

For a Sociology of Expertise: The Social Origins of the Autism Epidemic¹

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This article endeavors to replace the sociology of professions with the more comprehensive and timely sociology of expertise. It suggests that we need to distinguish between experts and expertise as requiring two distinct modes of analysis that are not reducible to one another. It analyzes expertise as a network linking together agents, devices, concepts, and institutional and spatial arrangements. It also suggests rethinking how abstraction and power were analyzed in the sociology of professions. The utility of this approach is demonstrated by using it to explain the recent precipitous rise in autism diagnoses. This article shows that autism remained a rare disorder until the deinstitutionalization of mental retardation created a new institutional matrix within which a new set of actors—the parents of children with autism in alliance with psychologists and therapists—were able to forge an alternative network of expertise.

In his seminal *The System of Professions*, Andrew Abbott (1988, pp. 2–3, 9–20) criticized the mode of narration prevalent in the sociology of professions, which followed the ideal typical “life history” of a profession. Abbott called instead for a history not of groups but of “tasks and problems” (p. 314), a history without a protagonist in the sense that the story it told would not be governed by projecting backward the necessary formation of

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a professional group nor by presumed functional identity between profession and task. While Abbott's approach has proven quite influential and insightful, I will argue in this article that it fell short of his own call to do a history of "tasks and problems." Jurisdiction being the "link between a profession and its work" (Abbott 1988, p. 20), the focus in this approach has been on who has control and of what kind over a task, while leaving aside the question of what arrangements must be in place for a task to be accomplished and through what processes these arrangements were created. To follow Abbott's own call for a history of tasks and problems, I will argue, requires an approach that complements the analysis of jurisdictional struggles with tracing how forms of expertise—analyzed as networks that link together objects, actors, techniques, devices, and institutional and spatial arrangements (Cambrosio, Limoges, and Hoffman 1992)—are gradually assembled.²

This attempt to respond to Abbott's call by introducing even more layers of complexity would be of no utility if it cannot be shown to shed light on the problems with which sociologists grapple. Therefore, the theoretical argument will be conducted by means of an empirical case study. The question I would like to tackle is how to explain the precipitous rise—from estimated prevalence of 1 in 2,500 in 1989 to 1 in 88 currently (Centers for Disease Control and Prevention 2012)—of autism spectrum disorder (ASD) diagnoses, a group of developmental disabilities with onset typically before three years of age, involving impairments in social interaction and communication, as well as the presence of restrictive and stereotyped patterns of behaviors, interests, and activities. This is a puzzle that other social scientists have been trying to solve as well (Nadesan 2005; Grinker 2007; Bearman and King 2009; Liu, King, and Bearman 2010; Silverman 2012).

Explanations for the autism "epidemic" typically fall into two types. On the one hand, there are naturalist explanations that treat the rise in the number of ASD diagnoses as indicating a real increase in the number of cases

² There are two bodies of sociological research that could be construed as tackling the same question but that ultimately share the limitations of the sociology of professions. The medicalization literature (Zola 1972; Conrad and Schneider 1980) focuses on the process by which moral, social, or legal problems become redefined as medical problems, while the social problems tradition (Blumer 1971; Gusfield 1981; Hilgartner and Bosk 1988) analyzes processes of collective definition that frame problems as worthy of public attention. Thus, the focus in both approaches is on the question of jurisdiction—who gets to own a problem—while the emergence of problems is usually analyzed as a process of attribution. Something is a social problem, argue Hilgartner and Bosk (1988, p. 53), not because it is an objective and identifiable condition that has intrinsically harmful effects but because such effects have been collectively attributed to it. As I will argue below, the approach developed in this article, focusing on the arrangements and conditions necessary for problems to become objects of expert labor, is geared precisely to overcome this opposition between what is real/objective and what is merely attributed/socially constructed.

caused either by environmental toxicity (Roberts et al. 2007), vaccines (Bernard 2004), or even TV watching (Waldman, Nicholson, and Adilov 2006). Social constructionist accounts, on the other hand, explain the rise in the number of ASD diagnoses as a function of changed diagnostic criteria; increased awareness of autism among parents, teachers, and experts; greater availability of services from 1991 onward when autism was added to the Individuals with Disabilities in Education Act (IDEA); the interests of parents in a less stigmatizing diagnosis that affords greater access to services; lobbying on the part of parents' organizations; and networks of influence among relatively privileged parents living in proximity to one another. All these combine to increase autism prevalence primarily through diagnostic accretion and substitution from mental retardation (MR) to the "low functioning" pole of the spectrum, and from language and learning disabilities to its "high functioning" pole (Fombonne 1999; Croen et al. 2002; Prior 2003; Yeargin-Allsopp et al. 2003; Shattuck 2006; Coo et al. 2008; Grinker 2007; Bishop et al. 2008; King 2008; Bearman and King 2009; Caruso 2010; Liu et al. 2010).³

Both types of explanations, however, are unsatisfactory. Naturalist explanations lose much of their plausibility when one learns that diagnostic criteria for autism had been successively broadened just before the epidemic began—first in 1987, with the publication of DSM-III-R, then in 1994 with DSM-IV (Grinker 2007).⁴ To this one must add that ASD is extremely heterogeneous. To give the reader a sense of this heterogeneity, as well as the range of symptoms that get classified as ASD, I draw below on DSM-IV (1994; see the appendix) diagnostic criteria for autistic disorder to describe four distinct types, loosely inspired by Wing and Gould (1979):

³"Diagnostic accretion" means that a child with MR diagnosis acquires also an ASD diagnosis as comorbidity. "Diagnostic substitution"—in a strict measurable sense—means that a child gets his diagnosis changed from MR to ASD. In this article, I am using the term "diagnostic substitution" in a less precise and more general sense of a child receiving ASD diagnosis who in the past would have been likely to be diagnosed as MR. While it is very hard, perhaps impossible, to accurately estimate such substitution, the foregoing historical analysis is designed to show that it is a highly plausible interpretation of the quantitative evidence.

⁴The DSM-III-R criteria dropped the requirement that onset of symptoms would be before 30 months of age. The diagnostic criterion of "complete lack of social responsiveness" was changed to simply "abnormal social responsiveness." Most important, as we shall see later, the internal structure of the three main diagnostic criteria was changed to reflect the understanding of autism as a spectrum. Children could receive the diagnosis by scoring on anywhere between 6 and 12 items that were arranged in decreasing order of severity. This structure was kept in DSM-IV (though the early onset criterion at 36 months was reinstated—see the appendix), which added, however, the diagnosis of Asperger's disorder for children whose intelligence and speech development were normal but who manifested deficits in social interaction.

1. In the most severe cases, the trio of impairments in communication, social interaction, and “restrictive and stereotyped pattern of behavior” manifest as “total lack of spoken language” and profound aloofness and indifference in most situations, accompanied by repetitive self-stimulatory behaviors such as hand flapping and head banging. There is almost certainly comorbidity with MR (currently estimated to be from 38% to 62% of the autism caseload) and potentially also epilepsy. At this level of severity, the male to female gender ratio is about 2:1 (Volkmar, Szatmari, and Sparrow 1993; Amiet et al. 2008; Centers for Disease Control and Prevention 2012).
2. At a lower level of severity, children may be able to speak, but in stereotyped and idiosyncratic phrases, often repeating how they were addressed without reversing the pronouns. Yet, their parents often report that they developed normally during the first 12–18 months of life and then suddenly regressed. They are typically indifferent toward other children but not toward adults, whose company they eagerly seek, though failing to use nonverbal communicative behaviors such as eye-to-eye gaze to regulate the interaction and insisting inflexibly on the repetition of certain routines. As a rule, the male to female ratio increases as severity decreases, though exactly how much for this type is impossible to estimate.
3. At yet a lower level of severity, children would be able to speak and learn, and would not be diagnosed with MR but would evince an “unusual learning profile indicating scatter in cognitive skills” (CDC 2009, p. 15). They might have exceptional skills in arithmetic but fail miserably at reading comprehension. They would be verbally and socially passive, seemingly unable to “initiate or sustain a conversation with others” though amiable when approached and affectionate with their parents. They would be content to watch spinning wheels over and over again, yet would display unusually strong reactions to specific noises or textures, and the explosive tantrums that follow often earn them a concurrent diagnosis of “emotional disorder.” They could also be suffering from some gastrointestinal or sleep disorder.
4. Finally, at the other end of the spectrum would be mostly boys—the male to female ratio at this level of severity is the oft-repeated 4 to 1 or higher (Gillberg 1998; CDC 2012)—who are “active, but odd” (Wing and Gould 1979, pp. 14–15), namely, they are highly verbal and intelligent, but they tend to be intensely preoccupied with a relatively narrow set of interests such as train schedules; and they make active social approaches but in inappropriate ways, seeming to lack emotional reciprocity. At a younger age, these boys would display a “lack of varied, spontaneous make-believe play.” Later, they

may receive a concurrent diagnosis of attention deficit hyperactivity disorder (ADHD).

This heterogeneity has led many scientists to suggest that autism is not really “a single syndrome with highly variable severity” but “an aggregate of specific disorders that share some common [behavioral] features” (Rapin 1994; Ronald et al. 2006; Szatmari et al. 2007; Waterhouse, Fein, and Nichols 2007, p. 308; Abrahams and Geschwind 2008; Pettus 2008). It strains credulity, therefore, to argue that some natural cause has increased the prevalence not of one syndrome but of a whole aggregate of disorders, yet of only these disorders and not related others (most importantly MR, with which ASD shares practically all genetic loci identified thus far [Betancur 2011]).

Social constructionist explanations, by comparison, are more plausible but, ultimately, just as unsatisfying. They do not solve the puzzle of the autism “epidemic” but merely push back the burden of explanation. If changed diagnostic criteria are the proximate cause, for example, the question obviously becomes why were they changed? Was it because science has now come to understand autism better or because of “medicalization,” that is, because the psychiatric profession sought to expand its jurisdiction and in the process redefined the odd and socially awkward as a social problem? The reader can see that the opposition between naturalist and social constructionist explanations has now been resurrected within this line of explanation. The debate has not been resolved or pushed forward but is replicated in a quasi-fractal fashion (Abbott 2001).⁵

In what follows, I would like to advance a different explanation for the autism “epidemic,” one that avoids this fractalization by inverting the original question. Instead of asking why autism is more prevalent now, I suggest that we ask first why autism was rare in the past. This line of questioning immediately draws our attention toward the conditions that are necessary for autism to be identified, differentiated, and diagnosed on a large scale. As we shall see below, as long as very young children were institutionalized in large residential institutions for the retarded there was hardly any way, or point, to distinguish between autism and retardation. This is why I will argue that the deinstitutionalization of mental retardation—a lengthy process that began in the early 1970s and lasted at least two decades—was a key cause leading to the autism epidemic. Deinstitutionalization erased the old categories that reflected the needs of custodial institutions (feeble minded,

⁵ The essential problem can be stated as follows: social constructionist theories argue that something becomes a problem not because of its objective nature but because of subjective attribution. Since many attributions are possible, they need to posit a selection mechanism that decides which attributions fare better. The selection mechanism itself may be construed objectively—involving nature, truth, efficiency, etc.—or subjectively as the power of the medical profession to impose its definitions (“medicalization”) or as competition for public attention (Hilgartner and Bosk 1988), and so on to infinity.

mentally deficient, moron, idiot, imbecile) while creating instead a new institutional matrix—community treatment, special education, and early intervention programs—wherein autism could be identified, differentiated, and multiplied.

