

The Politics of Autism

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Practice, Vol. 1, No. 1, 1983 (An earlier version of this article appeared in *Topics in Language Disorders*, 1982, pp. 64-72.)

Jonathan had been diagnosed as high autistic according to the DeMyer classification (DeMyer et al., 1971). He was 7 years 9 months old at the midpoint of his work with the 9WL. He was a higher functioning child than Leon. Of special note is that he had extraordinarily good speech. It was loud and clear and syntactically correct. However, his speech was almost entirely echolalic, showed pronominal reversal, and we knew Jonathan to be an extremely concrete child. His unusually good rote memory was exemplified by his reciting "The Night Before Christmas."

Jonathan also breezed through the entire 9WL, never faltering for more than a moment on any part. He moved with equal ease through two cross referencing tasks, using first an auditory then a visual discriminative stimulus. Finally, he did fairly well on all four generalization tests. In other words, Jonathan is another example of an autistic child who has extremely good speech, is eminently conditionable, and demonstrates full possession of those substrate functions which are explored with the 9WL. (Churchill, 1978, p. 79)

Although much of the time Raun was still remote and aloof his being with us was becoming more productive, the interaction more meaningful. In the park, he would now actually go up to other children. On one occasion with Suzi, Raun looked directly at one little boy standing near the swings and smiled. Then, with no apparent warning, he hugged the child and put his face to the child's face. The other little boy quickly became frightened and began to cry. Raun immediately backed off. Confused and concerned. He mimicked his little friend crunching up his face as if he too were sad. After several minutes, when the child's sobbing stopped, Raun moved cautiously to wards him and softly stroked his arm. His new friend looked at Raun curiously; an act of communion and affection by a very delicate and oftentimes frail human being. An act that was unsolicited and self motivated. This day the sun began to rise in Raun's eyes. (Kaufman, 1979, p. 126)

How does the way we talk about children, about their abilities and disabilities, their learning and not learning, relate to how we study, teach and help them? The above quotations raise this question strikingly. Reading through several books on the subject of autism, considered a severe disorder, one becomes aware of the great contrast between how parents of children labeled autistic and professionals who do research or work with children labeled autistic write and speak about these same children. Parents talk of real people, of anguish and pain and joy, of actual learning and change; professionals talk of quantities and absolutes and limitations, of utterances, imitations, numbers of head-bangings and “m & m” eatings. The issue of the language used to talk about autistic children and about their language or lack of it is an especially glaring example of the relationship between the categories we use to organize the world and what we are able to do about changing the world. The categories we use to talk about, study, draw conclusions from, categorize people, and make recommendations about policy need to be examined for the ways they constrain not only the answers that can be found to questions, but the very questions for which we seek answers. These constraints are neither timeless nor unchanging; they are reflections of social historical conditions. They are part of the ideology of contemporary society in increasing crisis and contradiction, where science no longer explains or predicts and the “helping” professions no longer help. If we are to have any hope of helping anyone children labeled autistic, the unemployed and poor, the elderly—it is necessary to change fundamentally our understanding of helping. Let us see how this looks for autism.

Descriptions of autistic children and explanations of what causes autism have changed drastically over the past 40 years, particularly since the late 1970s. Before then, autistic

children were described as withdrawn, self stimulating, willfully withholding, and expressing rage. The causes given for their “symptoms” were often located in the psychodynamics of the family: the parents were cold and aloof; there was a traumatic experience of separation during infancy; the mother did not know how to nurse properly. Today, autistic children are more likely to be described as poor interactants, incapable of self monitoring, and incapable of generalization. The sources now given for their difficulties are located in the neuropsychology of the individual: there are organic disturbances present from birth; the child has some deficient sensory channel.

The generic and official classification of autism into types of disorder shows this change dramatically: autism is no longer an emotional disorder; it is now classified as a biologically determined cognitive disability. For example, the recent categorization system of the American Psychiatric Association, the *Diagnostic and Statistical Manual III* (APA, 1981), lists autism as a developmental disorder; disturbances in rates and sequences of development have been elevated to a primary defining feature of autism (James and Barry, 1981); and the major journal of research on autism has changed its title from the *Journal of Autism and Childhood Schizophrenia* to the *Journal of Autism and Developmental Disorders*. A recently published popular book for parents and professionals in the field describes the change as “the shift from viewing autism as a withdrawal from inadequate parenting to understanding it as a developmental disability; the change from regarding it as an intra-psychic, emotional disorder to be treated with individual psychotherapy to seeing it as a biologically based disability of childhood” (Paluszny, 1979, p. ix).

