Instructors suggest that by following the child they discover what interests him or her, using it as a hook to engage the child in a joint activity, thereby practicing with the child how to form relationships with others around them:

Whatever their passion is, we want to identify it and engage in it with them, and then once we’re there we can show them our ideas in that passion, and they can join into this shared attention world with us, so we’re not just entering their world and staying there because then maybe that’s playing into their scripts all the time. (Tina, Head Teacher)
This moral narrative of discovery is not unique to the relational model and/or to Uptown. It is quite old and is characteristic of autism therapies in the 1950s and 1960s, before the rise of the behavioral model (Eyal et al. 2010). Moreover, the image of a child hidden behind defenses who needs to be drawn out (Shore 2003) is so well entrenched in the autism world that one could easily find it among behavioral therapists as well. The relational model responds to this conceptualization of disorder as obstacle (that behind the disorder is a capable child), reasoning that instructors must delicately reach out to the barricaded students (Greenspan and Wieder 2006). In accordance with this narrative, to heal the child, the child must want to be healed, and for that to happen the instructor needs to surrender control of the situation, follow the child, and discover not only where his passion lies, but also what he is capable of:

I find that if the child leads the play then you get to see more of the child’s development and you’re able to see what they’re capable of. If you’re constantly telling a student what to do you don’t know if they can do it independently or not. (Brenda, Transition Facilitator)

While the moral narrative of discovery is not unique to the relational model, when practiced systematically, as at Uptown, it entails a complete reorganization of scholastic space and time: witness how the key spatial opposition between inside and outside the classroom is erased in Nicole’s account of her first day at the school; or how the “dumplings or snack” vignette documents the marginalization of the schedule as a device of temporal organization. The conventional scholastic organization of time and space is a taken-for-granted and embodied practical sense. To change it entails unlearning engrained habits and acquiring new ones as embodied attitudes. Thus, without being hyperbolic we can say that instructors must undergo a certain personal transformation as they learn to be child directed. They must distance themselves from previous notions of instructor–student relationships that were habitual and engrained, and they must share their authority with the students to cultivate a subtle balance between following and leading.

Case 2: “Music time”

In a morning meeting of a class for 14 to 16 years old students, Student B (diagnosed with lower functioning ASD) makes an abrupt and adamant request for the “Hokey-Pokey” song. Teacher’s Assistant Lizza asks her if she could wait because it is not time for music. In response, she puts her arms over her face and whines, and the head teacher, Olivia, acquiesces, “Okay, guys, it looks like [Student B] really wants
to do the Hokey Pokey now.” The class then participates in the song. Later in the day, a different student requests a song. Dissatisfied with her peer’s selection, Student B insists on a different song. Olivia tells them that the class can sing both songs. To appease Student B who seems to be more emotionally affected, the class sings her song first.

What is the pedagogic value ascribed to this attitude of appeasement and flexibility? We routinely observed that the staff did not force students to follow class schedule, but more often instructors/therapists changed their schedules to fit the needs and interests of students. Instructors felt that in so doing they were cultivating something that was sorely lacking in their students, indeed something that went to the core of their disorder, namely the faculty of choice:

I’m always asking him about “what do you want to do during this time? Which activity do you want to”—there’s a lot of choice making. It’s not: I say this is your schedule. He has a say in making his own schedule too, and deciding what he wants to do, and when he wants to do it. There is so much with like him getting to say what he wants, that is a big part of [the relational model] for me.

(Margaret, Teacher Assistant)

It is often the case that individuals with autism are perceived by those around them to be unable or uninterested in exercising free choice, and efforts are made to impose it on them (Schelly 2008). Exercising choice is key to the moral narrative of discovery, yet one could say that instructors’ insistence on choice, to the point where they seem to be indulging mere whims, goes even deeper. The object of pedagogic action, the ethical substance upon which it works, is not the individual child per se, but the relationship between the child and others, a relationship practiced and honed in interaction with the instructors. For a relationship, however, to qualify as genuinely therapeutic it must be symmetrical. A whim, therefore, should not be frowned upon since it could be the first halting attempt to assert choice and to form a genuine relationship with others. Instructors routinely give up a piece of their authority to follow such whims. They explain their action by arguing that most students have had everything done for them, either at home or in previous educational environments. Consequently, instructors aim to nurture in students the capacity to exercise choice and communicate it in an appropriate manner. To promote independence and communication, instructors refrain from imposing their will upon the student, allowing the students to initiate, lead, and take the time they need to accomplish tasks:

