Ethical Issues in Early Intervention

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Alan Poling and Timothy L. Edwards

Keywords
Ethics

Professionals who provide early intervention services for children with autism (and related conditions) are expected to adhere to the code of ethics promulgated by their discipline. These codes set forth the principles of conduct governing an individual or a group. For example, ethical professional practices for Board Certified Behavior Analysts are outlined in the Behavior Analyst Certification Board Guidelines for Responsible Conduct (BACB Guidelines 2010). These guidelines, like those of other organizations that provide clinical services, such as the American Psychological Association (2010) and the American Medical Association (2012), provide general information about the kinds of actions by professionals and interactions between professionals and clients that are appropriate and, at least as importantly, those that are inappropriate. The former are "ethical," the latter "unethical," and some behavior analysts (e.g., Bailey and Burch 2011) base their consideration of ethical issues entirely on the code of ethics of their profession, specifically the *BACB Guidelines*. Such an approach is certainly practical and the book by Bailey and Burch is an excellent introduction to ethical issues likely to pertain to early interventions for children with autism. We believe, however, that focusing only on the *BACB Guidelines,* or the codes of conducts of other organizations, fails to address adequately some important ethical issues. Therefore, we cast a wider net in the present chapter.

From our behavior analytic perspective, it appears that "ethical" behavior involves patterns of responding that members of a particular culture or subculture, for example, people governed by a professional code of ethics, consider to be particularly important, tact (i.e., label) with the same descriptors (e.g., as "ethical" or "moral," which are functionally equivalent stimuli), and consciously attempt to foster with appropriate rules and consequences. Many decisions regarding early interventions for children with autism can be construed as ethical issues, insofar as they involve deciding whether particular actions that caregivers take with respect to children with autism are labeled by members of the relevant audience as good or bad, right or wrong, ethical or unethical. The problem with this approach in the present context is that many people (e.g., parents, siblings, classmates, teachers, medical doctors,

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A. Poling (✉) · T. L. Edwards
Western Michigan University, Kalamazoo, USA
e-mail: Alan.poling@wmich.edu

T. L. Edwards
e-mail: timothy.edwards@apopo.org

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speech therapists, occupational therapists, behavior analysts, taxpayers) have a legitimate interest in the interventions arranged for young children with autism, and they will not necessarily agree on the ethical acceptability of particular applications. Although philosophers and psychologists have suggested that there may be universal standards of "ethical" behavior and endeavored to develop models explaining why people do and do not behave "ethically," these efforts have been largely unsuccessful (Rogerson et al. 2011).

Our purpose is to introduce a range of issues concerning early interventions for children with autism that might, but need not, be construed as ethical issues. Framing them as ethical issues draws attention to their importance, but also is apt to generate counterproductive emotional responding. For example, in discussing the evidence for the effectiveness of early interventions, we note that the scientific evidence of effectiveness often is relatively weak. As a case in point, although aripiprazole (Abilify) and risperidone (Risperdal) are approved by the US Food and Drug Administration for treating "irritability" in children with autism, the studies on which approval was based lasted for only 2 months and there are no data regarding the effects of these drugs when taken for long periods beginning early in life. Anyone who prescribes aripiprazole or risperidone as an early intervention for children with autism is making a leap of faith in the hope that doing so meaningfully benefits the children. There is certainly a possibility that the quality of a child's life will be improved substantially by the drug, and that is why the physician prescribes it. But there is also a possibility that a given patient will be harmed in the long run, although the probability that such harm will occur cannot accurately be specified when treatment is delivered. A physician's decision to prescribe or not prescribe aripiprazole or risperidone for a young child with autism who exhibits high levels of inappropriate behavior could be construed as an ethical issue, and she or he could (but in our view should not) be accused of behaving unethically if the wrong choice is made. But what is the wrong choice? The answer, of course, is likely to depend upon whom one asks and our opinion is of no special importance. We are not arbiters of ethical conduct and, save for what should be an unnecessary warning against gross malfeasance or implementing treatments that are clearly harmful or valueless, we make no attempt to dictate which early intervention practices are and are not ethical. We do note, however, that there is much worthy of consideration when the topic is opened to full and fair discussion.

