Chapter One

Autism: The Very Idea

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There are many pressing questions that one might ask about autism. These include:

How will I know if my child is autistic?
What will be the prognosis if she is?
Is autism treatable?
Is autism curable?
Should autism be eradicated?
Why wasn't autism discovered before the 1940s?
Why have the rates of diagnosis risen so sharply over the past couple of decades?

Before those questions can be addressed, the more fundamental question must be answered: what *is* autism? Answering this question is tricky. For one thing, there is more than one way to take the question. It could be asking what *kind* of thing autism is (the *genus*, you might say): a complex of behaviors? a psychological condition? a kind of neurology? a genetic condition? Alternatively, it could be asking what makes it its own special instance of that kind (the *differentia*): *which* behaviors? *what* psychological condition/neurology/genetics? Call these *categorical* issues. On the other hand, it could be asking whether or not autism is a real knowledge-independent entity in the world for which we have just recently coined a term (on the model of something like Down syndrome) or if the concept is a human artifact that either does not track any real entity (like "neurotic" or other now-abandoned theoretical notions) or tracks behavior that is a product of human culture of a specific time and place (like "hipster"). This is a *metaphysical* question. As Locke might put it: once we establish the *nominal* essence of autism (the content of our concept of autism), we want to know if there is a *real* essence

out there in the world. We want to know if autism is like "water," where it emerged that there really was a distinct kind of molecular substance to the stuff we just used to pick out by its wetness, clarity and ability safely to slake thirst.

THE CRITERIA FOR DIAGNOSIS

Before we can address either categorical or metaphysical questions, we need to have a first pass of a description to work with, and it seems appropriate to begin by returning to the source: the seminal paper "Autistic Disturbances of Affective Contact"[1] in which Leo Kanner first posited the existence of a syndrome that we now know as autism.[2] Commenting on Kanner's article more than forty years after its publication, (now Sir) Michael Rutter wrote:

> There are few scientific papers that have stood the test of time as well as Leo Kanner's first description of the syndrome that came to bear his name. The fact that he was the first person to recognize that this constellation of behaviors constituted a condition that was different from the general run of problems grouped under "mental retardation" or "schizophrenia" was quite enough for the paper to receive an honored place in the history of psychiatry. It was indeed a reflection of Kanner's remarkable clinical acumen that he was able to see so clearly that which had escaped the notice of his many distinguished contemporaries and predecessors... [F]urther research demonstrated that he had been correct in his identification of the key features that held the syndrome together. As Leon Eisenberg commented in his preface to the 1973 collection of Kanner's papers on autism, "The genius of the discovery was to detect the cardinal traits...in the midst of phenomenology as diverse as muteness in one child and verbal precocity in another."[3]

Kanner's achievement, then, was picking out a "constellation of behaviors" that were the "cardinal traits" or "key features" that "held the syndrome together" that has since come to be called autism. So what were these key features? Kanner writes that "even a quick review" of the eleven case studies of children that had been brought to him "makes the emergence of a number of essential common characteristics appear inevitable," characteristics that together "form a unique 'syndrome,' not heretofore reported."[4] Those characteristics (the vast majority of which are today considered either indicators of autism or seen to be commonly related phenomena) included: late speaking; a use of language that was rote and focused mainly on the use of nouns to identify objects, colors, or numbers; excellent rote memory; "delayed echolalia" (delayed because the "parrot-like repetitions" could be stored for later); personal pronouns "repeated just as heard, with no change to suit the altered situation;" common failure to attend to people calling on them; fussiness about food; adverse reaction to loud noises and moving objects; lack of

spontaneity; treatment of people like objects; possession of "good cognitive potentialities" and "strikingly intelligent physiognomies;" clumsiness in gait allied with skill in finer muscle coordination.[5]

What kind of an answer is this to the question we began with? Suppose we say that *this* is autism: the exhibition of the set of characteristics in Kanner's list. Call this analysis the Bundle of Behaviors (BoB) Model. It is the simplest answer to the question "what is autism?" It is the answer: "what Kanner observed." In some ways it is the most optimistic, because it implies that the condition can be discarded in the way that any behaviors can be ended, however difficult that might be, and that successful behavioral therapy would not simply be a way to *mask* autism, but be a cure. Children could be autistic, and then later, not.[6]

Is it a satisfactory answer? Well, not really, for a number of reasons.

First, it seems more likely that the *essence* of autism lies deeper than the surface. Consider an analogous behavioral analysis of what "homosexuality" is.[7] To keep it simple, let's focus on what seems to be the key piece of behavior for homosexuality: same-sex sex acts. This is unsatisfactory as an analysis of what it is to be homosexual, because it seems neither necessary (the concept of a homosexual virgin makes perfect sense) nor sufficient (sex workers who perform same-sex sex acts could perfectly well be heterosexual). The behavior in each case seems to be an *effect* (or "symptom" in the medicalized language that used to apply to homosexuality and still does to autism) of the condition rather than itself *constituting* the condition.

Second, there is the problem of vagueness of boundaries. While some examples of behavior are clear-cut (e.g., misuse of pronouns), others are vague and meeting them would seem to be a matter of opinion and context. Just about every child is fussy about food to a certain extent—what counts as the degree necessary to meet the criterion here? The suspicion is that it is not the *degree* that matters but the *cause*. But referring to a (presumably nonbehavioral) cause means abandoning a simple behavioral model.

Third, we need to know if *every single* item on Kanner's list is necessary for a diagnosis of autism. Should lacking even one of those characteristics be sufficient to establish that one is not autistic? We are accustomed to think that this would be too strict a requirement, that "milder" versions of certain syndromes can lack one or two of the symptoms of the "full-blown" syndrome. But the simple BoB model is just a conjunction of all the "cardinal traits." There is no reason to believe that each trait cannot occur in people who do not have the condition. We cannot know whether or not there is a *separate* condition that lacks just one of the traits (a particular issue if we believe that Asperger syndrome is distinct). A diagnosis of autism would be like a conviction for breaking and entering in this respect: you can only be guilty of breaking and entering if you meet *every* requirement (breaking or entering/a building/without the owner's or tenant's permission/with intent to