Deinstitutionalization, however, was not an external cause, a *deus ex machina*, changing the trajectory of autism from without. From the moment that autism was first named and diagnosed by Leo Kanner in 1943, it represented a problematization of the distinction between mental retardation and mental illness. Its history was one of “reiterated problem solving” (Haydu 1998), namely, how to define, observe, and intervene in a domain of objects that were neither illness nor retardation. While Kanner made the initial move in this series of reiterated problem solving, he could not turn the problem he sketched into a task amenable to expert intervention. This was not because he lacked jurisdiction—child psychiatry enjoyed relatively unchallenged jurisdiction over childhood problems at the time—but because he could not assemble the necessary arrangements and actors to create a network of expertise adequate to this task. In a sense, as we shall see later, he was limited precisely because of the jurisdiction enjoyed by child psychiatry.

In this series of reiterated problem solving, deinstitutionalization was an extremely significant episode because it provided the ecology within which an alternative network of expertise could be assembled. The key actors in assembling this network were not child psychiatrists, but the parents of children with autism. Seeking to modify the relations within Kanner’s network of clinical expertise, which expropriated their knowledge and stigmatized them as “emotional refrigerators,” they set up alternative mechanisms of data collection and experimentation, which bypassed the clinician. To do so, they allied themselves with behavioral psychologists and occupational therapists who, due to their peripheral position, developed therapies that blurred the distinction between mental illness and retardation as well as the distinction between lay and expert. It was this new actor-network, composed of arrangements that blurred the boundaries between parents, researchers, therapists, and activists, that was finally able to “solve” the problem. The combination of this new actor, the new ecology created by deinstitutionalization, and the capacity of the therapies to secure the cooperation of the patients themselves, is what led to the autism “epidemic.”

The next section develops the theoretical approach guiding this analysis by drawing a series of contrasts between the sociology of professions and the sociology of expertise. The main point is not to demonstrate the superiority of one approach over the other but to argue for their complementarity, namely, that only by combining the analysis of how networks of expertise are assembled with jurisdictional analysis can we conduct a history of tasks

and problems. It is followed by a necessarily abbreviated historical narrative substantiating the argument made above about the causes for the autism “epidemic” while demonstrating how the theoretical approach developed here could inform a history of tasks and problems.

FROM THE SOCIOLOGY OF PROFESSIONS TO THE SOCIOLOGY OF EXPERTISE

Perhaps it is best to start with the most obvious point and build upon it. The sociology of professions—even in its broadest rendition—is too narrow to deal with what Abbott’s subtitle termed “the division of expert labor” in contemporary society. Jurisdictional struggles are waged not only between established professions but also between any groups that can lay a claim to expertise, whether on the basis of a body of abstract knowledge (Abbott’s minimalist definition of professions), control of technique (what he calls “crafts”), or perhaps other bases (Abbott 1988, p. 8). Moreover, recent studies have documented in ample detail that lay people as well may play an important role in addressing technical problems that are normally understood as professional jurisdiction (Epstein 1995, 1996; Wynne 1996; Rabeharisoa and Callon 2004).⁶

So the first point is that a history of tasks and problems must be able to take into account the wider scope of actors designated by the term “expertise.” But there is more to the term “expertise” than just a wider scope. It derives from the Latin root *experiri*, “to try,” and typically means know-how, the capacity to get a task accomplished better and faster because one is more experienced, “tried” (*expertus*; Williams 1976). “Profession,” on the other hand, derives from the term for the vows or public declarations taken upon entering a religious order. Let me suggest, therefore, another advantage of the term “expertise”: it permits us to make an analytical distinction between *experts* and *expertise*; between, on the one hand, the *actors* who make claims to jurisdiction over a task by “professing” their disinterest, skill, and credibility and, on the other hand, the sheer *capacity* to accomplish this task better and faster.

⁶Indeed, it is quite possible that the word “expertise” has come into wide usage precisely because of this historical change and the widened scope of jurisdictional struggles. Using Google Books Ngram Viewer tool, I found that the term “expertise” is quite recent, its wide usage dating from the mid-1960s, while the term “expert” entered public discussion much earlier, 1880–1920 (see http://books.google.com/ngrams/graph?content=expert%2C+expertise%2C+profession&year_start=1800&year_end=2000&corpus=0&smoothing=3). I would argue that the 1960s are when the relative dominance enjoyed by the established professions during the first half of the 20th century was challenged. Once the number of contenders for expert status increased and the basis for their claims became more heterogeneous, the word “expertise” began to be used, because the question was how to determine whose claim is legitimate.

In terms of this distinction, the sociology of professions has been primarily a sociology of experts and has had comparatively little to say about expertise. As Collins and Evans (2007, p. 2) note, the sociology of professions typically treated expertise as an attribution, a quality that the experts possessed by virtue of recognition granted by significant others and thereby reducible to their interests, role sets, and modes of organization. This emphasis on attribution and the struggle for recognition is also characteristic of studies of medicalization and the construction of social problems (Zola 1972; Aronson 1982). Hence the focus of the sociology of professions on organizational form: credentialing, licensing, and the formation of professional associations and lobbying outfits are all calculated to secure the recognition of significant others and enforce it with a legal mandate. This has been a hugely insightful and profitable hypothesis, but it is also partial. A sociology of expertise, on the other hand, would begin from the recognition, as Nikolas Rose (1992, p. 356) put it, that “the social consequences of psychology [read expertise] are not the same as the social consequences of psychologists [read experts],” that is, that experts and expertise are not reducible to one another and require two distinct, though combinable, modes of analysis.

If expertise stands for the capacity to accomplish a task better and faster, it may seem obvious that it should be analyzed, therefore, as a real and substantive skill possessed by an individual, typically by virtue of being socialized into a group of similar experts. This is the approach that has been taken by Collins and Evans (2002, 2007) as well as by Dreyfus and Dreyfus (1986, 2005). Beginning from Wittgenstein’s critique of the notion of “following a rule,” they emphasized the “background of practices which are the condition of possibility of all rule-like activity” (Dreyfus 1979). While the acquisition of expertise begins with learning a set of rules, what differentiates the true expert from the merely competent, or “contributory expertise” from “interactional expertise,” is the embodied and tacit mastery of this background of practices, the “form of life” shared by the “core set.”

While this approach is much closer to the etymology and colloquial meaning of “expertise,” ultimately it is unsatisfactory. The first point is that treating expertise as substantive skill possessed by an individual or a group inevitably involves the sociologist in playing the normative role of deciding who is or is not an expert, assigning differential worth to competing claims and performances. Collins and Evans (2007) embrace this normative role and claim that in a world of vaccine scares and global warming controversies it is indispensable that someone play this role. I have severe doubts, however, that sociologists can play this role without themselves becoming embroiled in a controversy about their own expertise and credentials. Put differently, by assuming this normative role Collins and Evans implic-

itly acknowledge that expertise is not only a real and substantive skill but also a claim and an attribution, only they present themselves as possessing the expertise necessary to make the correct attribution.⁷ Indeed, as is obvious in the case of Dreyfus, the substantivist approach to expertise is not only a descriptive account of what experts do but also a spirited defense of human experts against encroachments on their jurisdiction from artificial intelligence and expert systems. If it was not Collins or Dreyfus making these claims about expertise involving “an understanding of rules that cannot be expressed” (Collins and Evans 2007, p. 17), but a doctor testifying in court, wouldn’t we be suspicious?

The second, more analytical, point is simply this: if we want to account for the superior and speedy execution of a task it is not enough to focus on the actors and their skills. Clearly, a full account of anything but the most rudimentary task must include, at a minimum, also the tools and devices used in the performance of the task (and therefore also the makers of these devices). Very likely it requires also analyzing the contributions made by other experts, front-line workers, perhaps even lay people, and the mechanisms by which their cooperation has been secured. The problems that the task addresses are foregrounded and made observable and actionable by certain institutional and spatial arrangements (including regulatory agencies and standards), while other arrangements obscure them from view or impede addressing them. Finally, the observations and interventions of the experts are organized by means of certain concepts, and these too may prove important when accounting for the way in which a problem is made relevant or a task is executed. This complex make-up of expertise is typically much more evident when it is still “in the making” and alternative devices, actors, concepts, and arrangements are still viable candidates for formulating the problem or addressing it. Once a form of expertise has been developed, however, this complex make-up is obscured by a process of “black boxing” and standardizing that makes it appear as if expertise is embodied by the expert (Cambrosio et al. 1992, pp. 347–49).

Put differently, if—as the substantivist approach emphasizes—any rule-like performance is only explicable by reference to a “background of practices” that are its “condition of possibility,” then a full explication of expertise must explore indeed this background of practices and the social, material, spatial, organizational, and conceptual arrangements that serve as its conditions of possibility. This approach has been pioneered by Foucault (1972, 1973) and underlies a great deal of the work in science studies, especially actor-network theory (ANT; Latour 1987, 1988, 1999; Cambrosio et al. 1992; Keating and Cambrosio 2003; Lakoff 2005).

⁷ Put differently, this is the mirror image of the problem faced by social constructionist theories and leads to similar fractalization.

So there are two distinct questions and modes of analysis. On the one hand is the question of jurisdiction, namely, who has control and to what degree over a set of tasks (Abbott 1988, p. 20). On the other hand is the question of expertise, namely, what arrangements must be in place for a task to be accomplished. This distinction extends to the mode of historical investigation and narration. Abbott suggested that historical investigation into the emergence of professions should start with neither a group, nor a set of tasks, as neither is a given, stable entity preceding the formation of the contingent link between them, namely, the jurisdiction. Instead, one must trace “the assemblage of various sites of difference . . . into a set of boundaries in the topologically strict sense” (1995, p. 872). Each site of difference, or “proto-boundary,” is an event, arising out of local interaction and potentially ephemeral. The central question, therefore, is how these events are “yoked together” and acquire stability as a jurisdictional boundary between those who do, and those who do not, control a particular set of tasks (p. 868). This is a nonteleological, fully “eventful,” history of professions, but note that it is focused on the question of how jurisdictions are formed, that is, how the “who” and the “what” (the “things”) of a relationship of control (the “boundaries”) are formed.