Diagnosing Autism

When we make a diagnosis based on objective underlying differences between people, we are defining "natural kinds" in that the fundamental differences already existed in nature before our classification. We are cleaving nature at the joints, to use a common analogy, when we diagnose a child with Down syndrome because we can point to a chromosomal abnormality that is responsible for the manifestations of the syndrome. In contrast, when we do not have information about a fundamental underlying distinction and make a diagnosis based on social convention with respect to the signs and symptoms of interest, we are not defining "natural kinds" but rather applying a label to a set of characteristics. With autism, there is at present no measurable underlying mechanism that accounts for the symptoms of the condition, and diagnosis of autism is based on a socially defined set of behavioral characteristics, so autism does not fit our definition of a "natural kind." Currently, according to the *Diagnostic and Statistical Manual of Mental Disorders IV-TR*-(*DSM-IV-TR*), if an individual displays restricted, repetitive stereotypical behavior in addition to impairments in both social interaction and communication, she or he may be appropriately diagnosed with autism (American Psychiatric Association 2000). Some of the impairments or abnormalities must be present before 3 years of age. The items that are used to determine if the above criteria are met include such behavioral characteristics as "lack of social or emotional reciprocity," "stereotyped and repetitive use of language or idiosyncratic language," and "persistent preoccupation with parts of objects." In the end, diagnosing someone with autism is a judgment call and there is no "gold standard" for the diagnosis.

Autism is classified as a neurodevelopmental disorder, and there is quite a bit of evidence supporting this classification. For example, a general finding is that children diagnosed with autism often experience unusually rapid brain growth shortly after birth followed by slowed or arrested brain growth at around 2 years of age. The rapid growth appears to occur primarily in certain regions of the brain, such as the temporoparietal region. Other regions of the brain, including the corpus callosum, characteristically are smaller, relative to overall brain size, in children with autism than in typically developing children (Casanova 2007; Polšek et al. 2011). Although knowledge of these neurological differences may be useful in understanding the observed behavioral characteristics of children with autism and may eventually aid in diagnosis and the development of strategies for assisting people diagnosed with autism, they are themselves manifestations of an underlying factor or, more realistically, a constellation of factors that lead to both the neurological and behavioral characteristics of people with autism.

Moreover, recent research strongly suggests that the three behavioral domains characteristic of autism (social impairment, communication difficulties, rigid and stereotyped behavior) are relatively independent (see Happé et al. 2006). That is, there is not a strong correlation between the severity of a child's impairment in one of these areas and her or his impairment in either of the other areas. The independence of the three behavioral domains characteristic of autism makes it highly unlikely that there is a single genetic, biochemical, cognitive, or behavioral explanation that is able to explain the disorder (Happé et al. 2006).

The results of twin studies do suggest that there is a strong genetic component to autism (Muhle et al. 2004; Ronald and Hoekstra 2011), but the possibility that a single gene is responsible for autism has been definitively ruled out (Casanova 2007; State and Levitt 2011). Instead, it appears that a number of genes in combination with environmental factors, including prenatal development, lead to the group of behavioral characteristics we call autism. Children diagnosed with autism are remarkably heterogeneous, and it is becoming increasingly clear that "autism" comprises several subtypes of behavioral deficiencies, which are highly likely to differ in etiology. This point is made clearly by David Amaral, the director of the Autism Phenome Project, which is a large research project designed to "distinguish among subgroups or phenotypes of autism [and] link these different forms of autism with distinct patterns of behavior and biological changes" (UC Davis MIND Institute 2012):

> One of the major stumbling blocks of understanding autism is that it's incredibly heterogeneous. Some kids with autism have severe developmental delays, but others have normal or even enhanced I.Q.'s; some have epilepsy, mental retardation, or gastrointestinal problems. You are looking at kids who have very different biological and comorbid features, but all are under the umbrella of autism spectrum disorders. The goal of this project is to identify subtypes of autism. Once we identify those, we believe that we can go after the cause for each one in a more productive fashion. It is almost certain that autism has multiple causes, and it might be better to study each one independently. (Goehner 2012)

While it may be tempting to think of the individual diagnoses that are currently placed under the umbrella of "autism spectrum disorders (ASD)" (autism, Asperger syndrome, and pervasive developmental disorder, not otherwise specified) as separate disorders arising from distinct genetic abnormalities, this is a naïve viewpoint with no scientific support. At present, determining which label to apply to a child presenting with behaviors characteristic of autism is like cleaving meatloaf at the joints, although this may change if the Autism Phenome Project bears fruit.