I’ll be like, “alright, so what do you want to do in this time?” “Oh, I want to go to the gym and play basketball.” “Okay, that’s great.” And then I stand
there and wait for him to initiate and do what he wants to do . . . after a while I say something like, “so where should we go play basketball?” And he’ll be like “oh the gym,” and then we’ll go down to [floor] five and then we’ll stand at five and he’ll look at me and he’ll look at the door: “oh how are we going to get to the gym?” And he’ll be like: “oh, I need your key.” “Oh, you need my key, okay.” And then I’ll hand my key over and he’ll be like: “you do it.” I’m like “no, you could do it, you could open the door.” Then he’ll use my key, he’ll open the door, and then I’ll let him guide me and show me what he wants to do. (Brenda)

The injunction to follow the child’s lead requires instructors to maintain a delicate balance between following and leading, in which they suspend their authority in order to discover students’ interests. Ultimately, however, it is learning to interact and forming relationships which are the direct or incidental target of all lessons:

A lot of what they do is centered around their passions, because that’s what’s interesting to them and that’s what they, you know, want to learn about—and that’s how they’re going to learn to interact with one another. (Vivian, Teacher Assistant)

Creating opportunities for the student to develop initiative, capacity for choice, and a “concept of self,” the instructor must be patient, restraining the urge to assert her will and complete tasks for students, and providing only minimal prompting. Patience and self-restraint are personal qualities and a style of interaction that characterize what it means to be “doing floortime.”

Thus, instructors know they are practicing the relational model because they embody this style of interaction, and they can feel the emotional tension of self-restraint. The vignette below illustrates the role of patience in “doing floortime”:

Case 3: “You say!”

Student D (with a diagnosis of average functioning autism) is new to Monique’s classroom (composed of students 11 to 14 years old). On the day of observation, she is concerned about the schedule of her cooking projects. On her desk is a cooking schedule written in large letters. Throughout the morning, she regularly seeks Monique to confirm that at 1:30 she will be making guacamole, and on Friday she will be making salsa with a different classroom. Having memorized the schedule, Student D repeats the information and insists, “you say.” Despite the annoyance of being asked multiple times, Monique complies and repeats the information each time Student D demands, “you say.”
The child-directed pedagogic ethics encourage instructors to be patient in allowing students to lead and following students’ cues. Obviously, instructors may arrive at Uptown endowed with different capacities for patience, but they all must learn to practice a particular kind of patience, mixed with self-restraint, that is characteristic of the relational model. Uptown instructors must improvise how long they wait, when and how they prompt, and ultimately that gives their practice of patience a more inward quality. It is subordinated not to an objective standard but to the subjective struggle of self-restraint. For this reason, instructors recall their early experiences entering the school and learning to “do floortime” as incredibly hard, an exercise in personal transformation:

The first three months was really a struggle for me. I thought about quitting. The [relational] model is amazing but it’s really hard to catch on because you want to do everything for the kid, but taking that step back and letting them lead was extremely hard. (Jaleh)

Whether or not an instructor arrives to the school with inherent patience, it is a quality that is acquired through practice, as Jaleh suggests. When asked to give an example of what it means to “do floortime,” instructors often recounted an episode where they demonstrated the valued qualities of patience and self-restraint, thereby assisting a child to develop initiative and confidence:

We had streamers that we had to put up, and he just couldn’t figure out how to do it. So instead of saying “... you take the chair, stand on the chair, and hang it up”—allow him to figure it out piece by piece... and then he’ll try everything, like take a book and stand on it, or then finally, find the chair but then forget the tape, ... and instead of going to get it for him, like, allow him to think “okay, now I got to get down, get the tape, bring the tape, get back up on the chair, and get back up and do it.” (Jaleh)

Patience is a temporal-emotional style and an embodied attitude. Once it is acquired, it can provide an anchor and reference point for instructors to recognize that they are “doing floortime,” contributing to their sense of efficacy.

