
New Hope in the Treatment of Autism in Hawaii

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As recently as 15 years ago autism was regarded as an incurable disorder of unknown etiology for which the best management was institutionalization. Due to the grim prognosis, pediatricians and child psychiatrists placed great stress on the accuracy of diagnosis so as to rule out any treatable causes. This picture has changed entirely during the late 1970s and 1980s, as autism has come to be recognized as a developmental disability (central nervous system disorders which affect sensory, integrative and motor functions resulting in abnormalities of development. Examples include mental retardation, learning disabilities, attention deficit hyperactivity disorder and autism). As it has become recognized that many of these conditions simply represented a static encephalopathy (like stroke or traumatic brain injury), people have understood that they often can respond greatly to early recognition and intervention. Thus, the current emphasis in care is to identify possible cases, even mild cases, so that appropriate preventive care can be provided.

As defined in the most recent *Diagnostic and Statistical Manual of Mental Disorders, III, revised (DSM-III-R)*, autism is a developmental disorder with onset in infancy and early childhood. It ranges from mild to severe forms, characterized by impaired social interaction, impaired communication and repetitive behaviors or unusual interests.¹ The most typical clinical picture is that of an infant who fails to relate to the parent as early as the third month (ie, absence of the usual smile and expected mother-child reciprocity), who is unusually quiet and non-demanding of parental attention, and who does not develop communicative speech between the ages of 12 months and 18 months. Often the child will show unusual sensitivities or behaviors as well. Several good overviews of autism have been published.^{2,3,4}

In the past, the tendency was to follow the infant or young child in the expectation he or she would "grow out of it." Unfortunately, with developmental disabilities this is not the case, and waiting prevents early intervention and promotes

chronicity. It has been estimated that without early identification and appropriate correction of the social and communicative handicaps, some 40% to 60% of children who do not have useful speech by the age of 5 years will require long-term institutionalization at enormous expense to the family and the state.

Fortunately, that picture now is mostly preventable, which is the topic of this paper. Prior to 1992, autism in Hawaii was a much disregarded disorder. It was thought 1) to be a very low incidence disorder, with a prevalence in the range of 1 per 10,000. Recent studies have shown that the prevalence in fact is in the range of 1 per 1,000, a 10-fold increase! 2) there was lack of knowledge about etiology and the fact that autism represents a syndrome or set of behaviors of underlying neurobiological disorder; and 3) there was the absence of a well-defined system for diagnosis and follow-up. Thus, clinicians tend to be unaware of both the prevalence of the disorder and behavioral interventions which lessen or reverse autistic symptomatology.

Because of the above-mentioned factors, we can only approximate how many people may have mild to severe autism in Hawaii. According to 1992 statistics, the Department of Education reported only 65 children with the official diagnosis of autism. A 1991 survey by the Developmental Disabilities Planning Council identified some 120 in Hawaii with autism, 70 of whom were children. However, based on national statistics, for our population there are thought to be some 1,100 autistic people, including 250 children. Thus, the majority of cases in Hawaii are unrecognized and may be receiving inadequate or inappropriate services.

It was this combination of unmet needs for families and children, a newly emerging and exciting field of autism research and development of services along with the threat of multiplying life-long institutional care, that motivated the Hawaii State Legislature in 1991 to begin to address the issue of autism in Hawaii. Thus, in 1992 the legislature passed an act creating a Resource and Technical Assistance Project on Autism.⁵ The project was placed under the overall umbrella of the University of Hawaii Affiliated Program (UAP) which supports a number of projects related to education and training in developmental disabilities. Presently the Autism Project is staffed by a coordinator, 2 parent advocates, secretarial staff, an advisory committee, and active linkage to the Autism Society of Hawaii, a parent advocacy group composed of parents of autistic children.⁶

Overview of Present Services.—In the report of the State Planning Council on Developmental Disabilities to the legisla-

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ture,⁷ it was noted that: 1) There are few professionals in Hawaii who are experienced in differentiating between autism and other developmental disorders; individuals suspected of having autism often are referred to UCLA Medical Center or elsewhere on the Mainland at a cost to the family, private insurers and state of a minimum of \$40,000 per workup.