Because autism is not a "natural kind," the behavioral characteristics in the diagnostic algorithm and the number of characteristics in each category required for diagnosis can change. The changes to the new *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-V*) (American Psychiatric Association 2013), which may well restrict the range of individuals diagnosed with autism (or related conditions) and therefore limit the services that some people receive, have met with fierce opposition by those who want to maintain the status quo, and it appears that this opposition has affected the decisions of the DSM Task Force charged with revising the diagnosis of autism and related conditions. Be that as it may, DSM V no longer differentiates "autism" (or "autistic disorder"), "childhood disintegrative disorder," and "pervasive developmental disorder not otherwise specified," but instead groups these disorders under the collective classification of "ASD." Given the difficulties in distinguishing among the previously recognized disorders, this appears to be an appropriate change, although as noted previously, ongoing research may well reveal differences among children with "ASD" that are readily distinguished and both conceptually and clinically significant.

A change that may be even more significant is reducing the three domains characteristic of autism (or autism spectrum disorder) to two, "social/communication deficits," and "fixated interests and repetitive behaviors." The new language appears in Table 8.1. Three levels of severity of ASD are recognized. Level 3, "requiring very substantial support," level 2, "requiring substantial support," and level 1, "requiring support." It remains to be seen how changes in the diagnostic categories and criteria that eventually appear in *DSM-V* will affect the lives of people with special needs, that is, the ethical implications of those changes. Interestingly, the DSM Task Force indicates that "requiring two symptom manifestations for repetitive behavior and fixated interests improves specificity of the criterion without significant decrements in sensitivity." One wonders, sensitivity and specificity relative to what standard?

The *DSM-V* language describes ASD as a neurodevelopmental disorder that "must be present from infancy or early childhood, but may not be detected until later because of minimal social demands and support from parents or caregivers in early years." In actuality, neuronal structure or function is irrelevant to the diagnosis of the disorder, which is based purely on the basis of behavioral characteristics, and such structural or functional deficits are rarely if ever detected in diagnosed individuals, either early in life or subsequently. Instead, they are simply inferred, which is reasonable but not especially informative. Moreover, specifying that evidence of neurodevelopmental impairment at one point in life is evidence that such impairment was present earlier in life makes the requirement that ASD "must be present from infancy or early childhood" practically meaningless and of no diagnostic value.

Behaviors characteristic of autism appear to be normally distributed throughout the population (Constantino and Todd 2003; Hoekstra et al. 2007), meaning that most people display a few of the behaviors (i.e., the center of the distribution), a few people display none of them (i.e., one tail of the distribution), and a few people display all of the them (i.e., the other tail of the distribution). Put differently, autism represents one end of the spectrum of typically occurring behavior. From this perspective, essence of diagnosis is determining where the line separating "autistic" from "not autistic" should be drawn. Currently, the line is situated in such a way that about 1.1 % of the population falls on the "autistic" side of the line (Center for Disease Control and Prevention 2012). In a normal distribution, this point is about 2.3 standard deviations from the mean.

The ethical implications of moving the cutoff line in either direction are important and should be considered carefully before decisions about changes in diagnostic criteria are made. Members of advocacy groups, such as Autism Speaks, appear to be in favor of moving the cutoff line closer to the mean, but others argue that autism is diagnosed too liberally and that the line should be moved away from the mean. It should be noted that any discussion of "overdiagnosis" is irrelevant in the context of a socially defined disorder such as autism, but concerns about applying the label too frequently may be justified on other grounds. As noted previously, there is no "gold standard" for identifying autism and it is meaningless to talk about the sensitivity or specificity of particular diagnostic techniques. It is, however, highly meaningful to talk about the practical implications of applying those techniques.

When a child is diagnosed with autism, the world from the child's perspective can change

Table 8.1 DSM V criteria for diagnosing autism spectrum disorder

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history	
1.	Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions
2.	Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication
3.	Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative paly or in making friends; to absence of interest in peers
B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text)	
1.	Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases)
2.	Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day)
3.	Highly restricted, fixated interests that are abnormal in intensity or focus (e.g, strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest)
4.	Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement)
C. Symptoms must be present in the early developmental period (but may not become fully manifested until social demands exceed limited capacities, or may be masked by learned strategies in later life)	
D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning	
E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level	

dramatically. She or he might be immediately placed in an early intervention program or begin working with a therapist in the home. It is hard to imagine how these changes would be detrimental, even if the child is “misdiagnosed.” Indeed, a compelling argument could be made that *any* child would benefit from appropriate early interventions building on her or his behavioral strengths and remedying any weaknesses. Early intensive behavioral interventions (EIBIs) for children with autism are often characterized by intensive, individualized instruction, with a high instructor to student ratio. Such conditions are apt to maximize the full potential of anyone exposed to them.