A history of tasks and problems, however, should not be reduced to tracing the assembly of jurisdictions. A complementary line of investigation begins with the expert performance or statement itself, understood as an event (Foucault 1972, pp. 88–105; Summerson Carr 2010), and asks not who is authorized to do or say it but what conditions are necessary for this event, and not another, to have taken place. What are the conditions necessary for this event to be repeated in regular fashion? Finally, what are the conditions and arrangements necessary for the statement/performance to be disseminated, to become an “immutable and combinable mobile” (Latour 1987, p. 227) that can be transported from one site to another without deformation? In this way, the process of “black boxing” and standardization can be reversed to trace the other actors (even if they do not control any identifiable part of the task at hand), equipment (especially transcription devices), institutional and spatial arrangements, and concepts of which a form of expertise is composed.

Because it is easier to understand a tool by using it, I postpone further discussion of this mode of analysis to the next section, where I will attempt to demonstrate that it can shed light on the causes for the autism “epidemic.” For the moment, I would simply like to make a few points about it. First, while a history of the formation of jurisdictions analyzes the yoking together of differences into a boundary, a history of expertise analyzes the assembly of complementarities into an apparatus (*dispositif*) that produces, reproduces, and disseminates expert statements and performances. Put differently, if we follow the event of expert statement or performance to the

conditions and mechanisms involved in its formulation, replication, and dissemination, we end up with a view of expertise neither as an attribution nor as a substantive skill but as a network connecting together not only the putative experts but also other actors, including clients and patients, devices and instruments, concepts, and institutional and spatial arrangements (Cambrosio et al. 1992, p. 345).

Second, the distinction between the two aforementioned questions and modes of historical analysis is analytical. As we shall see, jurisdictional struggles often play an important role in setting up or impeding the conditions necessary for expert statements and performances to be formulated, repeated, and/or disseminated. By the same token, the process by which local differences are yoked together into a jurisdictional boundary can be significantly impeded or furthered by the relations of complementarity needed to forge a network of expertise. We shall see later how this observation applies to Kanner's attempt to use autism as a way to unify the jurisdiction of child psychiatry.

The third point is that this mode of analysis is suited both for an ethnographic analysis of expert work practices, provided that it is historically informed, and a historical genealogy of how a form of expertise emerged, provided that it is ethnographically motivated. This study belongs to the second genre, but the main point is that by treating the expert statement/performance as a historical event and tracing its conditions of possibility, the lines between ethnography and history are blurred. Opening the black boxes of which a form of expertise is made and tracing the network of associations contained therein, one is going both backward to "expertise in the making" (Cambrosio et al. 1992) and "sideways" to increasingly obscure and ignored aspects of expert work practices.

Thinking of expertise as network, I believe, can also shed light on one of the central debates in the literature about the character of expert knowledge, namely, whether it is practical or abstract. As we saw earlier, when Collins and Evans (2007) or Dreyfus and Dreyfus (2005) treat expertise as a substantive skill, they emphasize the embodied and tacit mastery of practices that serve as background for rule-like activity. When sociologists of professions, on the other hand, treat expertise as attribution, they underline abstraction as the distinctive way in which professions make claims. As Abbott argues, while crafts compete by controlling techniques, professions compete by controlling the abstractions that generate techniques, and this is what makes professions ultimately stronger: "Only a knowledge system governed by abstractions can redefine its problems and tasks, defend them from interlopers and seize new problems" (Abbott 1988, pp. 8–9).

This opposition is mediated by means of auxiliary concepts. Collins and Evans (2007) introduce the concept of "interactional expertise" specifically

because they recognize that expert knowledge exists also in an explicit, discursive form composed of more general propositions. Similarly, Abbott (1988, pp. 102–3) argues that too much abstraction spells weakness and renders a profession unable to defend its jurisdiction from interlopers. The relationship between abstraction and the control a profession is able to exercise over its jurisdiction is an inverted U-curve with the most control obtained at some “optimal” level of abstraction. This is very insightful but ultimately indicates that the concept of “abstraction” is relying on an unspecified auxiliary concept to explicate the role abstraction plays in jurisdictional struggles. The problem is that we have no way of knowing what is the optimal level of abstraction unless by hindsight, unless by the fact that the group was successful in defending its jurisdiction. Instead of gesturing at hypothetical values such as “too much,” “too little,” or “optimal,” we need a way of taking abstraction apart and investigating what it is made of.

One way of doing so is to replace “abstraction” with the notion of “immutable and combinable mobile” and investigate the chain of transcriptions by which an expert statement or performance is conveyed along the network toward its “centers of calculation” (Latour 1987, 1999). Each link in the chain consists of altogether practical devices and concrete forms of reasoning, yet each transcription means that the statement/performance loses certain qualities it possessed before and acquires new ones, until it gradually becomes mobile, combinable and “liquid” in the sense connoted by the term “abstraction” (Lakoff 2005). This approach, moreover, permits us to make qualitative distinctions between different forms of abstraction. Abstraction in laboratory science, for example, consists of a fully two-way chain of transcriptions. While each transcription subtracts references to local and practical details it does so in a way that permits one to trace it backward to these details. Legal abstraction, on the other hand, consists of only a one-way chain of transcriptions, with the possibility of returning to local details intentionally cut off because of the supreme value of preserving legal stability (Latour 2010). Abbott’s original insight about the optimal level of abstraction could, therefore, be preserved by investigating how long these different chains of transcriptions are; whether they can be traced backward or not; what qualities are added and subtracted along the way; how secure are the links, the transcriptions, from being taken apart by challengers; what other actors, devices, and arrangements were involved in constructing each link; and how their cooperation is secured.

The final distinction I would like to draw is between how the sociology of professions and the sociology of expertise each conceptualize and analyze power. In the sociology of professions, power is analyzed as a set of mechanisms designed to control the supply of and demand for professional services. The origins of this approach are in Weber’s (1963) classic analysis of the dynamics of religious domination as a struggle over the supply and demand for

salvation goods. Among sociologists of professions, Friedson (1970, 1986, pp. 63–73), for example, distinguishes between occupational credentialing (licensing, educational credentials, certification by professional associations) that controls the supply of professional services and institutional credentialing (chartering, accreditation) that controls the demand for professional services. Similarly, abstraction plays such an important role in Abbott's (1988) analysis because it stands as shorthand for mechanisms that reduce the dependence of the professional group on a specific context, or technology, or group of clients and allow it to maximize (if "optimal") control over demand for its services. Power, therefore, is understood under the twin forms of monopoly and autonomy. Monopoly over its knowledge base permits the professional group to control the supply of its services, while autonomy in defining the significance and relevance of its knowledge permits it to control the demand for its services.

Weber's (1963) original analysis, however, was more subtle. For a priesthood to exercise long-term domination over the laity, it needs to balance its monopoly over the interpretation of the scriptures (i.e., control over supply) and the emphasis on otherworldly salvation (i.e., control over demand) with pastoral ministering that involves instructing and educating the laity (to combat the influence of prophets) and supplying it with everyday salvation goods (to combat the competition from magicians). Put differently, if demand is defined too autonomously, the services offered by the experts become irrelevant to the needs of their clients; while if supply is controlled by a strict monopoly, expert knowledge becomes meaningless for the clients. In both cases, the putative attributes of power prevent a certain give-and-take—exchange or dialogue—that is crucial for securing the cooperation of the clients.

When power is analyzed not from the point of view of the actors, the group of experts, but from the point of view of expertise, that is, the point of view of putting together a network that produces, reproduces, and disseminates expert statements or performances, the focus shifts indeed to the mechanisms that secure the cooperation of the clients, as well as the other parties involved. Even in the textbook case of professional monopoly, namely, medicine, conversation analysts have documented the dialogic structure of the medical interview, with the outcome of diagnosis and prescription crucially dependent on the interaction between doctor and patient (Heritage and Maynard 2006), while Gadamer (1996, p. 111) argued that "doctors are becoming increasingly aware of the extent to which their work is dependent on the contribution made by the patient." Power then consists in exactly the opposite of monopoly and autonomy, namely, "generosity" and "co-production." By "generosity" I mean, following Rose (1992), the opposite of monopoly, namely, that a network of expertise, as distinct from the experts, becomes more powerful and influential by virtue of its capacity to

craft and package its concepts, its discourse, its modes of seeing, doing, and judging, so they can be grafted onto what others are doing, thus linking them to the network and eliciting their cooperation. Psychological expertise, as distinct from psychologists, is strengthened not by restricting the supply of expertise but by extending it, so that managers or educational experts, for example, borrow freely from its conceptual apparatus and draw on its methods to boost their own authority. By “co-production” I mean, following Rabeharisoa and Callon (2004), the opposite of autonomy, namely, that a network of expertise becomes more powerful and influential by virtue of involving multiple parties—including clients and patients—in shaping the aims and development of expert knowledge. Medical expertise, as distinct from medical doctors, is strengthened by letting patients take part in decisions about the direction of research and the aims of medical intervention, that is, by allowing the demand for medical expertise to be coproduced. In both cases, power consists not in restriction and exclusion, but in extension and linking (Foucault 1975, 1976).

The point of these considerations is not to refute the valuable analyses of professional monopoly and autonomy but to suggest that the power of experts and the power of expertise require different modes of analysis and may be linked to one another in complex and surprising ways. Epstein (1995, p. 424) noted the irony attending the struggles of AIDS activists, who, even as they won credibility as experts and managed to introduce important modifications in trial design, also found themselves accused of being co-opted and furthering the agenda of the medical establishment. Could we not say, then, that even as the power of the experts, the monopoly and autonomy of medical doctors, was diminished, the power of medical expertise was in fact augmented by the activists because now “people with AIDS and HIV infection would willingly participate in the trials and conform to the protocols,” that is, now there was a mechanism of exchange that secured patients’ (and experimental subjects’) cooperation? Could we not say the same about the recent trend in self-diagnosis, greatly assisted by the Internet and by the spread of evidence-based medicine? Doctors may lose jurisdiction, but the network of medical expertise is extended via generosity and dialogue. A similar argument has, in fact, been made by Whooley (2010) about the DSM: by making psychiatric diagnosis transparent and standardized, it has weakened the autonomy of individual psychiatrists, but it has greatly increased the authority of psychiatry or, in my language, has extended and strengthened the network of psychiatric expertise.