Quotidian pedagogic choices made by instructors are recognized as “doing floortime” because they refer to an ethic of child-directedness. Underlying the notion of being child directed, we argued, is the fact that the subject matter upon which the relational model works, its “ethical substance” (Foucault 1984, 25–28), is the relationship between the child and others, a relationship practiced and fine-tuned through interaction with the instructor. This is why the instructors’ description of the relational pedagogy involved also stories of
personal transformation, as they needed to work on themselves to conjointly work with the students on the relationship between them. This is also why they struggled to specify exactly their role vis-à-vis the students and especially the vexed question of their position as figures of authority, preferring a “fluid” relational understanding of their position:

You’re not necessarily a friend that they can just sort of boss around, and is going to give in to all their whims and demands, but you are also somebody that they can trust, that they can feel safe with, and somebody that respects them and shows them that respect. . . . I think it really depends on the individual child as to what kind of relationship you’re going to have. (Monique, Head Teacher)

Just as the relational model seeks to foster “relatedness” in the student, that is, an orientation to other people as partners to interaction, by the same token it requires the instructors to subordinate their authority to the imperative of “relatedness,” since what they are working on is not the child’s brain, or even “skills” or “development,” but the relationship between child and others. Herein lies perhaps one source of the opposition between the relational and behavioral models, to which we will shortly turn.

A final note is in order, however, about the consequences that follow from the fact that the subject matter upon which DIR/Floortime works is a relationship. However congenial it may sound to sociological and ethnographic ears, ultimately it means that DIR/Floortime often dabbles in parent blaming. Since what is being worked upon and what is being evaluated is not simply the child or even the disorder-within-the-child, but a relationship, it means that often what is being judged and found wanting is the quality of parenting. In our interviews with instructors, when mention of parents came up, it was usually criticize (mostly) or praise (sometimes) parents’ efforts at implementing the DIR/Floortime program. Instructors described variation in the level and type of parent involvement, indicating that while some parents are eager to apply the relational model at home, others fail to follow the prescribed program and/or set goals for their child that conflict with those of Uptown:

We try to get the parents on board because [otherwise] it kind of goes to waste then, everything that we’re doing . . . some of the parents don’t even have any interaction with their children at home and stick them in front of the computer and then when the child comes into school and we want him to sit at a desk or sit with a group and problem solve he wants no part of it . . . it’s really tough after weekends, too. You see how no work has been done at home. (Vivian)

While instructors emphasized how uncooperative parents could compromise the efforts of the school and thus have an adverse effect on the relations
between instructors and students, our impression was that the parent-blaming tendency of DIR had potentially adverse effects on the relations between instructors and parents. This evaluation of quality of relationship is even built into the Functional Emotional Assessment Scale (FEAS), which measures where the child is on Greenspan’s nine-stage developmental scale by evaluating the quality of emotional interaction and attachment between child and caregiver. As Beals (2003, 34) says about Greenspan, “the advice he gives us, his claims about how much influence parents have, and the kinds of mistakes he suggests we are making, together imply that our children would not be nearly so autistic if we had, from the start, conducted ourselves in ways that amount to what all good parents should do anyway.”

**Relational versus Behavioral**

Up until now we have shown that given the uncertainty surrounding pedagogic decisions at the school, instructors seem to not be guided by an explicit model but by a sense or a “feel” for the appropriate ethical relation between instructor and student, as well as the relation the instructor is called upon to maintain with herself. Now we will demonstrate that this feel for the right pedagogic action is supported by an opposition between the relational and behavioral models, namely, that instructors use this opposition as a resource in explicating and justifying the pedagogic value of being child directed.

Before we begin the analysis, let us enter a caveat and clarify our approach: the contrasts that instructors draw between the relational and behavioral model must be taken with a grain of salt. They often reflect only cursory knowledge of the behavioral model and are typically exaggerated precisely so as to explicate and justify the pedagogic value of being child directed. For our own part, we are equally skeptical of both approaches’ claims. None of the existing therapies and interventions “cure” autism, and our reading of the existing evaluation research is that the claims of “recovery” on behalf of existing therapies—ABA and DIR included—are impossible to verify and likely greatly exaggerated (Rutter 1983; Howlin 1997; Rogers and Vismara 2008). This fact may explain why we heard relatively little from the teachers about the subject of efficacy. Occasionally, they objected to behavioral approaches as ineffective, but they did not mount a defense of the relational model as being measurably more effective. The reasons they gave were different and had more to do with the ethical qualities of the relationship the model fostered. This sidelong of efficacy is not unique to the relational model. Behavioral approaches do the same by focusing on short-term “small steps,” rather than “an absolute and unattainable ideal of normalcy” (Lovaas 1981, 3). Ultimately, the teachers were not
contrasting therapies as measured by an external yardstick of commensuration, such as efficacy, but on the basis of how DIR/Floortime defines the goal of intervention, the ethical telos (Foucault 1984, 25–28) toward which it strives. This goal being relatedness—a state, once again, not simply of the child or even the disorder-within-the-child (like “remission,” “recovery,” or “improvement”) but of the relationship between child and caregiver—it is essentially incommensurable with the goal of ABA (and most other therapies) and leads the teachers to a dogmatic rejection of the behavioral model, most apparent in the accusation that ABA produces “robotic” behavior. We can only speculate that this dogmatism—which is not really common in autism therapies, which tend to be eclectic and modular, borrowing freely from one another (Green et al. 2006; Eyal et al. 2010)—is defensive and serves to protect teachers from external judgment. Whether it also harms the students because of the lack of openness to alternative approaches is not a question that we can address here. Finally, while one of the researchers has been trained in ABA, and both have first-hand familiarity with it, our research did not involve directly comparing DIR and ABA. We are skeptical whether such direct comparison is likely to yield much insight and prefer to focus on how Uptown instructors compare them and how they use the contrast to make sense of their own practices.