If a child is old enough to attend school when the diagnosis of autism occurs, he or she will most often be placed in a special education classroom, sometimes one specifically geared toward children diagnosed with autism (White et al. 2007). One potential disadvantage of children being exposed to such alternative education is that special education comes at the cost of typical education (Dunn 1968). That is, children receiving early intensive educational services are not exposed to the same environment as their typically developing peers experience and may become "atypical" as a result of the atypical educational environment. "Atypical" in this sense is not necessarily bad, but it is imperative that children educated under special circumstances have the opportunity to develop appropriate social skills and adaptive behaviors and to ensure that desired responses developed through early atypical interventions generalize to other situations.

Another issue that is particularly relevant to individuals who are, or will become, verbal (in the traditional sense of the word), is the effect of the label, "autism," on the individual. Although the reasons are not entirely understood, labels appear to have a strong influence on human behavior. A child who is told that she has dyscalculia may never attempt to improve her math skills and may indeed appear to have a disability, even if there were no grounds for the diagnosis. None of us was born with the ability to solve complex math equations, just as none of us was born with a repertoire of culturally defined social graces. Clearly, many individuals who have been diagnosed with autism are not able to learn social skills as readily as their typically developing peers, and some cannot reach a comparable skill level regardless of the amount of time invested. The diagnosis of autism is invaluable if it affords access to services that increase the likelihood of skill development, but the label itself may also affect social behavior. As Orsini (2009) observed:

> Calling a quark a quark makes no difference to the quark [Hacking 2000, p. 105]. Such is not the case with autism. Autistic labels, characterizations, or classifications have a 'looping effect' on autistic people, on non-autistics, and on the ways in which we understand the autistic descriptor. (p. 126)

The influence of the label on people deeply concerned with the child who has been diagnosed as "autistic" is especially important. When parents first hear the diagnosis, "autism," a wide variety of reactions can ensue. Some feel as if they have lost the child, and others feel relieved that they have found the reason for their difficulties in raising the child. Regardless of the specific reaction, it is unlikely that the parents will ever treat their child the same as they did before the diagnosis or the same as his or her siblings. Some likely changes in parenting behavior are appropriate and generally advisable, such as enrolling the child in early intervention programs and focusing on communication skills. But it is possible that the parent may use the label to explain and in a sense excuse inappropriate behaviors as stemming from autism, rather than recognizing that the inappropriate behaviors are the reason for the diagnosis of autism and can be changed in desirable ways. Changes in the behavior of siblings, educators, and peers who have learned of the diagnosis can also have a major impact on the child diagnosed with autism. It is almost as if the act of diagnosing a child with autism places her or him in an entirely different world. Determining whether that world is better or worse for the child is the crux of ethical diagnosis and treatment.

Increased Prevalence of Autism

In the USA and many other affluent countries, the number of people diagnosed with autism has increased rapidly in recent years. This accelerating trend, although alarming, may not be due to an actual increase in the number of people who exhibit behaviors characteristic of autism, but rather to changes in diagnostic practices and other social influences, and studies suggest that changes in diagnostic criteria, average age of diagnosis, accuracy of diagnosis, cultural practices, and awareness of autism account for much of the increase (King and Bearman 2009; Matson and Kozlowski 2011). It is unclear how much, if any, of the upward trend is due to an actual increase in the prevalence of the behaviors that define autism. Therefore, practitioners should be wary of any claims that the "autism epidemic" is anything other than a shift in social and diagnostic practices until there is evidence to support such claims.

Interestingly, recent studies have found that children born in areas associated with high rates of autism have a higher probability of being diagnosed with autism than children born in otherwise similar areas (Liu et al. 2010; Mazumdar et al. 2010). These studies examined the possibility that the effect is due to factors such as viral transmission or environmental toxicity, but the data suggest that the effect is due instead to social factors. For example, Liu et al. (2010) found that "when two children displayed the same level of autism symptoms, the one who lived closer to a child with autism was more likely to be subsequently diagnosed with autism, while the other was more likely to be diagnosed with sole [mental retardation]" (p. 8).

