# DOCUMENT RESUME

ED 244 453 EC 162 466

| | |
|---|---|
| AUTHOR | Morgan, Sam B. |
| TITLE | Understanding the Diagnosis of Autism: Initial Counseling of Parents and Other Family Members. |
| PUB DATE | Apr 83 |
| NOTE | 27p.; In: Meeting Their Needs: Provision of Services to the Severely Emotionally Disturbed and Autistic. p36-61. Conference Proceedings (Memphis, TN, April 27-28, 1983). (EC 162 463). Print is light in parts. |
| PUB TYPE | Speeches/Conference Papers (150) -- Guides - Non-Classroom Use (055) |
| EDRS PRICE | MF01/PC02 Plus Postage. |
| DESCRIPTORS | *Autism; *Clinical Diagnosis; Counseling Techniques; Emotional Adjustment; Handicap Identification; Intervention; Parent Attitudes; *Parent Counseling |

ABSTRACT

The paper offers guidelines for counseling parents of children diagnosed as autistic. Initial sections urge caution on the establishment of such a diagnosis, noting widespread careless use of the term. Changes in thinking about autism are traced from its consideration as a psychogenic emotional disorder to a developmental disorder with cognitive impact. Counselors are urged to facilitate parents' understanding of the condition at the time of initial diagnosis. Suggestions for the initial informing session center on the use of interdisciplinary staff, ways to interpret the child's behavior, assurances that parents are not responsible for the child's condition, explanation of the child's cognitive and adaptive functioning level (with information conveyed on the child's relative strengths and weaknesses), and straightforward answers about long-range expectations (with emphasis on the tentative nature of the projections). Guidelines are also given regarding responses to etiological questions and reactions to diagnosis and recommendations for treatment and education. (CL)

# Understanding the Diagnosis of Autism: Initial Counseling of Parents and Other Family Members

Sam B. Morgan

One of the most substantial responsibilities of the professional working with developmentally disabled children is the counseling of parents and other family members after the initial diagnosis is made. Because of its extreme complexity, autism presents a special set of problems in such counseling. Although they may have extensive training in certain diagnostic techniques, many professionals are inadequately prepared in effective methods of helping parents understand what autism means for their child and the family. The task becomes even more complicated in interdisciplinary settings where a number of staff members with diverse degrees of experience and training in autism may be involved in the diagnostic evaluation of the child and subsequent counseling of the parents. In training settings, the trainee (e.g., pediatric resident, psychology intern, special education student) might find himself or herself participating in the initial counseling session with inadequate training or experience, often leaving the parents befuddled and frustrated.

Parents justifiably consider the informing interview the culmination of an often lengthy search for answers to questions they have about their child. Many have gone from one specialist to another to be bedazzled by a variety of labels, such as "mentally retarded", "emotionally disturbed", "brain damaged", "aphasic", or "atypical". Then, when their child is finally diagnosed as autistic, they naturally want professional help in understanding the problem and assuring that the child gets the most effective treatment program. The parents have a right to know what the evaluation reveals about their child's abilities, problems, and potential; professionals, in turn, have the responsibility to communicate the evaluation results and recommendations in understandable and usable terms.

Instead of receiving sympathetic help, however, parents of an autistic child sometimes find themselves the victims of certain a priori assumptions held by many professionals--assumptions about their own personality and its crucial role in causation of autism. These parents have discovered that many professionals tend to assume automatically that if a disorder has strong "emotional" components then it is necessarily the result of a disturbed social environment, particularly the environment provided by the mother in the first years of the child's life. In his excellent article on counseling parents of the autistic child, Schopler (1976) refers to these "myth beliefs" about child rearing, beliefs perpetuated in our society by professionals whose conclusions are based more on theory than empirical evidence. Fortunately, within the past decade or so, research has changed our thinking about the nature and cause of autism; and professionals should be familiar with these changes before attempting to counsel parents.

In this paper I offer some guidelines for counseling parents whose child has been diagnosed as autistic. While the paper focuses on the initial informing interview, much of the material also applies to follow-up counseling of parents and other family members. Before presenting these guidelines, however, it seems appropriate to discuss two preliminary topics that bear upon counseling: the need for careful diagnosis of autism; and changes in thinking regarding autism that have occurred during recent years.

## Need for Careful Diagnosis

Unless a careful diagnostic assessment has determined that the child meets the criteria for autism, the diagnosis, of course, should not be conveyed to the parents. The symptoms of autism may appear in different degrees and combinations in children with other disorders and handicaps. These children, while failing to show the full constellation of symptoms, might be classified as autistic on the basis of one or two isolated features (for a detailed discussion of this problem, see Morgan, 1981). Further, the terms "autism" and "autistic" have come into such vogue in recent years and have been bandied so glibly in professional circles that many clinicians are probably primed to jump to hasty conclusions and apply the diagnosis too readily. Leading scholars in the area of autism, such as Kanner (1969), Rimland (1971), and Wing (1976), have strongly urged that the diagnosis of autism be carefully determined. They think that parents have been misled, treatment misguided, and research issues clouded by indiscriminate use of the term "autism" and by lumping it with other conditions that may show overlapping symptoms.