2) Educational services are inadequate to deal with autistic subjects for several reasons; the University system has no autism-specific classes in their special education curriculum, and the Department of Education has no training module on autism. Thus, the educational and communication training needs of autistic children tend to be inadequate.

3) Existing services in the state are even more inadequate. Oahu has a) the Autistic Vocational Education Center (AVEC) which provides vocational training to 21 adults with autism, and b) the Behavior Treatment and Training Service (BITTS), which deals with some 11 autistic clients. Unfortunately, support services such as home-support or extended day school with trained personnel are virtually nonexistent; case management by state social workers is impaired by high case loads. Family services, respite care, crisis intervention, and other essential services are both difficult to access and expensive. Obviously these problems are compounded on the Neighbor Islands.

Knowledge of autism by families and the medical community.—In order to assess physician and family awareness of the issues involved in services for autism, the first author (LP) surveyed families with autism and physicians in 1992. One hundred questionnaires were sent to each group, with responses returned by 24% of families and 17% of physicians.

Family survey.—Families responding to the survey reported the following:

1) their child was not identified as autistic until the average age of 4 years. Given the reports that preventive interventions need to be well underway before this time, this is a worrisome finding.

2) initial diagnoses for children with autism included “mentally retarded,” “developmentally delayed,” “attention-deficit hyperactivity disorder,” “autistic-like,” and “atypical pervasive developmental disorder.” This confirms the general lack of knowledge and confusion about the diagnostic characteristics of the disorder.

3) Six families relied on the family physician or an education specialist to make the diagnosis, 18 families needed specialist help from a child psychiatrist or psychologist, and 3 families went out of state for a definitive diagnosis.

4) Fifteen of the 24 children are in special education classes. Seven of these 15 live on the Neighbor Islands and describe their situation as being extremely frustrating due to the limited community resources to meet their child’s needs.

5) The top 5 services identified as most needed by the 24 families were: a) special education; b) behavioral management; c) day care/respite care; d) speech and language services; e) education of the medical community so they would be better able to identify autistic individuals at the earliest possible time to receive effective intervention and treatment.

Physician survey.—1) Of the 17 physicians who responded, 8 said they see or have seen autistic patients. This speaks to the large number of estimated cases that are not recognized.

2) These 8 said they provide “medical care,” and only 3 mentioned referral to specialists as part of their management strategies. This illustrates the past lack of knowledge about autism.

3) The 5 most needed services identified by physicians were: a) respite care; b) support system for families; c) behavioral management; d) psychiatric services for parents, siblings, child; e) special education.

Interestingly, only 2 of the 17 physicians surveyed identified education of the medical community as an important issue. The perceived need for psychiatric services (ie, for treatment) also reflects lack of knowledge about the etiology of autism. As we mentioned above, during the 1950s and 1960s autism was regarded as being psychogenic, caused by inadequate mothering (the so-called “refrigerator mother”). Child psychiatrists can be very helpful due to their knowledge of abnormal child development, ability to play an advocacy role, and support parents with child rearing and getting needed communication and educational services. However, it is now recognized that psychotherapeutic services usually are not necessary, and what is especially helpful is the use of psychoactive medications to help with abnormal behaviors (clomipramine for obsessive-compulsive symptoms, naltrexone for self-injury, haloperidol for aggression, etc.)

Discussion.—The parent survey reveals that misdiagnosis and late diagnosis are the key issues confronting physicians and parents in Hawaii today. The lack of identification of autism until age 4 virtually ensures a high level of chronicity and institutional care. Social and communicative relatedness are so basic to the rest of development that identification needs to be made between the ages of 1 to 1 1/2 years. Since it has been found that autism is syndromic, variable in severity and treatable, there is no longer the need to insist on diagnostic precision. What is important is to know that delays in social relatedness and speech are symptoms of developmental disability, including autism, and rather than following to see if will improve, referral to early intervention services like the Autism Project or Zero-to-Three Hawaii is indicated.⁸