Children who are diagnosed with autism may receive services that differ substantially from the services provided for children diagnosed with mental retardation. If local cultural norms have a major influence on diagnostic decisions and, as a consequence, the services to which children with special needs have access, labels such as "autism" and "mental retardation" may be less effective at grouping children with similar behavioral characteristics and ensuring that they have access to interventions with a high likelihood of benefiting them. With diagnoses of autism on the rise, this is an issue of increasing concern. The best course of action may be to focus on each individual's needs and skill deficits rather than making treatment decisions based on the child's diagnostic label.

Such an approach to service provision is often termed "non-categorical," or "needs-based." With this approach, the services that a child receives do not depend on her or his receiving a specific diagnosis, but rather on exhibiting general categories of behavioral impairment and specific difficulties within those areas which are targeted for treatment with appropriate evidence-based treatments (Stein and Jessop 1989). For example, if a child is not acquiring language at a normal pace, rather than attempting to attach a nebulous label to the child, such as autism, and base treatment options on that label, specific language acquisition difficulties would be targeted for change with the best available intervention. This approach avoids the ambiguity associated with all socially defined conditions, it does not involve labeling people, and it focuses attention on the specific needs of individuals. It requires, however, a reconceptualization of developmental disabilities and raises vexing issues regarding which children qualify for services beyond the ordinary in education and elsewhere. As with traditional diagnosis, one important issue regards where the cutoff separating children with "special" needs from those with "ordinary" needs is drawn. A second important issue regards how best to match individuals with special needs with interventions likely to be effective in meeting those needs. In all of the helping professions, matching individuals to appropriate treatments is the crux of ethical conduct. Traditional psychiatric diagnosis falls short in this regard, but it is unclear whether alternative approaches would fare substantially better.

Autism and Comorbid Conditions

Although relevant data are not extensive, it is generally recognized that many people with autism exhibit signs and symptoms that appropriately call for assignment to other psychiatric (or educational) diagnoses (e.g., Leyfer et al. 2006; LoVullo and Matson 2010; Simonoff et al. 2008; Yeargin-Allsopp et al. 2003). For example, Yeargin-Allsopp et al. (2003) reported that 68 % of their sample of 987 children with autism for whom relevant data were available had cognitive impairment, and Simonoff et al. (2008) found that, in a sample of 112 children with autism "70 % of participants had at least one comorbid disorder and 41 % had two or more" (p. 921). Like autism, common comorbid conditions often can be detected early in life (Matson et al. 2011a). It is important that this occur, because if untreated these conditions can adversely affect the child early in life and thereafter. Phobias, for instance, are more common in children diagnosed with autism than in children without this diagnosis (Matson and Love 1990). If these phobias are not detected and treated effectively early on, they may be inadvertently strengthened and become both debilitating and difficult to eliminate when treatment is eventually implemented.

Given the high prevalence of other distressing conditions in people with autism and the potential value of early interventions for treating these conditions, it is important that screening devices used for the early detection of autism make provision to detect significant comorbidities. Matson et al. (2011b) make this point clearly in a review of instruments for the early detection of autism:

> [I]nstruments should go well beyond measuring core symptoms of autism. The available research shows a marked overlap between core symptoms of autism, challenging behaviors, and some specific types of psychopathology (e.g., ADHD and anxiety disorders). Tests that cover this broader set of symptoms should be paired with an established measure of developmental milestones. We believe this approach to be best practice for early identification and diagnosis of autism, at this point, given current knowledge in the field. (p. 1323)

We agree. Best practices in a given discipline are ethical practices and the general strategy recommended by Matson and his colleagues has much to recommend it. They suggest that the age range of 17–24 months is appropriate for initially screening for autism, because doing so at an earlier age does not yield reliable results, and also argue that it is inappropriate for all children to be screened for autism. Because parents of children subsequently diagnosed with autism recognize that something is amiss early in the children's lives and pediatricians can also detect marked deficits in early developmental milestones, Matson et al. argue that only children who "evince red-flag variables, or who evince other at-risk variables" (p. 1323) require such specific screening. Taking this tack saves valuable resources and spares parents the agony of contemplating a disability that their child almost certainly does not have.

Autism, Money, and Insurance Coverage

Providing early interventions for children with autism is expensive. For example, early intensive behavioral intervention (EIBI) is extremely costly to implement, and it could be argued that financial resources, which are limited in every society, would be better allocated elsewhere. Given the generally positive findings of most reviews of EIBI (Reichow and Wolery 2009; Sallows and Graupner 2005; Rogers and Vismara 2008; Smith 1999; Warren et al. 2011), however, it can also be argued that providing EIBI to a certain percentage of the population is a sound economic decision in that some children respond well to the treatment, no longer require special services, and in the long run become productive members of society, that is, people who produce more than they consume (Chasson et al. 2007; Jacobson et al. 1998). In such cases, EIBI more than pays for itself.