The lack of agreement in the diagnosis of autism is, of course, related to the diversity of definitions used by diagnosticians. Clinicians may differ widely in the criteria they use in determining whether a child is to be diagnosed as autistic. Freeman (1977) and Freeman and Ritvo (1977) have done comprehensive reviews of the different diagnostic systems and have discussed the confusion involved in their use. Some researchers have attempted to alleviate some of the confusion by developing objective checklists and rating scales of symptoms and behavior. Rimland (1964), for example, has developed a detailed diagnostic checklist that has been used extensively in research on autism. This checklist, however, may be too lengthy for typical clinical use. A more practical scale has been developed by Schopler and his associates with the TEACCH program in North Carolina (Reichler & Schopler, 1976). The procedure, called the Childhood Autism Rating Scale, provides a structured basis for evaluating the child's behavior and yields a psycho-educational profile of the child's functioning that can be used for treatment and education.

For initial diagnosis in clinical settings, perhaps the most widely used and accepted set of criteria for autism are those outlined in the recently published DSM-III (*Diagnostic and Statistical Manual of Mental Disorders*, 1980). This manual lists autism under the general category of *pervasive developmental disorders*; these disorders, which consist mainly of what has previously been called childhood psychoses, are characterized by marked distortions in the timing, rate, and sequence of many basic psychological functions. The DSM-III definition specifies the following six criteria for infantile autism:

> (a) onset before thirty months of age; (b) pervasive lack of responsiveness to other people (autism); (c) gross deficits in language development; ([illegible]) if speech is present, peculiar speech patterns . . .; (e) bizarre responses to various aspects of the environment; e.g., resistance to change, peculiar interest in or attachments to animate or inanimate objects; (f) absence of delusions, hallucinations, loosening of associations, and incoherence as in schizophrenia (pp. 89-90).

Because autism is an exceptionally complicated disorder, an interdisciplinary team of specialists is often required for a complete assessment, which should cover physical, social, and psychological dimensions. A physician, such as child psychiatrist, pediatrician, or pediatric neurologist, should be involved to assess the medical aspects. A social worker or related specialist should do a careful study of the social history and family milieu. A psychologist should conduct a thorough evaluation of the child's cognitive and behavioral functioning. Other specialists, such as speech pathologists and educational diagnosticians, can often contribute to the assessment.

## Recent Changes in Thinking about Autism

In preparing for counseling of parents of the autistic child, one should be familiar with the changes in thinking about autism that have been prompted by recent research. An understanding of these changes is critical to conveying the nature of the disorder to parents, responding to their questions, and dealing with their emotional reactions, such as guilt.

Until the 1970s autism was still regarded by many professionals as a psychogenic emotional disorder which secondarily affects cognitive functioning. During the 1970s, however, some substantial changes in thinking emerged regarding autism--changes which cast a different light on the cause and basic nature of the disorder. First, more and more evidence suggests that autism is more consistently associated with organic rather than psychosocial variables (DeMyer, Hingtgen, & Jackson, 1981; Piggott, 1979; Rutter & Schopler, 1978). Second, in the eyes of most researchers, autism is no longer viewed as an emotional disorder but as a developmental disorder. As noted above, the DSM-III (Diagnostic and Statistical Manual of Mental Disorders, 1980) categorizes autism as a pervasive developmental disorder; further, the U.S. Office of Special Education has recently moved autism from the "severely emotionally disturbed" category to a special category (National Society for Autistic Children, 1980). Also reflecting this increasing developmental emphasis was the 1979 change in the title of the Journal of Autism and Childhood Schizophrenia to the Journal of Autism and Developmental Disorders. Third, a growing body of research suggests that the cognitive impairment in autism is at least as basic as the affective disturbance (DeMyer, et al., 1981; Morgan, in press).

The changes just noted reflect a definite shift toward the view that autism is a developmental disorder in which cognitive variables play a crucial role. Other changes relate to the alterations in the definition of autism that have evolved since Kanner's (1943) original formulation of the syndrome. Despite the intensive research scrutiny to which autism has been subjected over the years, Kanner's original behavioral syndrome has survived in fairly intact form. The changes in definition that have emerged relate more to Kanner's inferences about the disorder than to his actual description of behavior. The major alteration, based on long-term research with autistic individuals, concerns Kanner's inference that autistic children have "good cognitive potentialities" (Kanner, 1943). Another change involves the assumption that autistic children are neurologically sound, an assumption that led to the exclusion of children with known brain damage from the diagnostic category even though all behavioral features of autism were present.