Also, since the state legislature provided funding for the Autism Resource and Technical Assistance Project, the situation is becoming much more hopeful. The Autism project’s staff has been actively seeking the most current national and international knowledge on autism, case finding, developing a network of professionals to assist with evaluation, diagnosis and consultation; surveying needs in the community, and networking with local and national agencies. For example, the National Autism Society is a useful source of knowledge, publishes a newsletter called *The Advocate*, and holds well-attended meetings. Similarly, the Autism Research Institute in San Diego (founded by Bernard Rimland PhD) publishes a quarterly review of the published literature and reviews on autism therapies. Finally, the Hawaii Autism Project and the Autism Society have been highly successful in creating an annual meeting which brings a national

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life may best be subsumed under the general rubric of a religious world outlook. But surely there are many humane physicians who are not religious and, contrariwise, there are many religious physicians whose humaneness may be questioned. The important point is that even those without formal religious allegiance may have distilled from their cultures and background important and positive ethical messages. As Glick says, "Whether these ethical distillates, uncoupled from their religious moorings, will be transmittable to subsequent generations remains questionable and probably will be one of the major tests by which our secular societies will be judged."³

My plea then is for a return to ethical values which, in the past, were best supported by a religious framework. I do not think it is necessary for us to attest to a formal religion in order to become more humane. I do think, however, that the quest for values and ethical standards is now, more than ever, a goal for which the humane physician must strive. Unless we do so, the deterioration of our culture will be reflected by a continuing lack of humanity in our care-givers.

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autism expert to Honolulu. The first conference in 1991 featured Dr Gary Mesibov of Division TEACCH of the University of North Carolina at Chapel Hill, the 1992 speaker was Dr Douglas Bicklin of Syracuse University, and the 1993 conference presented Dr Temple Grandin, the best known person with autism in the U.S. She is a professor of animal husbandry and a national autism educator. To date, these annual conferences have trained more than 450 professionals and parents yearly.

Yet another contribution that will be of particular use to local physicians has been the availability of the newest screening questionnaire for autism, the Childhood Autism Test for Toddlers (CHAT). This straightforward 14-item questionnaire should be of great value for the initial screening of children as young as 18 months.⁹ It is hoped this will help make possible the recognition of autistic symptoms at an age when active intervention can prevent the more serious sequelae of unrecognized autism. Copies are available from the Autism Project and can be requested by phone.

Of course these developments, helpful as they are, are only the beginnings of what is hoped to be accomplished. For example, the aforementioned survey identified the following key needs.

- 1) a structured special educational program geared to the child's developmental level of functioning, especially the unique communication problems of autism; 2) daily, intensive, individualized speech and language therapy; 3) auditory training; 4) technical assistance on behavioral management; 5) respite care; 6) appropriate residential care; 7) better education of medical students, residents and physicians; 8) creation of a statewide network of services to support children and families on all islands.

In addition to the humanistic and medical issues above, Hawaii is at an ideological and economic crossroads with regard to autism. If we continue as we have in the past, an increasing number of children with preventable handicaps will require expensive, lifelong institutionally based care. In addition to the cost to children and families, as teenagers without social and language skills and unable to express their needs, autism victims become unmanageable at home and in the community (unlike Down's syndrome for example), and hence will require institutional care. The expense of such care eventually bankrupts families and requires state funding, a cost in excess of \$125,000 a year per adolescent, or a lifetime estimate of \$6,250,000 per child. We already lack the institutional capacity to adequately address this issue. By delaying needed services until they are forced on us by the developmental pressures of adolescence, we are unable to avoid the expensive, institutional care. It is our hope that the presence of the Autism Project, combined with aroused community awareness, will allow us to adopt the prevention and cost-effective models present in several states, eg, North Carolina, New Jersey and California. These family and community-based coordinated service systems utilize both autism-specific and generic disability services in order to provide a full range of service options for persons with autism. Such a system not only can prevent the needless handicap in the higher functioning autistic child, but also can maintain the more severely impaired, low functioning autistic child in the community.

Hawaii is now moving in this direction, and it is hoped that physicians will support this improvement in care.

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