Moreover, to base treatment decisions purely on financial considerations would strike most of us as unethical. There is within the USA growing acceptance that people with autism deserve to receive effective early (and subsequent) interventions and that the provision of such services should be covered by medical insurance. At the time this is written, 34 states and the District of Columbia have passed statutes requiring insurance coverage of autism (National Conference of State Legislatures 2012). Providing insurance coverage for people with autism raises interesting issues regarding who is to be covered and what kinds of services and service providers are eligible for reimbursement.

It is likely and understandable that parents of young children with special needs will press for those children to be diagnosed with autism, and for caregivers to apply the diagnosis liberally, if a diagnosis of autism provides access to insurance payments affording access to needed services. That is, providing insurance coverage for people with autism may move the cutoff for diagnosis closer to the mean, even if formal diagnostic criteria do not change. In our opinion, this is fine. Many people, including us, believe that it is appropriate for *all* children to receive the best possible services and that it is especially important that children who are at risk for developing significant behavioral deficiencies in any domain receive specialized early interventions designed to meet their needs. As noted, however, meeting these needs is costly and insurance companies will undoubtedly resist the "overdiagnosis" of autism.

Moreover, as the new *DSM-5* rules of classifying people with autism spectrum disorder by level of severity becomes commonplace, one can anticipate that insurance providers will attempt to limit services according to severity. That is, put crudely, more money will be available to provide services for a child with level 3 ASD, the most severe level, than for a child with level 1, the least severe. If this practice becomes widespread, one can anticipate protracted legal battles between insurance companies and representatives of children with special needs over whether those children are properly diagnosed with ASD or another, uncovered condition and, if autism spectrum disorder is the proper diagnosis, whether the level of severity is 1, 2, or 3. The outcome of these battles will establish legal precedent and affect the quality of life of many children with special needs and those who love them.

Advocacy Around the World

Even in wealthy countries, there frequently is resistance to supporting expensive educational (or other) programs designed to benefit a relatively small number of children. An advantage of traditional diagnostic schemes is that they help to unify parents and other caregivers as they advocate for appropriate treatment for their children. Autism advocacy groups, such as Autism Speaks, The Autism Advocacy Network, Autism One, Moms on a Mission for Autism, and Unlocking Autism, have been highly effective in calling attention to autism and in lobbying politicians to provide financial support for autism research and treatment. Although estimates vary widely (see Sharpe and Baker 2009), the USA and other developed countries currently spend enormous sums on providing services for people with autism. Whether sufficient funds are spent on early intervention is open to debate—we would argue probably not—it is clear that much less would be spent if there were no effective advocacy groups. Such groups are essentially nonexistent in resource-poor countries, where autism is rarely diagnosed and seldom treated (Samadi and McConkey 2011).

As Samadi and McConkey (2011) point out, there is very little information about autism in resource-poor countries, and this lack of information has led some writers (e.g., Sanua 1984; Zhang et al. 2006) to the unwarranted assumption that autism is rare in non-Western cultures. What is lacking in such countries is not children with the characteristics that lead to a diagnosis of autism in wealthy countries, but rather sufficient resources to look for, find, and treat those children. As Samadi and McConkey wisely emphasized:

> For those families in low- and middle-income countries who have a child with ASD [an autism spectrum disorder], access to professional support services will be limited. But even so there is a growing recognition of the need for cultural sensitivity in importing knowledge and practices from one culture—such as European nations—into societies with very different cultural backgrounds [Blacher and Mink 2004]. For example, different cultures can have different opinions about appropriate intervention and treatment of children with disabilities [Bailey and Powell 2005]. Hence indigenous research is needed to identify the particular needs of families in nonwestern countries and how information and supports can be better tailored to meet their needs and be respectful of their cultures. (p. 1)

Formation of the World Autism Organization (http://www.worldautism.org) should help to focus worldwide attention on autism in resource-poor countries. Important ethical issues concern the extent to which citizens of wealthy countries should provide financial support for autism diagnosis and treatment in developing countries and the extent to which early intervention specialists should share their skills and knowledge with professionals and laypeople in those countries. Technology, such as teleconferencing, now makes it possible to provide services at a distance, so that, for example, behavior analysts can help to arrange EIBI for children with autism whom they never contact directly. If those children live in resource-poor countries, it is likely that such services would have to be arranged on a pro bono basis. No ethical code requires behavior analysts to work for free, but the possibility of doing so occasionally certainly merits consideration by anyone truly devoted to making the world a better place.