The two assumptions regarding potentially normal intelligence and absence of brain damage have been until recently implicit criteria in the diagnosis of autism. However, recent definitions of autism, such as those offered in the DSM-III and by the National Society of Autistic Children (Ritvo & Freeman, 1977), make no reference to normal intelligence or the absence of neuropathology. Autism is assumed to occur at all levels of intelligence with or without demonstrable organic pathology. In short, autism can co-exist with mental retardation and organic conditions.

The exclusion of any stipulation of normal cognitive functioning is based on long-term research which indicates that most autistic individuals display substantial cognitive impairment that persists throughout their lives (Morgan, in press). A number of investigations have shown that although the level of functional intelligence may vary greatly in autistic children, most function within the retarded range (Bartak & Rutter, 1976; DeMyer, 1976; Rutter, Bartak, & Newman, 1971). About 60% of autistic children have IQs below 50; 20% fall between 50 and 70; and only 20% have IQs of 70 or higher (Ritvo & Freeman, 1977). Further, mounting evidence indicates that the intellectual level remains stable throughout the lives of most autistic individuals, with about 66 to 75% continuing to function at retarded levels (Ornitz & Ritvo, 1976; Rutter, Greenfeld,

& Lockyer, 1967).

Although many autistic children may present no demonstrable organic pathology, it has been shown that the behavioral syndrome will develop from a number of diverse neuropathological conditions such as phenylketonuria, congenital rubella, tuberous sclerosis, lead intoxication, and congenital syphilis (Piggott, 1979; Rutter, 1979). Further, recent studies have reported more signs of neurological dysfunction in autistic children than were noted in earlier studies; in fact, these dysfunctions become more apparent as the children grow older, even in those children who originally showed no such problems (Creak, 1963; Rutter, 1970; Wing, 1976). For example, the percent of these children who have abnormal EEGs is significantly higher than once suspected. As they grow older and enter adolescence and adulthood, about one-fourth or more develop convulsive or seizure disorders (Rutter, 1970). Although most autistic children exhibit no gross neurological problems, many may show one or more so-called "soft" neurological signs such as incoordination, reflex anomalies, strabismus ("cross-eye"), or poor muscle tone (Ornitz & Ritvo, 1976).

These recent changes in thinking about autism should be kept in mind by the counselor as he or she helps the parents gain a realistic understanding of the disorder.

## Conveying an Understanding of Autism

In order to facilitate the parents' understanding of autism and to enlist their vital aid in the treatment of the child, the counselor must first offer the parents help and understanding. Rather than implicating the parents, intensifying their guilt, and recommending therapy for their presumed personality problems, the professional should provide realistic information, practical guidance, and supportive counseling to help the parents in rearing their autistic child.

If at all possible, plans should be made to discuss the diagnosis of autism with both parents together. This avoids the problem of one parent having to assume the responsibility for interpreting complex findings to the other and for dealing with the initial reactions of the other. This also gives the parents opportunity to provide mutual support when presented with sometimes disturbing information. The counselor can also observe the interaction between the parents within the stressful situation of being faced with the diagnosis of autism in their child. In some cases, it might be appropriate or even desirable to include in the informing session other family members, such as siblings and grandparents, or to schedule later sessions for them.

In interdisciplinary settings the informing session usually involves more than one of the members of the diagnostic team. Selection of representatives from appropriate disciplines is important in planning the session and should be relevant to the child's problems. Each discipline has certain primary areas of expertise that may apply to a given child. If there are significant physical findings and recommendations regarding medication, for example, a physician should be involved; if there are anticipated questions regarding cognitive strengths and weaknesses, a psychologist should participate, and so on. The members of the informing team, despite differences in basic areas of expertise, share the common task of communicating to the parents what the diagnosis of autism means in a particular child.

There is a danger of having too many persons participating in the informing session; the parents may feel threatened or overwhelmed by the number of people and diversity of information. In most cases, two members of the diagnostic team can handle the interview quite well if their selection is carefully based on the individual findings and needs of the given case. If there is a great deal of specialized information requiring various professionals to talk with the parents, additional sessions might be held.

Interpretation of autism to parents should be both realistic and cautious. Autistic children represent different measures and blends of symptoms, and each child is an individual with a unique set of behavioral traits even though he shares common symptoms with other autistic children. Terms like "autist" (a noun used to refer to an autistic individual) should be avoided since they naturally offend parents. Such a term presents the child as a label or diagnostic entity, thereby destroying the child's individuality. Although the terms "autistic" or "autism" should certainly be used if the child fits the criteria, the counselor should strive to present the child as a unique person who happens to have autism.

Autistic children vary widely in the degree and type of symptomatology presented. One child may be able to speak, while another may be mute; one may show an intense resistance to change while another may be only mildly upset with change; and so on. A rating scale of autistic behavior, such as the TEACCH Childhood Autism Rating Scale (Reichler & Schopler, 1976), can serve as the basis for interpreting to the parents the particular profile of autistic behaviors presented by their child. The prime feature of autism--the one that distinguishes it most saliently from other developmental disorders and that most disturbs the parents--is the inability to relate to others and to form affectionate relationships. Parents often blame themselves for this problem since it appears to be social and emotional in nature. They should be assured from the start that they are not responsible for the child's apparent refusal to interact with the world.