These changes in classification were not fortuitous, far from it. The legal and political impetus for and ramifications of the shift in classification are only beginning to be examined in the professional literature. For example, Akerley (1979) presents a straightforward summary of the struggle to get autism included in the Developmental Disabilities Act of 1975. Titled “The Politics of Definition,” Akerley's article points to one political basis for classification; namely, the role that advocacy and lobbying groups play in determining so-called philosophical and scientific issues.

How are we to understand this shift in the language we use to talk about autistic children and the explanation we posit for the existence of such a syndrome? This paper will suggest some ways to locate this shift politically—that is, as part of social movement as reflected in the institutions of science, education and the family.

From the first diagnoses of Kanner (1943) to the present day, it has been noted that a large proportion of children identified as autistic are from white, highly educated, intact, upper class families. Relatively few children identified as autistic have suffered either economic or prolonged psychological deprivation such as institutionalization (Rutter, 1978a; Schopler, 1978). Studies that present data to discount family factors in autism (e.g., Cantwell, Baker & Rutter, 1978; Schopler, Andrews & Strupp, 1979) do not refute the class bias in diagnosis; they merely downplay it. They note, for example, that although many autistic children are from upper class, well educated families, there are others who come from less educated middle and lower-class families.

But there is an interesting aspect concerning this relationship between diagnosis and class. Most autistic children have been given other labels at some point in their young

lives, before the label of autism has stuck. This multi-labeling is one aspect of the horrendous experience that many parents of autistic children have had, pursuing help and being shuffled from one expert and research center or clinic to another, as documented in the several excellent case studies that have appeared over the years (Greenfield, 1979; Kaufman, 1979; Park, 1972). Why have these children received so many diagnoses? Why have their parents not been satisfied? And why has autism been the diagnosis to accept?

To begin to answer these questions, we must examine, if only briefly, what labeling is. If labels are viewed as commodities, as things to be bought, sold, and acquired, then it can be assumed that some labels are more valued than others. It is likely that autism is a more valued label than those, such as mentally retarded, which autistic children receive at some point in their lives (DeMeyer, 1979; Greenfield, 1978). People who are knowledgeable about specialists, who know where to go and can afford it, are more able to shop around for a diagnosis and treatment. Upper middle class, highly educated parents are likely to be more comfortable with a label which identifies their child as emotionally disturbed, developmentally disabled, or autistic than one which identifies their child as dumb. A similar argument can be made for the diagnosis of learning disability, which has historically been associated with economically and educationally privileged families. Thus although diagnosis is an activity that closely touches the families of those diagnosed, it seems likely that more than merely being touched by it, such families (especially those with some power) play an integral part in the labeling process. Middle class parents can (and do) pay for “better” labels.

Diagnosticians and researchers view the problem differently, as more of a scientific issue, one that is outside of and untouched by social conditions. They see multi-labeling as a problem that reflects the “state of the art,” and argue over the definition of autism, over how many behavioral criteria are essential for the diagnosis, over whether autism is the same “thing” in high versus low IQ children, etc. However, Rutter (1978) appears to represent the field in his belief that it is only a matter of time and good research before the “diagnosis and definition” problem is solved. (See Rutter & Schopler, 1978, for several other discussions of definition, diagnostic measures, and criteria.) No one seems to question the assumptions underlying the very activity of diagnosis and definition.

Parents are bewildered by the inexactness of the science and offended by the distance and professionalism that go along with it; researchers and clinicians continue debating and searching for the quantitative method that will solve the problem. Parents, researchers and clinicians alike tend to look at diagnosis as an imperfect but logical act, rather than as a social phenomenon. Diagnosis of the syndrome of autism and the subsequent labeling of certain children as autistic is something that people do to and with each other. What social, economic and political factors underlie autism?

While not denying that there are certain consistent, bizarre behaviors that cluster together, it is a mistake to define such behaviors as autism. Autism is not merely a name given to the behavior of a small but significant number of children. Autism is a social phenomenon that (a) organizes the life of a child so labeled in ways strikingly different from the life of a child labeled something other than autistic, and (b) organizes researchers to spend their lives studying it and trying to help autistic children and their

families. With autism thus understood, we can begin to ask questions about the history of autism, about how labeling and diagnosing have developed and functioned as complex activities involving families, researchers, clinicians, government officials, and others.