As noted in *DSM-IV* (American Psychiatric Association 2000), the naming of categories based on criteria sets with defining features is “the traditional way of organizing and transmitting information in everyday life and has been the fundamental approach used in all systems of medical diagnosis” (p. xxii). “Autism” is a broad, heterogeneous, even amorphous, diagnostic category. Although widely recognized and useful for focusing attention on the diverse needs of many children, “autism” leaves much to be desired as a diagnostic category. According to the *DSM-IV,* “A categorical approach to classification works best when all members of a diagnostic class are homogeneous, when there are clear boundaries between classes, and when the different classes are mutually exclusive” (p. xxii). None of this is true of autism.

Moreover, as noted previously, from an ethical perspective diagnostic categories are justifiable to the extent that they allow care providers to match patients to effective interventions. Consider, for example, a child who is very thirsty (a symptom) and urinates copiously (a sign). If that child is accurately diagnosed with Type I diabetes, insulin injections are likely to be an effective treatment. If, however, kidney failure is the appropriate diagnosis, then insulin is of no value. From a practical perspective, “autism” is a useful diagnostic category if (a) children who receive this diagnosis are especially likely to benefit from specific interventions that would not benefit children who behave similarly but are not diagnosed with autism and (b) receiving the diagnosis of “autism” affords relevant children access to needed interventions. With respect to behavior-analytic interventions, at least, it appears that the general procedures used to change behavior are similar regardless of the diagnostic labels assigned to clients. There are no “magic bullets” for treating autism, and anyone who makes assertions to the contrary is going well beyond the facts.

We have devoted a good amount of space to issues relevant to diagnosis, an area that may not appear at first glance to be directly relevant to ethics. Our goal has been twofold: First, we want to help parents and practitioners avoid common misunderstandings about the nature of autism and the precision with which the condition can be diagnosed. Second, we want to emphasize the impact that a diagnosis of autism can have on an individual, his or her family, and society in general. The label should be viewed as a rough guide, a sticky note placed above a group of people with some similar behavioral characteristics to emphasize these behaviors, but certainly not as the cause of these characteristics. To be clear, the behavioral differences between most people diagnosed with autism and their typically developing peers are very real, as those who live with autism can attest, but we do people with autism no favor by treating the label as anything more than a label.

Treatment Goals, Risk of Harm, and Ethical Conduct

Poling (1994) argued that ethical interventions are intended to benefit the people who are exposed to them, regardless of the nature of the interventions or the characteristics of the people exposed to them. We agree that this is certainly the case with early interventions for children with autism. Good intentions—that is, focusing first and foremost on the well-being of the child when considering the interventions, if any, to which she will be exposed early in life—is a quintessential part of ethical conduct by the adults who care for and provide services to that child. Interventions intended to serve other purposes merit careful scrutiny, although they are not necessarily unethical.

It is, of course, widely accepted that ethical interventions are intended not just to maximize benefit for those treated, but also to minimize harm. The so-called Hippocratic injunction, to first do no harm (in Latin, *primum non nocere*), has long been an axiom central to the education of medical and graduate students in the helping professions (Smith 2005) and it is clear that behavior analysts and other professionals who offer early intervention services have a fundamental responsibility to not harm their clients or to allow harm to occur under their watch (Bailey and Burch 2011). Occasionally, however, some degree of harm must be tolerated in the short term to reduce overall harm and maximize benefit over the long run. This is the case, for example, when a child is exposed to a painful and debilitating surgical procedure that corrects a cleft palate or a heart defect. As discussed elsewhere (Poling et al. in press; Weeden et al. 2010b), functional analysis (FA) of self-injurious behavior is similar in that participants are allowed to injure themselves under controlled conditions so that the variables responsible for self-injury can be isolated and subsequently manipulated to reduce, or ideally eliminate, such behavior in the participant's everyday environment.