The other problems presented by the child, problems that are frustrating and baffling to the parents, should be interpreted as part of the syndrome of autism. These include the bizarre responses to the environment, insistence on sameness, attachments to objects, deficient and unusual language, and so forth. Parents often gain some reassurance and comfort in being told that other autistic children show the same inexplicable and unsettling behaviors and that other parents have to cope with many of the same problems.

## Cognitive and Adaptive Functioning of the Child

One of the most difficult tasks of the informing interview is giving the parents a comprehensive interpretation of the child's level of functioning in cognitive and adaptive areas. Parents often think that the cognitive impairment is only temporary and once the other behavioral and emotional problems are improved, the child will suddenly become normal. They understandably question the validity of the formal tests of intelligence with their child. This misconception should be addressed at the start by tactfully telling the parents that the measures of intelligence (assuming, of course, that reliable measures are obtained) are usually valid representations of the autistic child's cognitive functioning (Rutter, 1979). The parent often argues that the low performance of the child stems primarily from negativism rather than from in intrinsic cognitive defect. Although negativism and inattention certainly can lower the performance of a given autistic child, they don't play as significant a role in altering performance as parents think they do. Often the child does not perform because the tasks are too difficult. Studies have shown that a valid evaluation of even the most "untestable" autistic children can be accomplished if they are approached with tests appropriate to their developmental level.

Parents often find the low scores on cognitive measures shattering to the illusions that they entertain about the autistic child's "true" intelligence. They often overestimate the child's intellectual potential because he may have shown normal early motor development or even early speech; he may also demonstrate certain isolated abilities, usually in rote memory and visual-motor abilities. The parents should be cautioned that these abilities are misleading and should not be equated with general intelligence. The abilities that the autistic child is most deficient in--conceptual, reasoning, and language skills--are those that are most critical to intellectual functioning and adaptation to life.

Despite their misconceptions about the autistic child's "true" intelligence or potential, parents of autistic children, as Schopler (1976) has noted, can often estimate accurately their child's level of functioning in social, cognitive, motor, and self-help areas. However, they frequently fail to realize the long-range implications of their child's impairment in these areas. In opening the discussion about the child's level of functioning, it often "breaks the ice" to have the parents estimate the child's overall level of functioning in terms of developmental age as well as performance in specific areas. This estimate can provide a starting point for discussion of the evaluative findings.

The findings should be presented in terms that facilitate understanding of the child's general level of cognitive or intellectual functioning, specific strengths and weaknesses, and probable educational and vocational potential. Certain terms glibly used by professionals to convey the child's general level of cognitive development and functioning are meaningless to most parents. To say that their child is functioning within the "moderately retarded" or "severely retarded" range is not very comprehensible to most parents nor is it initially acceptable to them to think of their child as retarded.

In trying to gain an understanding of their child's general level of cognitive functioning, parents frequently want to know the child's IQ. While IQ scores can be useful to the professional in evaluating the child's functioning, for most parents they have no valid meaning since the parents usually do not understand the statistical assumptions necessary for interpretation of a given IQ. Further, there is a tendency for many parents to view the IQ as a fixed,

infallible index. In most cases, the professional can give the parents an understandable picture of the child's functioning without reference to the specific IQ score. Some parents, however, insist on knowing the score, and they have a right to know it; the professional, though, has the responsibility to assure that the parents understand what the IQ means and what its limitations are. The parents should be told that the child's level of functioning is not determined solely by an IQ test and that other observations and reports on behavior (e.g., developmental accomplishments, adaptive skills, educational achievement) are also considered. Parents should also understand that IQs vary from time to time and from test to test, depending on the reliability and validity of the particular test.

If age scores, such as the Stanford-Binet Mental Age (for intellectual functioning) and the Vineland Social Age (for adaptive and social functioning), are interpreted with caution, they can be useful in helping parents understand the degree of retardation in their child. These should not, however, be presented as precise scores but rather as approximations and ranges ("Johnny is functioning in many ways at about the level of an average four-year-old.") It should also be stressed that the mental age or social age represents an average of many abilities and skills, some of which may be relatively high or relatively low. Further, it should be explained that the discrepancy between mental age and chronological age usually increases proportionately as the child grows to adulthood. The child whose mental age is two years below his chronological age at four years will likely have a mental age four years below his chronological age at eight years. Parents can relate mental age approximations to concrete behavioral accomplishments of normal children at certain ages.