By the same token, monopoly and autonomy may serve to prevent the extension of a network of expertise and weaken it. Given that expert performances crucially depend on dialogue and exchange within networks of expertise, monopoly must be understood not only with respect to occupational credentialing but also as a local feature of the network, how it arranges the

Origins of the Autism Epidemic

TABLE 1
DIMENSIONS OF THE CONTRAST BETWEEN THE SOCIOLOGY OF EXPERTISE AND THE
SOCIOLOGY OF PROFESSIONS

	Sociology of Professions	Sociology of Expertise
Scope	Limited to professions and would-be professions	Inclusive of all who can make viable claims to expertise
Mode of analysis	Expertise reducible to the experts' interests and worldviews	Experts and expertise distinguished as two different modes of analysis
What is privileged?	Organizational and institutional form: credentialing, licensing, association, etc.	What experts actually do. The capacity to perform a task better and faster than others
Question	Jurisdiction: who has control over a task?	What does it take to accomplish a task?
Mode of historical investigation and narration	How local differences are yoked together into a jurisdictional boundary	How complementarities are assembled into an apparatus that produces expert statements/performances
What is expertise?	Attribution, a formal quality reducible to actors' interests	A network connecting together actors, devices, concepts, and institutional and spatial arrangements
Abstraction	The most distinctive characteristic of professions is their possession of esoteric, abstract, decontextualized knowledge	Abstraction is shorthand for a chain of practical transcriptions. Different forms of expertise abstract differently, because their chains are different
Account of power	Maximal monopoly and optimal autonomy	Dynamic interdependence between monopoly, autonomy, generosity, and coproduction

flows of information and credibility. To possess a monopoly means to occupy an “obligatory point of passage” (Latour 1988, pp. 43–49) to which flow all the information and contributions from the other nodes of the network. As we shall see in the next section, this was the position occupied by Kanner, the discoverer of autism, in the network of clinical expertise. Yet precisely because of this arrangement, Kanner lacked mechanisms to secure the cooperation of the clients—specifically the parents of children with autism. It was only when the parents challenged the authority and credibility of the clinician and rearranged the relations within the network around circuits of generous exchange and dialogue that autism expertise was able to extend itself and become strong.

Table 1 summarizes the set of contrasts I drew in this section between the sociology of professions and the sociology of expertise. In the following section, I propose to narrate the history of autism expertise and explain the

causes of the contemporary epidemic by following the event of an expert statement backward to the conditions and mechanisms necessary for its formulation, replication, and dissemination.

TRACING THE STATEMENT

As noted earlier, there is a great deal of agreement even among medical researchers that the proximate cause for the autism epidemic were the changes in diagnostic criteria for ASD in DSM-III-R (1987) and DSM-IV (1994). The latter are presented in the appendix. Instead of treating them as evidence for psychiatric jurisdiction over autism, I would like to treat them as an expert statement and ask what conditions permit one to formulate this statement, repeat it, and put it into wider circulation. What is the “network of production and stabilization” upon which the existence of the statement in its repeatable, mobile, and combinable materiality is contingent (Lakoff 2005, p. 32)?

This is, as I said earlier, an ethnographically motivated history. The data it draws upon are primarily historical and consist of secondary sources about the treatment of mental retardation, autism, and childhood schizophrenia in the United States from 1943—when autism was first reported—to the present. It is also supplemented by documents from the archive of the National Society for Autistic Children (NSAC) at Washington, D.C. (1965 to the present) and other parent-generated sources such as autobiographies, the “Parents Speak” section of the *Journal of Autism and Developmental Disorders* (1971 to the present), and the online archive of the newsletter of the parent-based *Autism Research Institute* (1986–2006). While this research was ongoing, I was also involved with a research group that conducted 35 interviews with parents of children with autism, observed multiple diagnostic and therapeutic sessions, and trolled the vast terrain of autism-related online discussion groups and blogs. The data from this more contemporary research are not reported here in any systematic fashion, but they have motivated the questions I ask of the historical data and the lines of investigation pursued.

Between Mental Illness and Mental Retardation

Examining DSM-IV diagnostic criteria in the appendix, we can ask: What is this statement about? We are told that it is about a “disorder,” or several distinct “impairments,” or about “abnormal functioning” (A1, A2, B), but alternatively that it is also about quite specific “delays” (A2a, B) and behaviors “inappropriate to developmental level” (A1b), with this point about the disorder being “developmental” underscored by the requirement that onset be prior to age three (B). Some of these delays overlap considerably

with a global cognitive deficit (A2a), but others do not (A1b). Moreover, the format of a checklist makes the presence of the condition a matter of relative degree (6 of 12, etc.). It thus militates against identifying it with mental retardation yet makes it possible for ASD and MR to be concurrent diagnoses. Primacy is implicitly given (by priority) to an impairment in “social interaction,” but the terms used to describe it—“use,” “behaviors” “regulate,” “reciprocity”—studiously avoid implication of an emotional disorder or psychosis. In short, for this statement to be formulated it needs to exist in relation to a correlative domain of objects (Foucault 1972, pp. 40–49, 91) that are “developmental disorders” or “developmental disabilities”; that is, they are neither mental illnesses nor MR but in hybrid fashion combine some elements from each. This directs the analysis to the institutional conditions that are necessary to make such objects observable and differentiable. In particular, it led me to look at the deinstitutionalization of mental retardation in the 1970s as a crucial watershed moment. The term “developmental disabilities,” in fact, was first used in 1970 by Congress as part of the legislation that began the process of deinstitutionalization (Akerley 1979, p. 222).

From this point of view, the answer to the question why autism was rare in the past is that the institutionalization of children deemed “mentally retarded” acted as a barrier to the identification and differentiation of autism. Without engaging in dubious “retroactive diagnosis,” it is still possible to state that contemporaries thought that there were many autistic children institutionalized as mentally retarded (Kanner 1943, p. 33; 1949, pp. 11, 27–28; Rimland 1964, p. 13; *Medical World News* 1966), and they offered some anecdotal evidence to support this claim (Kanner 1971, p. 144). The more important point, however, is that the institutional matrix of custody was simply indifferent to the distinction between MR and autism. IQ testing typically played a marginal role in the process of commitment (Norsworthy 1906, p. 77; Kanner 1949, p. 3; 1964, pp. 122–23; Wallin 1949, pp. 43–62; Clausen 1966, pp. 731, 741–42), which instead focused on the social and legal fact of “social incapacity” (Tredgold 1947, pp. 1–6; Wallin 1949, pp. 20–36; Noll 1995, pp. 30–33). The very concept of mental deficiency, to be precise, was a medicolegal interpretation of the practice of locking up those who were “socially incapable” and from this point of view the distinction between autism and MR was meaningless. Put differently, since the observations and interventions of the experts were organized by means of the concept of “social incapacity,” the problem of autism could not be formulated within the institutional matrix of custody. Moreover, the institutional and spatial arrangements of custody offered no basis for observing or differentiating autism since overpopulation and neglect at the residential institution produced what looked like autistic symptoms on a massive scale—withdrawal, indifference, and self-stimulatory behaviors were widely understood to be reac-

tions to institutional environments seen also in psychiatric patients or prison inmates (Spitz 1945).

Autism, consequently, was discovered by Kanner on the margins of the institution. In his seminal article he presented the cases of 11 children, of whom he said "several . . . were introduced to us as idiots or imbeciles, one still resides in a state school for the feeble-minded, and two have been previously considered as schizophrenic." All 11 children were white and middle class. Crucially, their parents brought them to Kanner because they disputed the diagnosis of feeble-mindedness given to their children. Kanner concurred: "Even though most of these children were at one time or another looked upon as feeble-minded, they are all unquestionably endowed with good *cognitive potentialities*" (Kanner 1943, pp. 33, 39).

Autism, put differently, was the way in which Kanner sought to problematize the prevailing conceptual, institutional, and jurisdictional distinction between mental retardation and mental illness. Illness was opposed to retardation as a form of social incapacity that was temporary and rectifiable. Tredgold (1947, p. 1) likened the mentally ill to a person in "temporary financial embarrassment," while the mentally deficient he compared to the poor who never had any possessions, that is, the first had a right to be restored to the sanity they once possessed and "good potentialities" to do so, while the latter did not. The treatment of mental illness was "restorative" in the sense that it aimed at a "cure," that is, at a spontaneous restoration of the native powers of the ill person that acts as a multiplier of however much time and resources were invested in treatment. Care for the mentally retarded, on the other hand, was deemed nonrestorative. The condition was inborn, so there was no prior state to be restored, and, more important, one could not count on a multiplier effect, since there was no "good cognitive potential." Retardation is not illness, declared a psychiatric textbook, but simply slowness, like a bottle that is filled through a clogged funnel (Langone 1974). Consequently, there would be diminishing returns for the time and effort of intervention. Treatment, therefore, aimed not at a cure but at the minimum necessary for enlightened custody.

Jurisdictionally speaking, the small group of psychiatrists who served as superintendents of residential institutions for the retarded and played a leading role in the American Association on Mental Deficiency (AAMD) were relatively isolated from the mainstream of the profession that dealt with mental illness. This was especially true when it came to the treatment of children. Despite the initial focus of child guidance on "saving" immigrant and lower-class children liable to become delinquent, by the 1930s there was a fairly clear jurisdictional division between the child guidance clinics dealing with the behavior problems of the middle-class child, typically understood to be caused by emotional conflict and correctable by dynamic therapy (Kanner 1964, pp. 141–42; Jones 1999, pp. 7–8; Nehring

2004, pp. 371–72; Nadesan 2005, pp. 44–45, 58–73), and the residential institutions for the retarded taking in the “socially incapable,” typically adolescent “morons” from the lower rungs of society, whose feeble-mindedness was understood to be a congenital “organic defect” predisposing them to crime and sexual promiscuity (Malzberg 1952, p. 35; Trent 1994, pp. 141–81; Noll 1995, pp. 33–35; Kline 2001; Castles 2004, pp. 352–53; Jones 2004, pp. 322–23, 348, n. 41).

As the founder of child psychiatry in the United States, Kanner saw this division of labor as a major obstacle. While he worked squarely within the tradition of child guidance and was the first director of the first Child Psychiatry Clinic in the United States at Johns Hopkins Hospital, he also insisted that “it’s a luxury . . . to give child guidance only to intelligent children” and that “occupation with mental deficiency” is one of the “integral functions” of child psychiatry (Kanner 1964, pp. 142–43). At the same time, he also thought it was high time to modernize the field of mental deficiency and recognize that the feeble-minded were not a homogeneous group (Kanner 1949, pp. 6–11). In short, Kanner’s discovery of autism must be understood within the context of his effort to bring mental deficiency and child guidance together within a unified jurisdiction for child psychiatry, to “yoke together” these differences into a defensible boundary. No less important, it must also be understood as a way of aligning the interests of the fledgling new specialty with those of middle-class parents—telling them that their children were not feeble-minded but possessed “good cognitive potentialities.”

This became apparent a few years later, when Kanner (1949, pp. 4, 10–11, 17, 20) introduced a distinction between absolute, relative, and “apparent feeble-mindedness.” The latter category included cases where some specific delay, injury, disability, or illness masked the otherwise considerable intellectual potential of the children affected and made them seem feeble-minded. They were in need not of institutionalization but of careful diagnosis and therapy, which would “not only bring hidden potentialities to light but can also do something to turn the discovered potentialities into realized actualities.” Kanner thought that infantile autism underlay many of the cases of apparent feeble-mindedness. He thus crafted autism as a wedge with which to open up a space between illness and retardation and to outline a radically new set of tasks for child psychiatry involving, as he put it, “human engineering” (Kanner 1949, pp. 29–31), namely, surveillance of the full range of childhood ailments, from problem behaviors to illness to feeble-mindedness, and assignment to different tracks on the basis of careful diagnosis and therapy.