Instructors opposed the “naturalness” of the relational pedagogy to the “artificial” feel of behavioral pedagogy. This opposition between natural and artificial extended to a whole set of associated oppositions: between rote (learning by memorization) and “meaningful” learning, between external and internal, superficial and deep, dependence and independence, and of course, adult-directed vis-à-vis child-directed. Instructors used the opposition to the “artificial” and adult-directed behavioral model to justify their preference for the relational model.

Really, I don’t like [behavioral therapy] anymore . . . [the behavioral model] looks pretty on the outside because the kids can tell you what you want to hear, . . . you know, a lot of parents are very concerned about them appearing normal and typical . . . but to me, I’d rather him solidly know actually what one thing really means and really understand it, as opposed to be able to tell me ten different words of things—so, no [behavioral therapy]. I think I really like this model, I really, really do. It just seems like a natural kind of thing. I like the playfulness. (Carol)

Instructors identified, for example, the reinforcement system of the behavioral pedagogy as particularly “artificial” because it does not reflect how consequences follow actions in reality and does not instill self-motivation in
students. They argued that students’ behaviors should be reciprocated with “natural” responses that are as close as possible to real-world interaction, thereby cultivating self-motivation and independence:

Because I think a lot of the work with the teenagers is kind of almost undoing what other programs have damaged them to be [sic] . . . like a lot of them are just robots from [behavioral therapy] and what not—if they’re not wired for a question that was asked of them, they’re just screwed. So a lot of that work has to be undone and then they have to build these relationships and start filling in their developmental gaps. (Tina)

The behavioral method is mobilized not only as part of an opposition to validate instructors’ pedagogic decisions but also as a way of seeing efficacy in what they do, despite the often slow progress and meager results. If things are going slow, it is because instructors are unraveling all the bad habits instilled by the behavioral model.

While many instructors at the school did not have prior experience working with the behavioral model, they often drew on a contrast with how presumably behavioral methods would treat this or that situation to validate their own pedagogic decisions.

I’ve never seen it, so I don’t know how [behavioral therapy] is, but I would imagine that when they act out on staff, they don’t stay with them. We do. As long as we’re safe, we do. (Brenda)

Orientation toward data offers another point of contrast between the relational and behavioral models. The behavioral model is similar to other standardizing responses to uncertainty, such as evidence-based medicine (EBM; Timmermans and Angell 2001), in that it involves meticulous quantitative data collection meant to be used to monitor progress and effectiveness. Instructors, however, disparage quantitative assessment as reductionist, contrasting it with the qualitative and “human” strategies of data collection conducted at Uptown—video/audio recordings and narratives. Qualitative data is better, they argue, because it is sensitive to the uniqueness of each student, while the behavioral model’s quantitative measures cannot fully express the individuality of students:

[Behavioral therapy] is data driven to me. It’s a very well thought out methodology, in fact. It just cares almost more about filling in grids than it does about the child. The child becomes the paper. The child just becomes check offs and numbers and that’s not what children are ever . . . we still collect data by video, by narratives, because they’re not a check-off list. They learn differently than typical children, so we cannot just expect them to fit into a check-off mold. (Tina)
Some instructors, finally, find the two models to be altogether ideologically incongruent. They commend the relational model for being progressive, and dismiss the behavioral approach as “old school” in its approach toward autism, namely restrictive, judgmental, and requiring conformity—a producer of “robots.” The child-directed pedagogy, on the other hand, embraces differences and individuality:

They’re [at] two opposite ends of the world! [Behavioral therapy], I feel, is old school. . . . [T]hey don’t allow the children to kind of learn intentionally; . . . they kind of lay it out for them . . . they tell them what a normal person should be doing or saying in these moments and have them practice it and practice it and practice it to the point where they almost become robots. . . . [T]he [relational model] is basically helping the child developmentally [to] build those milestones and . . . honoring who they are as individuals and building a relationship with that. (Vivian)

Finally, the opposition between “progressive” and “old school” often seamlessly spills into a political analogy where the contrast is between democratic/liberal (that is, tolerant of diversity and individual differences) and conservative or even “Republican”:

I consider [the relational model] to be very democratic and liberal and . . . the more republican side to be [the behavioral model] because I feel like they don’t honor individualization. They just kind of have this one idea and that has to apply to every single child, but they don’t understand that every child is different, especially a child with autism. (Vivian)

This political analogy, we believe, is neither accidental nor far-fetched. As George Lakoff (2002) has shown, the language of moral politics in the contemporary United States is suffused with the metaphor of parenting (“tough love” vs. “care”), and to be “liberal” in the United States is often associated with a particular image of tolerant child-rearing that is very close to “child-directedness.” We argued in earlier sections that the ethical substance upon which the relational model works is the relationship between self and others, as well as the relationship the instructor has with herself. So when instructors depicted the relational method as “natural” and “child directed,” they were also drawing on a political opposition between commanding/dictating to the students how to behave and governing them, seeking to lead them toward self-control, maturity, and engagement on the basis of their own interests and abilities. The government of the self and of children is an ancient metaphor on which are articulated different conceptions of how the state should be governed (Foucault 2010). This relation to moral politics can explain, to a certain
extent, the findings of this paper. It is not so much that autism therapies reflect preexisting political values, or that instructors opt self-consciously to act on their political commitments. What is more likely is that the oppositions of moral politics, their metaphorical modeling upon the relation between parents and children, are a widespread prepolitical idiom that structures multiple experiences in the contemporary United States. It is, if you will, a prepolitical habitus that predisposes new entrants into the space of autism therapies to recognize its oppositions as significant and fundamental and which, as they are converted to one or another side of this space, serves as the basis for judgments of pedagogic taste and a feel for the correct pedagogic action.

Conclusions

Confronted with ambiguities at the most fundamental levels of their work, how do Uptown instructors manage the uncertainties related to their students’ diagnoses, the treatment program they are expected to deliver, and their own lack of experience? Analyzing data collected from observations at Uptown School and interviews with instructors, we argue that they cope not by altering their external conditions but by modifying themselves.

Sociological research on the medical profession analyzes the strategies that medical students and practitioners employ to contend with uncertainty. While earlier researchers disagreed whether medical education was “training for uncertainty” or “training for control” (Fox 1957, 1980; Eddy 1984; Katz 1984; Light 1979), Timmermans and Angell (2001) have argued that the opposition is better grasped as two alternatives styles of coping with uncertainty: a skeptical style alert to the irreducible limits presented by uncertainty; and a dogmatic style that reduces uncertainty by hewing closely to treatment protocols, routines, and scripts. What we found at Uptown, however, confounds the distinction between dogmatism and skepticism. Instructors who were initially in the same situation of uncertainty and self-doubt as medical interns have learned to marginalize this uncertainty by performing not “bridging work” meant to render situations more determinate but ethical work on the self, shaping it so it can thrive on the openness and ambiguity of situations. In some respects, Uptown instructors were similar to the medical trainees studied by Light (1979), who managed uncertainty by subscribing to a “school of thought,” it being in this case the “relational model.” As we saw, instructors responded to the uncertainties that pervaded their work environment by constructing dogmatic “conversion” narratives centered on their latent compatibility with the relational model, and by being quite dogmatic in their rejection of ABA. At the same time, however, Uptown instructors were more similar to Timmermans and Angell (2001) “researchers,”13 because their main strategy...
for dealing with uncertainty was not to reduce it but to marginalize and then invert its significance. By embodying child-directed traits (such as patience, flexibility, and a willingness to be led), they worked to modify themselves so they were comfortable with uncertainty, thus turning uncertainty into a resource (Shenhav 1999; Stark 2009) rather than an obstacle.