Often a general level of cognitive and adaptive functioning is given to the parents without further specification. The autistic child, like any other child, has relative strengths and weaknesses which parents should appreciate in order to effectively deal with and plan realistically for the child. The typical autistic child is relatively good in visual-motor, spatial, and memory skills but quite deficient in conceptual and language skills. This pattern, however, certainly does not hold for all autistic children. The person presenting the findings should attempt to convey the child's own unique profile of strengths and weaknesses. In interpreting the child's relative skills, the informant can make the parents feel less threatened and more receptive by starting on a positive note.

Age scores are preferable to standard scores in presenting a differential picture of the child's abilities. For example, parents can readily understand the statement, "Johnny is about like an average six-year-old in motor skills but his language skills are at about the level of a three-year-old." As noted above, parents often place too much emphasis on isolated skills and do not understand what significance they may or may not have for long-term adjustment. The professional should stress to them that language and conceptual skills are much more potent predictors of later functioning than are visual-motor and memory skills.

The autistic child might also show significant variability in academic skills. Grade scores are probably the most easily understood indices since they provide concrete points of reference for most parents. Caution should be exerted, however, in interpreting the seemingly precocious reading skills demonstrated by some autistic children since parents tend to surmise that these indicate high intellectual potential (Cobrinik, 1974; Morgan, 1981; Rimland, 1964). In most cases, these reading skills represent rote perceptual analysis and are unaccompanied by any apparent comprehension. Cobrinik (1974) has explained these rote reading skills on the basis of the isolated facility for pattern recognition that many autistic children have. To these children, words may merely represent complex spatial patterns that are instantaneously processed like subway maps.

The parents should be cautioned against viewing the indices reflecting the child's current level of functioning as limiting factors for behavioral change. For this reason, it is helpful to discuss in behavioral terms what the child can do in certain areas and what he might be realistically expected to do. It should be stressed to them that, although the child is autistic and has cognitive impairments, with effective educational and behavioral management techniques, he can learn to function higher in certain areas, especially in self-help skills.

The parents should also understand that the evaluation is an ongoing process that should not end with the initial diagnostic study. In most cases, especially with young children, periodic re-evaluations will be needed to assess progress in certain areas as the child grows older.

## Long-Range Expectations

Parents always want to know what the future holds for the child, that is, what they can expect from the child in terms of long-range educational and vocational accomplishments and adaptation to life. Reliable answers to these questions about long-range expectations are difficult to provide. The only basis for answers is the available information we have on autistic individuals who have already reached adolescence and adulthood. From such data we try to determine those characteristics that appear to be associated with long-term improvement and adjustment. These answers, however, should be presented to the parents in tentative terms because many of the individuals studied, especially those who are now adults, did not have the benefit of the intensive early treatment and educational programs now available in some communities.

The parents should be given a cautiously phrased statement regarding prognosis for autistic children. The parents should understand that in most cases autism is a severe, long-term disorder and that the likelihood of an autistic individual achieving completely independent adjustment, even as an adult, is small. A recent review of all follow-up studies on autistic children revealed that only five to seventeen percent of all children eventually achieved a "good outcome", which meant that their social life was near normal and their school or work performance was satisfactory (Lotter, 1978). On the other hand, sixty-one to seventy-four percent of formerly autistic children had "very poor outcomes", which meant that they were incapable of leading any kind of independent life.

The evaluation findings on the child should also be interpreted in light of factors that are associated with later adjustment of the autistic individual. Two of the strongest predictors have to do with language and measured intelligence (Kanner, Rodriguez, & Ashenden, 1972; Lotter, 1978; Morgan, 1981). The use of language for communication before age five or six has been found to be a crucial prognostic sign in most studies. The child who displays some functional speech by this age stands a chance to achieve some adjustment; the child who is mute stands very little chance. The measured intelligence of the young child is also predictive of later functioning. The higher the IQ, the closer the child will approach normal adjustment. The same rule, of course, holds for typically retarded children. While autistic children differ in many respects from most retarded children, it appears that they, too, represent different levels of functional intelligence.

There are other factors related to prognosis that should be kept in mind when helping parents form realistic expectations. Seizures and other signs of neurological dysfunction or damage are correlated with severity of retardation

*16*

and long-term impairment in autism (Lotter, 1978). The play activity of the child serves as another prognostic sign. If the child plays appropriately with toys before age f[illegible] or so, the prospects for later adjustment are better (Brown, 1960). The severity of the early symptoms shown by the child also is associated with later adjustment; the more pronounced these symptoms, the lower the response to treatment and educational programs.

In interpreting these prognostic signs to parents, one should try to help the parents achieve a balance between realistic expectations on one hand and strong motivation to improve the child's condition on the other. The factors summarized above should not be presented as final answers to questions of long-term prognosis for the autistic child, nor should they be regarded as infallible predictors of success or failure. If this occurs, we may lead the parents into the web of self-fulfilling prophecies. The five-year-old child with no language and an IQ of less than forty should not be summarily written off as hopeless and relegated to life in an institution. The prophecy that the child will never adjust will, of course, be fulfilled if the parents throw up their hands in hopelessness and never give him a chance in various treatment and educational programs. In fact, it should be emphasized to the parents that one favorable prognostic sign is their willingness to commit themselves to a systematic behavioral program in which they play primary roles (Lovaas, Koegel, Simmons, & Long, 1973). And the earlier such a program is started in the child's life, the better chance he has for later adjustment.