So we have Kanner already in 1949 attempting to bring into being this hybrid or interstitial domain of objects that are neither illness nor retardation. Yet this vision only came to fruition in the 1970s, and not through

Kanner's own efforts. In fact, by the mid-1960s Kanner was arguing that autism was being overdiagnosed and that it was a distinct and rare illness; that is, he completely inverted his position from 1949 (Kanner 1965, p. 414). What happened in the interim? Should we chalk it up to the inconsistencies and foibles of one man? I do not think so. To understand what happened we need to return to the fact that for his 11 cases in 1943 Kanner relied on middle-class parents to bring their children to him and that the diagnosis of autism was calculated to secure their allegiance and support. I said earlier that the yoking of differences into a jurisdictional boundary can be significantly impeded by the inability to stabilize a network of expertise. This is exactly what happened in the fraught relations between child psychiatrists and middle-class parents.

Between Expert and Lay

Returning to the appendix, we can ask another simple question: Who can formulate, repeat, and modulate this statement? Not simply who has the authority to diagnose autism, though this is an important part of the inquiry, but what actor-network or "enunciative modality" (Foucault 1972, pp. 50–55, 95) is necessary for these diagnostic criteria to make sense? Note that some of the criteria can be obtained by firsthand observation in a natural situation (A1a, A2a, A2c, A3c); others require setting up a semistructured testing situation, most likely with the assistance of a parent or caregiver (A1c, A2b, A2d, A3d); while others could only be scored by obtaining information from parents and/or educators and therapists (A1b, A1d, A3a, A3b). Where observation is involved, it requires an appropriate physical setting and toys; it requires setting conditions of visibility and invisibility (a two-way mirror, a closed door, a video camera); and it requires a transcription device, typically a standardized interview/observation schedule—this is crucial for making the statement repeatable and transportable. This directs the analysis to the relations between clinicians and parents and to the mechanisms, devices, and spatial arrangements that organize the flows of information and attribution between them.

The main data used by Kanner and those who followed him to diagnose and describe autism were, in fact, parental reports. Kanner observed the children during their relatively short visits to his office and administered or improvised a few tests, but the relevance of these was always in doubt (Kanner 1943, pp. 11, 15). Ultimately, his detailed case studies relied heavily on what the parents reported: for example, a typed 33-page detailed history provided by one father, detailed monthly letters or "copious notes" provided by some of the mothers (pp. 1–2, 6–8, 12). We could say, therefore, that the actor-network producing clinical diagnoses included, at a minimum, both the clinician and the parents and that at least implicitly there

was a problem of attribution (Latour 1987, pp. 118–19): If both sides were making contributions, to whom should the diagnosis be attributed? The network of clinical expertise, however, included several mechanisms that attributed the diagnosis to the clinician rather than the parents. First, there was the closed door of the clinician's office. When the child was seen by the clinician, the parents often had to wait outside (Kanner 1943, p. 7). What happened inside was mysterious. So even though they furnished most of the observations, the diagnosis could still be attributed to what happened behind the closed door. Second, there was the—fairly short—chain of transcriptions. The parents spoke, or provided detailed diaries and logs, and the clinician wrote it all down in his notes, transcribing or “abstracting” (p. 6) only what he considered important. These notes, which were used to write a case summary justifying the diagnosis, were not usually seen by anybody apart from the clinician. However short the chain of transcriptions, therefore, it was not easy to trace it backward to the parents' story. Third, there was the fact that the clinician occupied a central node in the network into which flowed also the observations of referring physicians, interns, or experts at various residential schools or child study homes (pp. 17–19). Finally, there was “mother blaming,” that is, a style of interpretation inherited from child guidance (Schumacher 1946, p. 53; May 1958, pp. 121–22; Jones 1999, pp. 7–8; Brockley 2004, pp. 148–49) that downgraded the credibility of parents' reports even while drawing on them. In the 1943 article, Kanner used the word “obsessive” at least seven times regarding parents and concluded by suggesting that the detailed diaries, reports, and remembered developmental minutiae he obtained from the parents “furnish a telling illustration of parental obsessiveness” (p. 42). Considering that he described one of the two distinguishing characteristics of autism as “anxiously obsessive desire for the maintenance of sameness” (p. 36), he seemed to be creating an intimate link between the parents' psychological makeup and their children's, a link that could be interpreted genetically or psychogenically but, in either case, precluded any straightforward return along the chain of transcriptions to the parents' reports. Indeed, he later insinuated that perhaps the parents were the cause of the disorder: “We find almost invariably that the children have been brought up in emotional refrigerators in which there was extremely little fondling and cuddling, in which the infants have been treated more as coldly watched and preserved experiments than as human beings enveloped in the warmth of genuine parental affection” (Kanner 1949, p. 27).

Mother blaming has often been interpreted as one of the excesses of psychoanalysis, but Kanner (1941) was scathingly critical of psychoanalysis. Mother blaming is better understood as a device that had a precise function to play in the network of clinical expertise. It permitted the clinician to appropriate the parents' work, erase their contribution by discrediting the

credibility of their testimony, turn it into *his* clinical insight (Sullivan 1984, p. 239), and then direct it back at them as a power of accusation. The chain of transcriptions was thus one way. It stopped at the clinician's office, which functioned as an obligatory point of passage (Latour 1988, pp. 43–49). Arranging the flows of information and attribution in this way, Kanner the expert enjoyed something very similar to the image of professional power as monopoly, but the network of clinical expertise remained weak precisely because it lacked power as generosity that could secure the parents' cooperation. Or put more precisely, however strange it may seem to us today, mother blaming was simultaneously a mechanism for channeling the flows of attribution in the network to the clinician and a form of generosity meant to secure the cooperation of parents. As physician Jacques May (1958, pp. 124–25)—himself a father of autistic twins—observed, parent blaming enjoyed popularity even among the parents because it gave hope that a cure is possible and removed the stigma of organic defect akin to retardation. Moreover, parent blaming is a confessional form of power (Foucault 1976). It works by stigmatizing individuals as sinners but also by eliciting their confession and teaching them to view themselves through the categories taught by the confessor. As May (1958, pp. 126–27) acutely observed, the bond formed between therapist and parents “has some deep, unhealthy charm. Centuries ago most religions discovered the importance of confession and the considerable help and lift that could be derived from a public or private catharsis of one's sins.” For this reason, mother blaming played a crucial role in forging the distinctive identity of “autism parents,” first because it distinguished their brand of affliction as “middle class” (unlike retardation), but second and more important, because it was through resistance to this confessional power that the parents were led to rearrange the relationships within the network of clinical expertise.

It should be noted from the outset that many of the parents involved in this process were professionals in relevant fields. A key role was played by Bernard Rimland, a navy psychologist and father of an autistic boy, and in the United Kingdom by Lorna Wing, a child psychiatrist and the mother of an autistic girl. Among the other mothers involved there were special education teachers and nurses. This fact should be interpreted in the context of the jurisdictional struggle between psychiatry and psychology (and other subordinate professions—special education, occupational and speech therapy, etc.), which intensified during these years (Abbott 1988, pp. 311–13). It should not be taken, however, to imply that the parents were “really” professionals struggling for jurisdiction. Rather, the parents of autistic children were in the unique position of being linked both to forces that challenged psychiatry and combined in the deinstitutionalization and “normalization” movement a few years later, namely, the larger middle-class movement of parents of retarded children (Trent 1994, pp. 253–66)

and the subordinate professions. Precisely for this reason they were able to forge a completely new network of expertise organized around the figure of the parent-researcher-therapist-activist.

The key move was to go around the obligatory passage point occupied by the clinician, redirect the flows of information away from it, and turn the chain of transcriptions into a two-way road. In 1964, Bernard Rimland published a book, *Infantile Autism*, which challenged the psychogenic hypothesis and is widely acknowledged today as a forerunner of modern autism research. More important for our purposes, however, was the insert at the end of the book. It was a checklist—that is, a transcription device—that parents could fill, tear out, and send back to Rimland. Within a week of publication, Rimland began receiving completed checklists from parents containing detailed individual histories of their children, descriptions of symptoms, and the timing of their appearance. He found a way, in short, to redirect the flow of information that until now was monopolized by the clinicians so that it flowed to him. Rimland would score the form and return the result, along with an analysis of the child, back to the parents. The chain of transcriptions, therefore, could be traced backward as Rimland spoke at length with parents over the telephone, explaining the results (Rimland 1968, 1971).

Initially, Rimland did not know how to help the parents who sent checklists. The following year, however, he heard about Ivar Lovaas, a behavioral psychologist at UCLA, who was developing a method for the treatment of autistic children. After meeting Lovaas and observing him at work, Rimland was so impressed that he introduced Lovaas to local parents of autistic children and even tried the method on his own son (Rimland 1972). Why was Lovaas interested in collaborating with parents? Working with autistic children was so time consuming and labor intensive that Lovaas developed the principles of applied behavioral analysis (ABA) working with only one autistic girl, Pamela. He had no numbers to make even his fellow psychologists listen to him. As he himself put it in a retrospective account, “you do not get tenure” doing this type of academically uninspiring work. As he came to appreciate the amount of work involved, he realized that he needed a whole army of paraprofessionals. He turned, therefore, to parents, saying that “this means that we will have to give away our professional skills to lay people, and the sooner the better” (Lovaas 1993, p. 628).

Note the explicit language of generosity used by Lovaas in this retrospective account. The resulting circuit of exchange and dialogue went thus: parents provided Rimland with their reports by filling out the checklists. Rimland gave them back a score and brief report explaining what the answers said about their child. He also gave them directions on how to treat their children with ABA and similar therapies. At the founding meeting of the

parents' organization, the National Society for Autistic Children (NSAC), Rimland gave a speech based on his observations of Lovaas emphasizing that this was a "technique that parents could learn with demonstrable success" (Rimland 1972, p. 573; Warren 1984, p. 102; Lane 2008). Through NSAC and a newsletter started by Rimland, parents were able to exchange information about what worked and for whom. Rimland often followed up on these leads and reported on what he found—this was how he came to advocate megavitamin therapy (Rimland 1971, p. 57; 2006). By the same token, Lovaas gave his knowledge and methods to parents. As we shall see later, ABA not only addressed a great many of the everyday problems parents faced, it also worked to secure the begrudging cooperation of the children themselves (Park 1974). In return, Lovaas obtained not only an army of paraprofessionals but also the ability to sum up the results of multiple home experiments, each with an "*n* of 1" (Lerner 2006), to make his claim for the efficacy of his therapy stronger. In parent-run special schools as well as at their homes, parents adopted behaviorist tools for recording and charting observations, thus rendering results measurable in exquisite detail and constructing a fully two-way chain of transcriptions (Lettick 1979, pp. 145–49; Silverman 2004, p. 158). In this alternative network of expertise, no single node could control and appropriate the exchange as the clinician did previously. At its core was not a mechanism of monopolization but, on the contrary, a generous exchange that extended the network and increased its power by valorizing the expertise of parents. In his retrospective account of the development of ABA, Lovaas (1993, pp. 622–28) calls parents his "colleagues" and declares that "there are no 'experts' in this field." Indeed, the new autism expert was no longer the clinician, but neither was it the behavioral psychologist, it was rather a team or an actor-network composed of therapists, psychologists, psychiatrists, and parents, with the latter occupying the leading role.