It has been suggested that the labeling activity related to autism has historically served to distinguish upper class and upper middle class children from poor and lower class children (DeMeyer, 1979; Morgan, 1981); it has provided a way for the privileged to avoid labeling their children as “dumb.” Let us examine whether this function has been changing, for if diagnosing children as autistic is a social activity, it will have far reaching ramifications that go beyond the particular children who are labeled and treated. We need to look for historical trends in labeling, since it is only in its social and historical context that such labeling is understandable.

The tendency for autism to be associated with upper class and upper middle class families appears to be changing. The proportion of children labeled autistic from upper class and white families seems to be declining, whereas the proportion of children labeled autistic from lower class and minority families is increasing. For example, in Goldfarb, Meyers, Florsheim and Goldfarb's (1978) follow-up study of psychotic children receiving treatment in one New York City institution between 1953 and 1969, there was a definite trend toward an increase in children from poor families:

Our earliest analysis of social class composition of our children showed an unusually high number of upper class families very much in accord with other studies of early childhood psychosis. In recent years, however, there has been a shift to children from

poor families in all likelihood a reflection of the burgeoning number of social agencies concerned with the problems of the poor.

(p. 117).

It should be noted that the children were from intact families, and only 8 of the 78 were minority children.

Let us examine this statement carefully, for it is reflective of the scientific methodology that is prevalent, a methodology that hides its politics (which are at best liberal) and presumes what it purports to question. First, notice that in “suggesting” that their study consists of more poor children now than previously because of the “burgeoning number of social agencies concerned with the problems of the poor,” Goldfarb et al. are placing above question the very claim that needs to be questioned, namely, that there is in fact an increase in agencies concerned with the poor. They suggest (“... in all likelihood”) not that this may or may not be true but that this truth is relevant to their findings. The fact is, however, that it is not true that there are more agencies concerned with the problems of the poor (even if we could agree for the moment on the definition of “concerned”).

This leads to a second methodological error, again, one that has a politic (of neutrality) that is implicit. If autistic children who are poor are getting help because social agencies are finding them (or they are finding social agencies), this implies that there is a fixed number of autistic children, with those who happen to be poor existing in similar numbers both before and after the appearance of the “burgeoning number of social agencies concerned with the problems of the poor.” In other words, according to Goldfarb et al.'s logic, it is neither the disease nor the labeling of such children that is on

the rise; these, presumably, remain the same. Rather, it is the increase in the identification and services provided for poor families that accounts for the shift in social class. Putting aside clear evidence to the contrary, it is as if autism exists out there in the world and what is changing is our capacity to diagnose it. This is a clear example of the dualism of contemporary bourgeois science (between what there is in the world and how we understand what there is). It keeps one asking the (same) kinds of questions the answers to which distort reality and lead nowhere.

Even a cursory examination of the history of other labels should make us cautious about accepting this blatantly insensitive and biased explanation. In the area of mental health, there are numerous counter examples which document that diseases are socially created products of particular social circumstances (such as hysteria, which has all but disappeared, and narcissism, which is a distinctly 20th century disease). Even more relevant to autism is learning disability. In the past couple of years, there has been increased concern about the assessment of learning disability (Coles, 1978). One study in particular directly addressed the question of who was being assessed and why. Tucker (1980) examined the ethnic breakdown of children classified as learning disabled in over 50 school districts in the Southwest between 1970 and 1977. He suggests that the huge increase in learning disability as an educational designation for all students has hidden the fact that the increase for black students is far greater than that for white students: “Since 1970 the disproportion of minority students in LD [learning disabled] and EMR [educable mentally retarded] classes (combined) has remained virtually the same for Mexican Americans relative to Anglos but has steadily increased for Blacks” (p. 104). What is even more interesting is that this increase in minority representation in learning

disability classes has occurred simultaneously with a decrease in the number of Blacks in classes for the retarded.

Tucker's data indicate that the learning disability designation provides a convenient alternative to educably mentally retarded placement for a disproportionate number of minority students. This alternative, he suggests, comes at a time immediately after civil rights gains and an increase in sensitivity to the disproportionate number of minority children classified as retarded. Learning disability classification and its accompanying institutionalization and industry can give a false sense of security that something is being done to educate our children. Instead of addressing the problems of inequality in society as represented in schools, a new label is applied to the same children, and a "new" educational program is developed to deal with their "deficits." While this concern has quietly been voiced in the professional literature—"it will not be so easy to expose the racism hidden behind the overrepresentation of Blacks in the LD category" (Grossman, 1980, p. 527) it has not been heeded. And why should it? This kind of non-solution is so often used that it is difficult to see beyond reforms to a fundamentally different kind of solution.