In phrasing predictions, one can be realistic and still show regard for the feelings of the parents. Parents are less likely to be upset by, and more likely to accept, predictions phrased in positive rather than negative terms. The statement, "We feel that Johnny will be able to learn some useful speech and basic self-help skills," is much more palatable and no less realistic than the dismal forecast, "Johnny will never learn high-level language or be fully independent in taking care of himself."

Dealing with Etiological Questions and Reactions to Diagnosis

After being told that their child is autistic, most parents understandably want to know why he is that way. In most cases by far, the cause will not be definitely known, even though extensive diagnostic studies are done. If there appears to be a clear cause (e.g., Rubella syndrone, Fragile X syndrome), then the parents, of course, should be informed of it. Despite the absence of a demonstrable cause, one should assure the parents that most research findings would strongly indicate that the parents are not the causal agents. The parent should be told that although the cause of autism is not clearly known in most cases, there is an overwhelming body of evidence suggesting that it is probably the result of some neurological defect that might be caused in various ways. Assuring the parents that they did not cause the disorder will help them deal more realistically with feelings of responsibility and guilt.

Although etiological factors are certainly important in research and prevention, little is usually accomplished by speculating at length with the parents on possible causes of their child's autism. Once alleviating the parents' guilt by dispelling the notion that they caused the child's condition, the professional can be of greater aid by concentrating on the child's current functioning, the factors that continue to contribute to his handicap, and realistic plans for helping him.

Aside from guilt reactions over their presumed role in causation, parents show a variety of reactions upon being told for the first time that their child is autistic. Many parents respond realistically; others are justifiably defensive. One of the most common initial defenses is that of denial. The parents may openly reject the idea that their child is different, even in the face of overwhelming evidence for autism. Others ostensibly accept the diagnosis but privately cling to the belief that nothing is wrong and that the child will outgrow the problem. In these cases of denial, it will take time and often subsequent counseling before the parents can realistically accept the fact that the child has autism and that it is a severe handicap that will not disappear with time.

The atmosphere of the initial counseling session should be such that the parents feel free to express their feelings and reactions. In addition to guilt and denial, parents may show such reactions as depression, loss of self-esteem, projection of blame to others, and ambivalence. Often the professional presenting the diagnosis becomes the target of the parents' frustrations and pent-up anger over previous experiences with professionals. Such reactions should be viewed as natural and not taken as personal affronts. In an acceptant atmosphere, the parents' feelings can be recognized and openly dealt with to avoid later difficulty, and the need for further counseling can be better determined. The encouragement of the expression of feelings, however, should be done with sensitivity and discretion. To some parents, the hearing of the diagnosis and its implications serves as confirmation of what they had suspected or acknowledged all along; and they attempt to accept the findings realistically with few emotional defenses. These parents, while comprehending the findings, might contain their emotions during the informing session. Professionals should accept these reactions as appropriate and should not view the session as a failure if intense feelings are not expressed.

## Recommendations for Treatment and Education

In his article on counseling parents of autistic children, Schopler (1976) calls attention to the traditional conflict in roles between professionals and parents--a conflict that interferes with effective treatment of the autistic child. The professional has traditionally assumed the role of the "authorit giving the "expert" knowledge but remaining detached from the responsibility for the child's day-to-day problems. In contrast, the parents have traditionally had the responsibility for rearing the child and meeting his everyday needs. Schopler advocates a merger of these two roles. Most parents are experts about their own child and can provide valid and useful information to th professional. They can also contribute actively to the treatment and education of the child, instead of leaving such functions completely in the professional's hands. The professional, in turn, should share some of the responsibility and "accountability" for the child's overall welfare and should work to assure that appropriate treatment and special educational programs are available in the community.

Regardless of the amount of specialized attention given the autistic chil by professionals, any treatment or educational program is futile without the cooperation and involvement of the parents. As noted above, those autistic children who show the most lasting and generalized benefit from behavior modif cation programs are those whose parents are willing to apply treatment at home Further, such home treatment is much more effective in improving the child's b havior if it begins when the child is quite young. Rather than being exclude from treatment programs, then, parents are becoming more and more the primary therapists for their child.

The professional has the responsibility to provide current information on the effectiveness of various treatment and educational programs available to autistic children and their parents. Despite the claims of the more ardent practitioners of different therapies, there appears to be no "cure" for autism The parents should be cautioned about treatment programs that offer quick cure or substantial improvement through special diets and so forth. Such claims offer false hopes to parents who are often desperate and vulnerable to exploitation. One should be prepared, then, to respond to questions about these approaches and should share information based on current research.