Within this network, the alliance between parents and psychologists worked to undo the mechanisms that earlier protected the monopoly of the clinician. The psychologist Eric Schopler—whose Treatment and Education of Autistic and Related Communication-Handicapped Children (TEACCH) became a statewide program in North Carolina due to lobbying by the local chapter of NSAC (Park 1971, p. 4)—subjected mother blaming to scathing critique, arguing that the coldness observed by Kanner was not a cause of autism but the consequence of having to raise a child who did not reciprocate the parent's emotional overtures (Schopler and Reichler 1976, p. 355). Psychiatrists were unable to see this, he said, because they were baffled by autism, secretly frustrated, and needed a scapegoat on whom to pin the failure (Schopler 1971*b*). In short, he completely inverted the attribution of credibility and expertise. Psychiatrists were not credible, while parents' reports were the best data to be had (Schopler and Reichler 1972).

This reapportioning of credibility was complemented by a simple material device Schopler added to autism programs in North Carolina, a one-way glass screen that permitted parents to watch clinicians and therapists working with their children without being seen (Schopler 1971*a*; see also Fields 1975). The one-way screen, said Schopler, takes away “the mystique and unfounded authority” of the therapist. Gone were the days when parents waited anxiously outside the closed door of the clinician’s office. Now they saw exactly what the therapist did, and they quickly learned to discriminate between superior and inferior performances. They were assigned the role of “cotherapists” within TEACCH and many quickly came to surpass the therapists who originally trained them. The one-way screen was a physical device that rewired the flow of information within the new network of expertise, leaving no room for monopoly or scapegoating. Today clinicians are encouraged to let parents watch the evaluation of their children, since their observation “demystifies” it and helps “establish a long-term collaborative relationship” (Koenig et al. 2000, pp. 304–5). Rimland’s checklists worked similarly to establish transparency and remove the mystical authority of the clinician. Using them, he was able to show that out of 445 children who saw two different clinicians only 55 received the same diagnosis (Rimland 1971, pp. 165–66).

One way of reading the story told in this section is that it was about jurisdictional struggles—though with a wider cast of characters. Child psychiatry was challenged by an alliance composed of competing professions and its very own clients, who forced it to share jurisdiction over autism diagnosis and therapy. After Rimland, psychologists developed more checklists—the Autism Behavior Checklist (ABC; Krug, Arick, and Almond 1980) and the Childhood Autism Rating Scale (CARS; Schopler et al. 1980)—drawing on the same principle of being a two-way transcription of parents’ reports bypassing the psychiatrist. No less important, in later years NSAC came to exert a strong influence over shaping the diagnostic criteria for autism (Ritvo, Freeman, and National Society for Autistic Children 1978; Akerley 1979), while ABA became a therapeutic juggernaut far outstripping psychiatric treatments for autism (Green et al. 2006).

Sociology of expertise, however, has to attend to both parts of the story. While the experts, the child psychiatrists, have lost their monopoly, the rewired network of expertise became stronger, able to secure the cooperation of parents and, equipped with ABA therapy, even the begrudging cooperation of the patients themselves. Kanner’s monopoly rendered his network unstable, and the one-way chain of transcriptions meant that the statements he produced were not easily reproducible. Indeed, the field of child psychiatric diagnosis was extraordinarily balkanized, with each clinician specializing in his or her own pet diagnosis and none able to achieve liquidity (Hersch 1968; Ornitz and Ritvo 1968). This situation was completely

changed by the checklists, the systems of observation and measurement central to the functioning of the rewired network. Ultimately, psychiatry would incorporate these into its arsenal, especially with the DSM-III (1980), which was explicitly designed to guarantee diagnostic reliability in response to studies like Rimland's demonstrating lack of agreement among clinicians. Most important, the rewired network was far better equipped to realize Kanner's original vision, which he himself was forced to abandon. Another way of reading the story told in this section, therefore, is as an episode in a series of reiterated problem solving (Haydu 1998). Kanner sketched a domain of objects between illness and retardation and the problem of how to define, observe, and intervene in these. He envisioned the task of the child psychiatrist as distinguishing among the full range of childhood ailments on the basis of "practical, communal, educational and clinical possibilities for human engineering" (Kanner 1949, pp. 9–11). Yet without securing the cooperation of middle-class parents he had no chance of realizing this vision. In terms of resources it required a program of intensive therapy and follow-up extending over many years, yet child guidance clinics were few and far between, treating no more than 12,000 children by 1960 (Nehring 2004, pp. 371–80). The clinical network of expertise was simply unsuited to handle large volumes (Hersch 1968, p. 498), but as Lovaas, Schopler, and Rimland demonstrated, a network that outsourced this labor to parents as "cotherapists" would be equal to this task. Similarly, what Kanner envisioned—distinguishing between the absolutely, relatively, and apparently feeble-minded and assigning some to institutions, others to menial occupations, and others to intensive treatment to actualize their potential—was tantamount to medical diagnosis of social destiny, something for which child psychiatry lacked the necessary legitimacy. The rewired network, on the other hand, especially in the context of deinstitutionalization, would disperse it onto multiple local authorities—psychologists, therapists, special education teachers, and most important to the parents themselves as "experts on their own children"—and multiple local decision points where "adjustment and treatment possibilities" would be assessed but the diagnosis of social destiny postponed.

Between Cure and Custody

Returning to the appendix, we can ask another question about the statement contained in it: What can be done with it? How does it render its subject matter actionable and to what end? It is extremely instructive, at this stage, to compare it with Eisenberg and Kanner's (1956) distillation of Kanner's observations into two "cardinal symptoms": "extreme aloneness" and "preoccupation with the preservation of sameness." While the cardinal symptoms are general, phenomenological, meaningfully interlinked (aloneness could be interpreted as an extension of the need to maintain sameness), and

emotionally tinged (“preoccupation” harks back to “obsessive”), the DSM-IV criteria describe autism in granular detail, breaking it down into “items of autistic behavior” (Wing 2008) that are not necessarily connected with one another and could be worked upon separately. Most important, the first two sets of criteria are organized by a comparison to normal development of skills or abilities for social interaction and communication. While the cardinal symptoms rendered autism a “fortress” to be broken into, inviting images of heroic cure (Bettelheim 1967), DSM-IV criteria describe a set of loosely connected disabilities, ranged by the degree of delay they represent, to be addressed by the gradual building of skills. This directs the analysis to the relations between therapists (or parent “cotherapists”) and the patients themselves, and the techniques, devices, and arrangements that secured the latter’s cooperation.

These relations were fundamentally changed by deinstitutionalization. The first point is that the deinstitutionalization of mental retardation meant that young children, however disabled, remained at home with their parents. The proportion of intellectually disabled children and youth in all out-of-home placements peaked in 1965 at about 49% and then began declining to 37% in 1977 and 18% in 1987 until it reached 6.2% in 2005, with the proportion of children under 14 only 1.8% (Prouty et al. 2005). There was a “concerted effort by most states to restrict the admission of children to large state institutions” (Prouty, Smith, and Lakin 2007, p. 41).

The second point is that deinstitutionalization replaced custody with a new set of legally mandated goals for treatment. In 1970, the National Association for Retarded Children (NARC) persuaded Congress to introduce a new grouping of handicapped individuals, the “developmentally disabled,” who were characterized as needing neither “cure” (because their condition was chronic) nor “rehabilitation” (since they never experienced normal development) but simply “habilitation,” that is, enabling, making able. Congress also created a new category of treatment facility, the “intermediate care facility—mental retardation” (ICF-MR). The term “intermediate” indicated precisely that it was neither a medical acute care facility nor a custodial one, but one which provided treatment geared for habilitation (Akerley 1979; Shapiro 1993, pp. 20–23; Prouty, Smith, and Lakin 2001, chap. 8). The principle behind these reforms was “normalization,” or “letting the mentally retarded obtain an existence as close to the normal as possible.” It implied a complete recasting of the goal of treatment when it comes to developmental disabilities (Wolfensberger 1972, pp. 27, 96).

Thus, deinstitutionalization created a changed institutional terrain in which the family, surrounded by support services, became the preferred locus for the diagnosis and treatment of children with developmental disabilities. In this institutional terrain, the object crafted by Kanner could come into a much sharper relief. Just as autism was indistinct within the institu-

tion, so now, within the new institutional matrix of early intervention, community treatment, and special education the distinction between the socially capable and incapable was rendered meaningless. The goal was to habilitate the children, to increase their ability to “obtain an existence as close to the normal as possible,” which meant that everybody had to be “socially capable” in a different sense: interactive and communicative at home, in the classroom setting, and with age peers. Similarly, in this new milieu the network of expertise developed by the parents could thrive. It had a built-in advantage over all other networks since it had already established solid links inside the family home, as a site of surveillance, diagnosis, experimentation, and therapy.

Yet to be able to make these fine distinctions in terms of abilities for social interaction and communication, as we saw in the appendix, the parents’ network of expertise needed to draw upon techniques of habilitation that could elicit also the cooperation of the children themselves. I have already described how Ivar Lovaas and his ABA therapy became linked to the parents’ network of expertise. Now I would like to argue that the new behavioral, sensory, and educational therapies were able to attach also the patients themselves to this network, thereby increasing its power and extension. This is not an argument that these therapies are better suited to treat autism. The contemporary landscape of autism treatment is a smorgasbord of more than a hundred different therapies (Green et al. 2006) and a heated debate about their efficacy (Rutter 1983; Howlin 1997; Rogers and Vismara 2008). From the point of view of the sociology of expertise, however, therapy should be analyzed as a set of mechanisms for translating the interests, securing the cooperation, and manipulating the performances of patients so as to stabilize a network of expertise. It was in this sense that the new therapies were superior. In the process, they also completely transformed autism as an object of diagnosis and intervention, preparing the ground for its rapid expansion afterward.