It is possible that a similar trend is beginning with the diagnosis of autism. For many years it was (among other things) a labeling activity that separated upper class families with handicapped children from middle class and lower class families. The folklore among the community of the handicapped supports this; parents of autistic children have been accused of being elitist by parents of retarded children. Until very recently, what went along with this rather "privileged" disability was the stigma of the parents being

somehow responsible. From their position of relative power, parents of autistic children struggled to remove that stigma and at the same time get some benefits for their children. In the late 1970s they were finally successful; autism has been reclassified as a developmental disorder, a categorization that “cleans up” autism even more and removes the blame. An accompaniment to this is the search for biological determinants and increased reliance on drug treatments (Rimland, 1964, 1970). Not accidentally, there is simultaneously an increase in the number of children from poor and minority families who are diagnosed and treated as autistic and designated as candidates for drug therapies. Such diagnosis and treatments are consistent with the general pattern in research and education today; as social problems increase, researchers and clinicians turn inward to biological and individualistic causes and cures. This curious trend is not politically neutral, and it is particularly frightening because of the class character of the relationship. Minorities, the poor, and other oppressed people are those first and most susceptible to the abuses inherent in socio-biological and other genetic pseudo explanations as well as individualistic methods in general.

How are these contradictions and ways of looking at and treating autism related to recent trends in psychology? For example, the notion of social context is important in psychology today. Much research in developmental psychology, language development, and communicative disorders has been concerned with delineating the social contexts in which certain kinds of learning take place. Clinicians and practitioners in special education and learning disabilities are becoming more familiar with these advances and perhaps they are finding them useful. There has also been some work concerned with the researchers' social context, that is, the context in which theory and practice get delineated

and new models of learning, new theories of explanation, new etiologies, and new methods of treatment get developed. (This is most often identified with the field of the sociology of knowledge, e.g., Berger and Luckmann, 1966.) There are a few studies concerned with the relationship between these too often separated social contexts. A classic example is William Ryan's *Blaming the Victim* (1971), which describes the ideology behind social science methodology, an ideology that continually leads to explanations and solutions that blame the victims (the poor, the elderly, the uneducated, as well as the handicapped) rather than the actual causes for what are problems of and for everyone. Other more recent studies socially locate genetic explanations of learning disabilities (Coles, 1980) and examine the “psychology of child psychology” (Ingleby, 1974).

Such attempts at locating social science objects of study, findings, and methods in the wider world are an advance over the insistence of many that science is neutral and somehow outside of society. However, such a linking is still reflective of the same dualistic methodology, one that assumes a separation and then attempts to bridge the gap and bring it all together.

I have presented some beginning steps toward a non-dualistic methodology for language and learning research in a recent series of articles (Hood, 1981; Hood, in press; Hood, Fiess and Aron, 1982). I have argued that researchers, educators and practitioners need to take into account the relationship between how people learn (and don't learn) and the specific ways we study how people learn. That is, as professionals, we must examine carefully not only the social context of how children learn but also the social context of

how we learn how children learn, and the relationship between these two “learning” activities. Here, in this brief discussion, I have attempted to raise this issue from the point of view of the researchers' accountability to clinicians and practitioners. We must be accountable to those we serve, and in order to be so, we must self consciously give a socio historical accounting for why and how we do what we do. We must explore the relationship between our underlying conceptions of learning, of development, of disability, of language, etc.—conceptions that inform our theories, diagnoses, and methods of treatment and the very way we understand, see, label, and teach children. While so much time, money and energy go into treating children with particular symptoms, it is at least as important to “treat the treaters,” by examining the whys and wherefores of particular treatments. Scientific research is not neutral or value free, but is socially and historically determined, just as are childrearing practices, our educational system, and everything else people do with each other.

We need to be conscious of scientific trends that affect how we work with children—‘normal,’ “disabled,” “autistic,” etc.—and realize that such trends are social and political as well as scientific. The recent trend toward biological explanation and individualistic solution is dangerous and misleading. It denies the reality of symptoms and the conceptualization of disease and even the discovery of disease as social activities. And it denies the human experience of practitioners working with children. It is from this perspective that changes in diagnosis and treatment of children labeled autistic should be viewed. The historical relationship between the symptomatology of autism on the one hand and diagnosis and treatment of autism on the other hand is where to locate the definition of autism.

Finally, this perspective is relevant to looking at communicative disorders of such children. To make sense of the language of autistic children, we must examine its relationship to the language about autistic children. If we want to know how and why autistic children talk and what their talk means about being autistic (if anything), then we must look at how and why we talk about autistic children and how these children talk.

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