Questions are often asked about the effectiveness of drugs and special diets in the treatment of autism. Although a number of different drugs have been tried, none has eliminated the basic symptoms of autism. Some, however, have been helpful in partially controlling some of the problems sometimes found in autistic children, such as hyperactivity, distractibility, stereotypic behavior, and sleep disturbances (Campbell, Geller, & Cohen, 1977; Ornitz & Ritvo, 1976). These drugs generally are employed when behavioral treatment has proven to be ineffective by itself; in all cases, drug therapy should be recommended only as an adjunct to other treatment programs.

Parents are drawn, too, toward special diets or vitamin therapy for the child. Although some researchers (e.g., Rimland, Callaway, & Dreyfus, 1978) have reported that some autistic children, particularly the classically autistic ones, show improvement in behavior with high doses of single or multiple vitamins, the results are still far from conclusive; and further research is needed to establish the effectiveness of such treatment. Too often, parents initially view these approaches as panaceas but later are severely disappointed with the outcomes.

Parents should also be informed that traditional psychoanalytic and "play therapy" approaches have been ineffective in the treatment of autism. In fact, such approaches are not at all correlated with later adjustment and consume time and effort that could be directed toward more productive programs.

By far the most effective treatment programs that can be offered are those that flexibly incorporate recent research findings and proven techniques into a comprehensive whole--a whole that includes tested principles of behavior modification and special education, parental counseling and participation, useful diagnostic methods, and treatment that pervades the child's total life. For the pre-school autistic child, the application of behavior modification principles by parents has been shown to be effective and enhances later adjustment. It is critical, then, that parents learn behavior management techniques that can be applied at home as early as possible in the child's life. One of the crucial features of parents who are most successful in helping their child is a willingness to apply strong, tangible consequences, such as food and spankings, to the child's behavior (Lovaas, Koegel, Simmons, & Long, 1973). Such parents also reject the notion that their child is "ill"; instead of treating him as a sick person, they place demands on him and are willing to commit a major part of their lives to their child and the daily management of behavior contingencies for him.

Once the child becomes eligible (in some states this is at four or five years of age), the parents should pursue, with the help of the professional, appropriate special educational programs and community based treatment programs. Such programs represent the most effective means of teaching the autistic child adaptive, language, social, and other skills. The TEACCH (Treatment and Education of Autistic and related Communications handicapped Children) program in North Carolina is a good example of a program that provides a comprehensive educational and treatment service to autistic children and their parents. Unfortunately, most communities do not have such specialized services for the autistic child. The professional, then, should help the parents in finding the most appropriate special education program available in the community.

The initial informing session usually conveys a substantial amount of diverse information, some of which might be difficult for parents to understand and accept in so short a period of time. Invariably, questions and problems emerge after this session. The professionals conducting the session should assure the parents that they will be available to answer questions and provide follow-up counseling as needed.

During the initial session, the parents should be strongly encouraged to join the local Society for Autistic Children (if one is available) and the National Society for Autistic Children (NSAC). The local Society can offer invaluable support to the parents and family as well as furnish useful information on autism. Because of the very special and demanding problems that they confront every day, parents of autistic children often share a deep kinship with one another. Parents who have had experience in rearing an autistic child can usually establish ready rapport with parents coping with the initial diagnosis and can offer effective and realistic support. Membership in a parents' organization will also allow the parents to participate in development of better community facilities for autistic children and in promotion of greater public awareness and acceptance of autism.

In counseling parents, one should consider the impact of the autistic child not only on the parents but on other members of the family and on the family system. Because of urgent demands presented by the typical autistic child, parents sometimes focus all of their attention on him and neglect the needs of their other children. As noted above, counseling of siblings is often necessary to aid them in realistically understanding and accepting their brother's or sister's condition. Further treatment, offered either individually or to the family as a whole, may also be needed to help siblings and other family members deal constructively with their feelings toward the autistic member and his influence on family relationships.

Autism is the most baffling behavior disorder of children. Parents and family of the autistic child have to deal with frustrations that usually exceed those associated with other childhood disorders. Professionals engaged in the diagnosis and evaluation of the autistic child should acknowledge that even the most intensive of studies are of little value unless the parents understand the diagnostic findings and their implications. The same professional concern and thoroughness shown in the evaluation should be applied to the initial counseling of the parents and other family members. Such counseling should help the family take a significant first step toward gaining a better understanding and acceptance of the autistic child in their home.

## References

Bartak, L., & Rutter, M. Differences between mentally retarded and normally intelligent autistic children. Journal of Autism and Childhood Schizophrenia, 1976, 6, 109-120.

Brown, J. Prognosis from presenting symptoms of preschool children with atypical development. American Journal of Orthopsychiatry, 1960, 30, 382-390.