We suspect that our findings are relevant beyond the field of autism education and treatment, and that similar strategies would be found in the burgeoning field of CAM. The increased use of CAM (Eisenberg et al. 1998) and its gradual inclusion within more conventional medical protocols (Winnick 2005) suggests that medical sociologists should pay more attention to how uncertainty is managed by the providers of unconventional treatments.

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Notes

1. Fox (1980, 7–8) has described three coping mechanisms that medical students employ when confronted with uncertainties: (1) managing emotional reactions when faced by “disquieting” events and situations; (2) improving “cognitive command” by honing their technical skills, developing their medical knowledge, and improving their “probability-reasoning logic”; and (3) incorporating medical humor to make light of highly uncertain and difficult situations. There are some limited similarities between our findings and the first of these mechanisms. We found that instructors at Uptown worked on themselves and modified their emotional economy in response to the uncertainties that pervade their work. Similarly, medical students learned to regulate their own emotional reactions to challenging circumstances. Yet, the hallmark of such situations was not ambiguity, but their character as particularly stressful or distressing events, being exposed to the life-and-death character of their work. This is clearly very different from the uncertainties faced by instructors in our study, though in both cases some form of emotional labor was involved.

2. Our understanding of “ethical work” is loosely based on Foucault’s (1984; see also Martin, Gutman, and Hutton 1988) discussion of “technologies of the self.” It refers to all the means, techniques, and conscious strategies by which individuals problematize a certain part of themselves, their conduct and/or their relation to others, and work to modify it to conform or approximate to a desired goal understood as a state of perfection, moderation, self-mastery, self-control, or any
similarly valued goal. A good example would be the activities of weight-watchers or members of Alcoholics Anonymous.

3. Throughout the article, we will refer to the “behavioral model” and to “ABA” (Applied Behavioral Analysis) as if they are interchangeable. For the purposes of this article, the minute differences in nuance between different versions of behavioral therapy are unimportant. Our interviewees, as well, do not observe such nuances and refer to “ABA” or “behavioral therapy/model/approach” interchangeably. The contrast is drawn, therefore, with a group of therapies that all derive from the approach pioneered by Ivar Lovaas (1971, 1981) applying “operant conditioning” to the treatment of children with autism. In all these approaches, undesirable behaviors to be modified and skills to be acquired are broken into their smallest component units, each to be addressed separately in “discrete trials.” A trial is typically composed of a prompt by the therapist, response (or not) by the student/patient, and reinforcement (typically a food item, but there are many variations). Once a component is achieved, a new set of discrete trials starts for the next component, until painstakingly the skill is mastered or the undesirable behavior extinguished.

4. Six head teachers, three teacher’s assistants, and one transition facilitator were interviewed.

5. Three mothers and one father were interviewed.

6. A more sustained examination of the gender patterns involved in autism diagnosis and treatment is not possible in the framework of this article, and merits a separate article. A useful and perceptive examination of some of the issues involved is in Gillis-Buck and Richardson (forthcoming).

7. While enormous funds have been invested up till now in biomedical research on the prenatal, environmental, and genetic risk factors of ASD, at this time there is no definitive answer as to what is causing the condition (Centers for Disease Control and Prevention 2012).

8. Our observations were conducted before the release of DSM-5, and so were not affected by the much publicized revisions to ASD diagnostic criteria therein. Moreover, it is unlikely that these revisions would reduce the level of uncertainty faced by teachers and therapists. The gist of the revision is eliminating the distinction between named disorders such as autistic disorder, Asperger’s disorder, and pervasive developmental disorder—not otherwise specified, and replacing them with a single diagnosis of ASD modulated by degrees of severity. The essential structure of the diagnosis, therefore, as a spectrum of social communication deficits and restricted/repetitive patterns of behavior, remains unchanged. (American Psychiatric Association 2013)

9. All the names used in the quotes and vignettes are pseudonyms.

10. On the role of recognition in the formation of habitus, see Bourdieu (2000).

11. A “clicker” is a hand tally counter. In behavioral therapy, clickers are often used to keep track of quantifiable behaviors, such as self-injury or verbal/physical stereotypy.

12. “Doing floortime” is the phrase used by teachers to describe the child-directed pedagogy in practice.
13. As opposed to “librarians,” who merely consult literature, “researchers” are residents who manage uncertainty by critically evaluating medical knowledge and evidence-based studies (Timmermans and Angell 2001).

References


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