This argument could be profitably illustrated by means of a comparison with childhood schizophrenia. If any condition was ripe to become an epidemic in the 1960s, it was not autism but childhood schizophrenia. Mosse (1958, p. 791) reported “an enormous increase in the diagnosis of childhood schizophrenia,” and Bender (1953, pp. 663–64) claimed that it was even “more common than generally supposed.” Yet, already by the early 1970s there were grave doubts raised about the validity of childhood schizophrenia, and by the end of that decade it was definitively relegated, as Rutter (1972, p. 315) suggested, to “the section on the history of psychiatry.” Why would childhood schizophrenia go from “enormous increase” to virtual oblivion in a matter of 20 years? I would argue that the key to the answer was the prescribed treatment for childhood schizophrenia: six months of hospitalization, in the course of which the patients had to endure 20 rounds of electro-

convulsive shock therapy and/or Metrazol (which induced convulsions; Bender 1953, pp. 666, 678).

Such therapy was not calculated to translate the interests or secure the cooperation of either the parents or the patients themselves. The parents were excluded from the process of diagnosing and treating their children, who were literally taken away from them and hospitalized. The treatment that the patients received was not only harsh but also standard issue, one size fits all. To compound matters, the patients were typically minority adolescents who were referred to treatment after being labeled “juvenile delinquents” because of suspected gang membership or truancy. After discharge, they were typically still tagged with a “behavior disorder” diagnosis, and the side effects of the treatment were often evident (Mosse 1958, pp. 791–92). No wonder, then, that the parents eventually refused to play their assigned role. Bender (1953, pp. 668–69) reported that she was finding it harder and harder to persuade parents to give their permission to treat their children with electric shock. Put differently, because the treatment of childhood schizophrenia emulated the medical model of acute care—hospitalization-treatment-discharge—securing the cooperation of patients and parents was completely staked upon obtaining a “cure,” and when it failed to materialize the initial begrudging cooperation turned into open resistance.

Now, behavioral, educational, and sensory therapies also do not cure autism, but they do a much better job of translating the interests of patients and parents and securing their cooperation. They do this by rejecting the medical model of illness and cure, as well as the model of enlightened custody, and instead direct their efforts at habilitation goals that are coproduced with the parents and that permit the child to become better integrated within the family, school, and community. ABA, for example, breaks the behavior of autistic children “apart into smaller units (self-destruction, imitation, vocalizations, units of grammar, labeling, etc.)” and attempts to shape each one separately. The target of treatment, therefore, is not autism (which they regard as a “hypothetical” entity [Lovaas 1979, p. 315]), but concrete behaviors to be modified, skills to be acquired, or basic postural, vestibular, or perceptual mechanisms to be jump-started. The techniques apply across categories to all developmentally disabled children. The point is not to cure autism but to provide building blocks for cognitive and psychic growth so that it “will become sufficiently camouflaged . . . to be unnoticeable” (Schopler and Reichler 1971; Ayres 1974, pp. 56–62; Lovaas 1979, pp. 320–21; 1981, p. x). These therapies, therefore, seek to translate the interests of parents from a desire for “heroic” cure to an appreciation for tangible improvements in functioning, self-determination, and quality of life. As Lovaas (1981, p. 3) put it: “Set small goals so both you and your child will be rewarded. Find pleasure in small steps. Do not struggle for an abso-

lute and unattainable ideal of normalcy." Ultimately, the cooperation of parents is secured because they are included as "cotherapists" and, unlike the medical model of cure, setting the standards and defining the goals of therapy is coproduced between parents and experts.

No less important, these therapies also work assiduously to secure the cooperation of the children themselves. It is worth quoting at length here the report by David Park (1974), father of an autistic girl, about the success that he and his wife had in treating their daughter with "operant conditioning" at home. By breaking up tasks into their behavioral components, he said, operant conditioning "concentrated the child's attention on a few problems at a time" and "made no impossible demands" so "the child was surrounded by success." More important, "the child took a responsible part in her own treatment" while "the system utilized and turned to advantage the peculiarities of autistic children: their interest in systems, in counting, in ritual, and their literal honesty" (p. 190). He concluded by underlining that the "child . . . welcomes this liberation as much as the parents do. Elly has told us so herself" (p. 191).

Compare the report by two occupational therapists on the results of using sensory integration therapy with a young autistic girl at her school district. Prior to therapy, the girl had lost "verbal contact with people and reality." Yet, after six months of tactile and vestibular stimulation (including rubbing, brushing, spinning in a hammock-net, and riding prone on a board scooter) there was marked improvement, as the girl began to "direct her own therapy," instructing the therapist to emulate the sounds of different animals while she spun or "firmly directing a great deal of pretend play . . . involving the therapists, classmates, and the therapeutic equipment" (Ayres and Heskett 1972, pp. 178–80).

I use these two stories not as evidence that these therapies were successful in treating autism. For that purpose, they are purely anecdotal and worthless. The stories are useful, however, for the purpose of describing the common mechanisms employed by behavioral and sensory therapies, in the context of deinstitutionalization, to elicit the cooperation of the patients. First, treatment takes place in the children's home or school environment, is continuous with everyday activities, and is conducted not by medical personnel but by parents or school personnel. Second, the goals of treatment are modest, achievable, and pertain to everyday functioning, so not only is the child "surrounded by success" but each success means further integration in the activities of the family, school, and community. Compared with these modest goals, however, treatment is intensive and intrusive, calculated to impinge upon the children's initial resistance and involve them in interaction. Indeed, if there is one thing that is common to all autism therapies, notes Grinker (2007), is that they all involve "being in your child's face." Schopler and Reichler (1971, p. 94) called it "the adult's non-

specific impingement on the child,” and Rutter and Sussenwein (1971, p. 380) counseled that “the adult must intrude on the child in order to deliberately engage him in interaction” (see also *Medical World News* 1966; Siegel 1996, pp. 196–208). Yet to achieve this intrusion, therapy seeks to graft itself onto the “peculiarities” and concrete behaviors of the children and turn them to its advantage. Park’s observations about the intrinsic charm of counters, clickers, schedules, rituals, and “contingent reinforcement” for the children have been echoed by others (Siegel 1996, pp. 230–52). Sensory integration therapy similarly builds on what children find enjoyable. “Fun,” says Ayres (1998, p. 7; see also Ayres 1983, p. 115) is the word that children use for sensory integration. Most important, these therapies involve the children as responsible participants in their own treatment. Park noted this feature as crucial to the success he achieved with his daughter. ABA therapists added “child-directed” sequences, also called “incidental teaching procedure,” to the protocol for working with autistic children to capitalize on the interactions initiated by the children (McGee et al. 1985). Similarly, we already saw how sensory integration proceeded with the girl beginning to “direct her own therapy.” Ayres (1983, pp. 127–28) often emphasizes that the therapist needs to follow the child and not vice versa: “Occasionally, a child seems to know more about the nature of his dysfunction and what to do about it than the therapist does.” Finally, common to all these therapies is that they individualize the patient, tailoring for each child a unique treatment plan adapted to his or her deficits, strengths, and sensitivities.

No doubt these qualities of autism therapies enumerated here are partially explicable by reference to jurisdictional struggle. The developers of these therapies were psychologists and occupational therapists, who competed with psychiatry. Yet the tactics that they chose cumulated not in challenging psychiatry’s jurisdiction directly, nor in securing a new jurisdiction for themselves, but in blurring the boundaries between jurisdictions (between retardation and illness, for example) as well as between expert and lay (both parents and patients). Outsourcing therapy to parents, patients, students, and paraprofessionals; permitting therapies to be combined in a purely pragmatic manner (Schopler and Reichler 1971, pp. 91, 95–100; Lettick 1979, pp. 33–37, 78–80; Grandin 1995, p. 53; Siegel 1996); downscaling their claim from curing autism to modifying concrete behaviors or postural mechanisms; engaging in hands-on work continuous with the work of parenting (Lovaas provided practical advice on toilet training and spanking, for example); all these tactics meant that the autonomy and monopoly of the experts was minimized, while maximizing the generosity and coproduction that bound together the network of expertise.

Summing up the state of the therapeutic art in 1983, Rutter (1983, pp. 210–11) noted that the main advance in the field of autism treatment has been the rise of educational and behavioral methods of treatment that

have replaced insight psychotherapy. The new therapies changed the site of treatment from the hospital to the school and the home and involved parents as cotherapists. They broadened therapeutic goals in line with the goals of habilitation and normalization and were extended to ever younger children. He also noted, however, that none of them could cure autism or significantly undo severe initial handicaps of intelligence and language. The success and spread of these therapies, therefore, was not due to their technical superiority but to the propitious ecology provided by deinstitutionalization and the social innovativeness with which they were able to graft themselves onto the practices of parents and patients, translate their interests, and secure their cooperation.

The main consequence of the rise of the therapies and of their capacity to secure the cooperation of patients is that they transformed autism (1) from a syndrome with "cardinal symptoms," as Kanner called it, to a list of "items of autistic behavior" that could be worked upon separately and (2) from a rare illness into a wide spectrum of social and communicative deficits. Let me give a couple of examples of this dynamic. In the 1960s, it was generally accepted that self-injurious behaviors, such as head banging and hand biting, were universal among autistic children (Rimland 1964, p. 59). They were part of that obsessive turning upon oneself to maintain sameness and shut out the environment. In the DSM-III (1980), self-injurious behaviors were still a key criterion for diagnosing pervasive developmental disorder. Yet, in the DSM-III-R (1987), they were merely an "associated feature," and in the DSM-IV (1994) they were no longer mentioned. Two years later, a leading psychiatrist asserted that self-injurious behaviors were quite rare in autism, yet she added that "it's my clinical impression that there is a lot less hand biting now than twenty years ago" (Siegel 1996, p. 74). What had happened in between is that self-injurious behaviors began to be treated with behavior modification therapies and, consequently, were discounted as outside the core symptoms of autism (Siegel 1996; Schopler 1978, p. 169). A more central example is Kanner's "cardinal symptom" of "autistic aloneness" and utter lack of interest in other people. Both Kanner and Rimland (1964, p. 8) thought it was *the* main distinguishing feature of autism. In DSM-III, one of the main diagnostic criteria was "pervasive lack of responsiveness to other people (autism)," that is, it was so central as to be essentially identified with the disorder. Yet in the DSM-III-R it was replaced by a variable of "qualitative impairment of reciprocal social interaction" of which the aloofness and flat affect noted by Kanner were a possible but no longer necessary component. Once again, the transformation was due to the effect of the therapies. As we saw earlier, they are intensive and intrusive but seek to graft themselves onto the peculiarities and rituals of the children. They established, therefore, an equivalency between the multiple ways in which the communicative rapport necessary for therapy could break down

and were able to make distinctions along a single scale between the very few who were aloof and indifferent in all situations; those who liked merely physical contact with others; those who were indifferent only toward other children but not adults; those who were passive but amiable when approached; and finally those who made active social approaches but in inappropriate ways (Wing and Gould 1979, pp. 14–15; Wing 1997).