Campbell, M., Geller, B., & Cohen, I. L. Current status of drug research and treatment with autistic children. Journal of Pediatric Psychology, 1977, 2, 153-161.

Cobrinik, L. Unusual reading ability in severely disturbed children: Clinical observation and a retrospective inquiry. Journal of Autism and Childhood Schizophrenia, 1974, 4, 163-175.

Creak, E. M. Childhood psychosis. A review of 100 cases. British Journal of Psychiatry, 1963, 109, 84-89.

DeMyer, M. K. Motor, perceptual-motor, and intellectual disabilities of autistic children. In L. Wing (Ed.), Early childhood autism (2nd ed.). Oxford: Pergamon Press, 1976.

DeMyer, M. K., Hingtgen, J. N., & Jackson, R. K. Infantile autism reviewed: A decade of research. Schizophrenia Bulletin, 1981, 7, 388-451.

DSM-III: Diagnostic and statistical manual of mental disorders (3rd ed.). New York: The American Psychiatric Association, 1980.

Freeman, B. J. The syndrome of autism: the problem of diagnosis in research. Journal of Pediatric Psychology, 1977, 2, 142-145.

Freeman, B. J., & Ritvo, E. R. Diagnostic and evaluation systems. Helping the advocate cope with the "state of the art". In J. Budde (Ed.), Advocacy and autism. Lawrence, Kansas: University of Kansas Press, 1977.

Kanner, L. Autistic disturbances of affective contact. Nervous Child, 1943, 2, 217-250.

Kanner, L. The children haven't read those books. Acta Paedopsychiatrica, 1969, 36, 2-11.

Kanner, L., Rodriguez, A., & Ashenden, B. How far can autistic children go in matters of social adaptation? Journal of Autism and Childhood Schizophrenia, 1972, 2, 9-33.

Lotter, V. Follow-up studies. In M. Rutter & E. Schopler, (Eds.), Autism: A reappraisal of concepts and treatment. New York: Plenum Press, 1978.

Lovaas, O. I., Koegel, R., Simmons, J. Q., & Long, J. S. Some generalization and follow-up measures on autistic children in behavior therapy. Journal of Applied Behavior Analysis, 1973, 6, 131-165.

Morgan, S. B. The unreachable child: An introduction to early childhood autism. Memphis: Memphis State University Press, 1981.

Morgan, S. B. Early childhood autism: Cognitive-developmental perspectives. In J. B. Gholson & T. L. Rosenthal (Eds.), Applications of cognitive-developmental theory. New York: Academic Press, in press.

National Society for Autistic Children. Advocate, September, 1980, 12, 1-3.

Ornitz, E. M., & Ritvo, E. R. The syndrome of autism: A critical review. American Journal of Psychiatry, 1976, 133, 609-621.

Piggott, L. R. Overview of selected basic research in autism. Journal of Autism and Developmental Disorders, 1979, 9, 199-218.

Reichler, R. J., & Schopler, E. Developmental therapy: A program model for providing individualized services in the community. In E. Schopler & R. J. Reichler (Eds.), Psychopathology and Child Development. New York: Plenum Press, 1976.

Rimland, B. Infantile autism. New York: Appleton-Century-Crofts, 1964.

Rimland, B. The differentiation of childhood psychoses: An analysis of checklists for 2,218 psychotic children. Journal of Autism and Childhood Schizophrenia, 1971, 2, 161-174.

Ritvo, E. R., & Freeman, B. J. National Society for Autistic Children definition of the syndrome of autism. Journal of Pediatric Psychology, 1977, 2, 146-148.

Rutter, M. Autistic children--infancy to adulthood. Seminars in Psychiatry, 1970, 2, 435-450.

Rutter, M. Definition of childhood autism. In L. A. Lockman, K. F. Swaiman, J. S. Drage, K. B. Nelson, & H. M. Marsden (Eds.), Workshop on the neurobiological basis of autism (NINCDS Monograph No. 23, NIH Publication No. 79-1855). Washington, D. C.: U. S. Government Printing Office, 1979.

Rutter, M., Bartak, L., & Newman, S. Autism--a central disorder of cognition and language? In M. Rutter (Ed.), Infantile autism: Concepts, characteristics, and treatment. London: Churchill, 1971.

Rutter, M., Greenfeld, D., & Lockyer, L. A five to fifteen year follow-up study of infantile psychosis: II. Social and behavioral outcome. British Journal of Psychiatry, 1967, 113, 1183-1199.

Rutter, M., & Schopler, E. (Eds.). Autism: A reappraisal of concepts and treatment. New York: Plenum Press, 1978.

Schopler, E. Toward reducing behavior problems in autistic children. Journal of Autism and Childhood Schizophrenia, 1976, 6, 1-13.

Wing, L. Diagnosis, clinical description, and prognosis. In L. Wing (Ed.), Early childhood autism (2nd ed.). Oxford: Pergamon Press, 1976.