These distinctions were not merely the result of applying the therapies; they were also the result of thinking from the point of view of the therapies and from the point of view between illness and retardation enabled by deinstitutionalization. This point of view was articulated most forcefully by Lorna Wing. In a speech at NSAC's annual conference she said it was "pointless . . . to draw sharp lines between autistic and 'not really autistic' in educational practice. . . . The question to ask about each child is—what are his handicaps, what are his skills and what can we do to help him?" (Wing 1973, p. 118). Instead of sharp lines, she "wanted to . . . see how much [*sic*] items of autistic behavior, features of autistic behavior, how often they occurred among children in general . . . approaching the thing bottom up, instead of top down" (Wing 2008). Looking at each "item" separately as the therapists did, and letting it vary in accordance with how it responded to therapy, she recomposed autism into a "triad" of impairments in language, social communication, and behavior, each constructed as a spectrum (Wing and Gould 1979). She explained that "the justification for regarding . . . [low-functioning and high-functioning cases] as related is that all . . . require the same kind of structured, organized educational approach" (Wing 1981, p. 124).

Similar triads and spectrums were developed around the same time by Rutter (1978), Schopler et al. (1980), and Ritvo et al. (1978) on behalf of NSAC. But Wing chaired the committee that wrote the DSM-III-R criteria eight years later, and her version was adopted (Waterhouse et al. 1992). In her work, the lines of development I charted earlier all converged and came to fruition in the most evident fashion. She was a British child psychiatrist and trained clinician specializing in the object that Kanner outlined. Yet she was also the mother of an autistic girl and cofounder of the British parents' association, that is, she was an integral part of the new agent represented by the parents' network of expertise. At the same time, she was running an active treatment program for children with communication problems, collaborating with educators and therapists, as part of the British deinstitutionalization drive.

So over the long term, what happened between autistics and therapists began to redefine what autism really was, both the boundaries and the core of the syndrome. These changes were inscribed in new diagnostic checklists (Schopler et al. 1980) and in the work-arounds employed by clinicians even before the DSM itself was amended (Waterhouse et al. 1987; Whooley

2010). Then the new understanding was reported back to parents in books such as Siegel's, which meant that clinicians would indeed see in their offices more or less what they knew they should be seeing. In this way, the movement started by Kanner completed a full 180 degree loop and ended up with a substantial revision of how autism looks and feels, is understood and classified.

ENDGAME: THE SELF-ADVOCATES AND DIAGNOSTIC SUBSTITUTION

Ian Hacking (2009) argued that autistic self-advocates—individuals who are “on the spectrum” yet capable of speaking for themselves and telling others how it feels to have autism—played an important role in the dynamic that led to the autism epidemic. They did this by writing memoirs and blogs (Grandin 1986, 1995; Williams 1992, 1994; Shore 2003; Tammet 2009) that told of the experience of having autism and coping with it from their point of view. Their writings were avidly read by parents, experts, and the general public. In this way, the self-advocates created a language and a set of mental images with which it became possible for the first time to represent a “thick” autistic person, that is, one with emotional and cognitive depth, whose actions are meaningful and intentional if hard to decipher. This sort of language made the behavior of children with autism intelligible to parents, experts, and conceivably also to children and adults with autism themselves (Shore 2003, p. 139). There is hardly any doubt that the attention garnered by the self-advocates and their capacity to render autistic behavior intelligible contributed mightily to the autism epidemic.

I find Hacking's argument extremely insightful, yet it leaves completely unexplained the appearance of the self-advocates themselves. There is good reason for approaching this question cautiously: anybody who reads their memoirs cannot fail to recognize the extent to which these are extraordinary individuals who, against enormous obstacles, managed to compensate for their deficits through ingenious techniques of the self: diaries, alternative personalities, and highly elaborate cognitive devices for processing experience and endowing it with meaning (Williams 1992, pp. 18–20, 56; Grandin 1995, pp. 18–19, 95–97). Nonetheless, even if the self-advocates themselves remain *sui generis*, I would argue that the slot into which they stepped was prepared for them by the processes described thus far. Perhaps the most obvious point is that if autism had remained a relatively rare disorder and had not been transformed by the therapies into a spectrum accommodating different levels of severity, it is highly unlikely that the self-advocates would have been recognized as autistic, and their testimony would not have been taken as relevant. For significant portions of their lives, indeed, they were

considered “neurotic,” “psychotic,” “retarded,” “partially deaf,” or just plain “weird,” but not autistic (Williams 1992, pp. 29, 64; Shore 2003, p. 38).

Deinstitutionalization and the normalization movement, moreover, played a crucial role in setting up early self-advocacy. As early as 1972, academics and professionals in the United Kingdom acting as advocates for the developmentally disabled organized “speaking up” events where disabled individuals took the stage to advocate for themselves. The cultural repertoire of self-advocacy, at least in the United States and the United Kingdom, was thus created by disability-rights advocates. This has meant that unlike other countries where “speaking up” organizations developed under the wing of parents’ organizations (Canada, Denmark, Japan), self-advocacy in the United States and the United Kingdom was marked from early on by a certain tension with the aims of parents’ organizations (Buchanan and Walmsley 2006). In recent years, this tension has exploded into open conflict, culminating in British patients with Asperger’s syndrome seceding from the parent-led organization to form their own movement (Wing 2005) and an increasingly assertive younger generation of self-advocates challenging parents (Sinclair 1993). These self-advocates embrace the notion that autism is not a disorder or even disability, but simply who they are. They insist that they are not ill and do not need to be cured. They are simply different, part of a wide spectrum of “neurodiversity.” Yet the parents, they argue, are unable to tolerate this difference and instead keep looking for a cure by all means (see <http://autisticadvocacy.org>). The parents of severely disabled children, for their part, resent the neurodiversity talk as glib and damaging to the cause of their own children.

Nonetheless, parents and parent organizations played a crucial role in widening the spectrum to accommodate the self-advocates and in certifying them as credible public representatives of autism. In the early 1970s, the British and American parents’ associations collaborated in a project on the “near normal autistic adolescent.” The project was coordinated by two mothers who wrote an article suggesting that this group “would benefit . . . from recognition of their condition as a separate category of autism” (Dewey and Everard 1974, p. 355). They also translated a lecture given by Hans Asperger, thereby leading directly to Lorna Wing’s (1981) seminal article suggesting that Asperger’s disorder should be included within the autism spectrum. Rimland wrote the preface for Williams’s book (1992, pp. ix–xii), essentially certifying that this was indeed a report about autism and not something else (Williams herself only learned about autism in 1989, three years before the book was written; Shore only in 1996 [2003, p. 139]), and he also wrote the blurb on the back cover of Grandin’s book.

Some of the language of the self-advocates, moreover, has unmistakable affinities with Sensory Integration Therapy. Grandin (1995, pp. 42–48) says that the autism spectrum is a continuum of “sensory processing disorder-

der” and makes numerous references to sensory integration, as does Shore (2003, pp. 39–51). This affinity is not accidental. We saw earlier how sensory integration therapy requires the active participation of the patient in their own treatment, precisely because like Grandin or Williams, the child knows more about the nature of his or her problem than the therapist. Autism therapies constitute the patient as agent, as active participant in the dialogue and exchanges of which the network of expertise is made, playing a role that is similar in principle—though obviously much different in scope or impact—to the one played by the self-advocates. If the self-advocates elaborated a language with which to represent a thick autistic person, the therapies provided the grammar of this language. Ultimately, this affinity rests on the profound transformation represented by deinstitutionalization. Once autism was no longer an illness to be cured, nor a feeble mind in need of custody, it became possible for it to be simply who one *is*, a subject about whom the best testimony comes from his or her own lips.

The appearance of the self-advocates, therefore, can be explained within the framework offered in this article. Their acrimonious debate with parents’ organizations notwithstanding, the extension of the language of the self-advocates to cover the whole spectrum, as well as the fact that they constitute living proof that recovery is possible, made the autism diagnosis vastly preferable—from the point of view of parents—to mental retardation, with which it now overlapped significantly. The powerful idea encoded in autism of a dormant potential that may be actualized; the greater availability of therapies purporting to do just that; the empowerment of parents as experts and cotherapists; the new needs and goals created by deinstitutionalization; all these combined into a huge wave of diagnostic accretion and substitution that followed hard on the heels of the DSM-III-R and the appearance of the self-advocates. There are various and competing estimates, yet also agreement, that during the 1990s a sizable portion of the growth in autism diagnoses could be directly imputed to diagnostic accretion and substitution from mental retardation (Shattuck 2006; Coo et al. 2008; King 2008; Bearman and King 2009). Moreover, while this wave fed into the “low-functioning” pole of the spectrum, there was in all likelihood another pathway of diagnostic substitution, leading from less severe and “borderline” diagnoses, like “specific language disorder,” into the “high-functioning” pole of the spectrum (Bishop et al. 2008; Fombonne 2009).

CONCLUSION

In this article, I argue that Abbott’s (1988) call for a history of tasks and problems can best be addressed by replacing the sociology of professions

with a more comprehensive project of sociology of expertise. This approach combines the considerable achievements of jurisdictional analysis with an analysis of how forms of expertise are gradually assembled. It differs from the sociology of professions by being inclusive of all who can make viable claims to expertise; by carefully distinguishing between experts and expertise as two modes of analysis that are not reducible to one another; by asking not only who controls a task and how jurisdictional boundaries are assembled but also what arrangements, devices, concepts, and other actors are necessary if an expert statement or performance is to be formulated, reproduced, and disseminated as an immutable and combinable mobile. This means that expertise is analyzed as a network and abstraction as a chain of practical transcriptions, and that arguments about power must take into account the distinction and dynamic interdependence between the monopoly and autonomy experts pursue and the generosity and coproduction involved in putting together robust networks of expertise. The approach developed here is thus particularly useful for investigating the dynamic causes and effects involved in the elaboration of authoritative and socially consequential forms of knowledge and expertise, examining not only how certain problems—environmental risk, terrorism, pain, obesity, or minimal traumatic brain injury—rise to public attention (or not), or who controls them, but also the conditions and social work necessary to turn them into expert tasks.

APPENDIX

DSM-IV Diagnostic Criteria for 299.00 Autistic Disorder

- A. Six or more items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):
1. Qualitative impairment in social interaction, as manifested by at least two of the following:
 - a. marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
 - b. failure to develop peer relationships appropriate to developmental level
 - c. a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
 - d. lack of social or emotional reciprocity
 2. Qualitative impairments in communication as manifested by at least one of the following:

- a. delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
 - b. in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
 - c. stereotyped and repetitive use of language or idiosyncratic language
 - d. lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
3. Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
- a. encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
 - b. apparently inflexible adherence to specific, nonfunctional routines or rituals
 - c. stereotyped and repetitive motor manners (e.g., hand or finger flapping or twisting, or complex whole-body movements)
 - d. persistent preoccupation with parts of objects
- B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.
- C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder. (DSM-IV 1994)

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