In the seminal study of FA of self-injury, Iwata et al. (1982/1994) took great care to ensure that protections were in place to minimize the risk of harm to participants. Iwata and his colleagues indicated that procedures were approved by a human subjects committee (i.e., an institutional review board), individuals who were at risk of severe physical harm were excluded from participation, and all potential participants received a complete medical exam, with neurological, audiological, and visual evaluations as appropriate "to assess current physical status and to rule out organic factors that might be associated with or exacerbated by self-injury" (p. 199). Criteria for terminating sessions were established through consultation with a physician. The physician or a nurse observed sessions intermittently to assess whether or not termination criteria needed to be adjusted. If termination criteria were met, participants were immediately removed from the therapy room and evaluated by a physician or nurse, who determined whether or not the sessions would continue. After every fourth session, each participant was examined by a nurse. Finally, each case was reviewed at least weekly in both departmental case conferences and in interdisciplinary rounds. Using safeguards such as those arranged by Iwata et al. and limiting the number and length of sessions to the minimum required to provide useful information minimizes harm to participants during FA.

Despite the possibility that harmful behavior will be temporarily reinforced (and thus increased) during FA sessions, it is important to point out that a properly conducted FA does not increase the risk of harm to participants relative to that they encounter in their everyday environment, a point made by Iwata et al. (1982/1994). If it is ethically acceptable for a target behavior to occur outside FA sessions, then the same should be true within such sessions, although safeguards to prevent serious harm might be required. Interestingly, published studies rarely mention such safeguards. Of 116 articles describing the FA of self-injurious behavior recently reviewed by Weeden et al. (2010), nine (7.7 %) described session termination criteria and 23 (19.8 %) described other procedural safeguards for reducing risk to participants.

As Weeden et al. pointed out, it is possible, even probable, that appropriate safeguards to prevent harm to participants were in place in the other studies but were not described. Nevertheless, it is important for those implementing FA procedures to consider the potential importance of having in place structured termination criteria and safeguards to protect individuals engaged in FA. Regardless of the procedure involved, before a young person with autism is exposed to the procedure, ethical researchers and care providers should carefully consider the potential adverse effects of that procedure and take appropriate steps to minimize the likelihood and severity of such effects.

Although punishment, in the technical sense of operant behavior being weakened by its consequences, is ubiquitous in the everyday world, it is noteworthy that prominent behavior analysts, including Skinner (1953) and Sidman (1989), have been critical of the use of punishment to reduce behavior and the use of punishment procedures in education and therapeutic settings is strongly restricted. It is the case, however, that behavior analysts differ widely in their opinions regarding the effectiveness of punishment procedures and the ethicality of using them to reduce problem behaviors. For example, a national survey of the efficacy and ethics of punishment mailed to 500 members of the Association for Behavior Analysis in 2004 (DiGennaro Reed and Lovett 2008) produced results revealing that "the range of opinion among respondents was very large, suggesting that any statements in both the popular media and professional publications claiming that 'professionals' think punishment to be ineffective or unethical (or, for that matter, effective or ethical) are not credible" (p. 65). Nonetheless, respondents generally agreed that punishment should be used only to reduce dangerous behaviors, punishment procedures have more negative side effects and are less effective than reinforcement procedures, and obtaining informed consent and administrative approval are not sufficient ethical safeguards when punishment is used.

Although it is often ignored, as when people content that punishment inevitably has serious side effects, there is a substantial literature dealing with the effects of punishment and alternative methods to treat problem behaviors in developmentally delayed persons, although most of the research appeared more than 20 years ago. For example, Matson and Taras (1989) reviewed 382 relevant studies published from 1967 to 1987 and found that punishment procedures were often effective and no more likely to produce negative side effects than alternative response-deceleration procedures. Despite such findings, in a recent review of punishment as it pertains to therapeutic applications of behavior analysis, Lerman and Vorndran (2002) contend that "further understanding of punishment processes is needed to develop a highly systematic, effective technology of behavior change, including strategies for improving the efficacy of less intrusive procedures and for successfully fading treatment" (p. 431).

It is perhaps worth noting as an aside that punishment procedures and procedures involving negative reinforcement are often grouped together as "aversive" or as "aversive control" operations. There is little to recommend this grouping. Although exposure to punishers and to stimuli that generate escape or avoidance responding (i.e., negative reinforcers) is often, but not inevitably, unpleasant, environmental events that serve as punishers may or may not serve as negative reinforcers and vice versa, and under some circumstances people will avoid or escape from procedures involving positive reinforcement (i.e., positive reinforcement can be "aversive"). Grouping together all punishment and negative reinforcement procedures and considering them as "aversive" is misleading and in our view unfortunate, especially in view of the strongly negative position regarding aversive procedures taken by advocacy groups. For instance:

> The Arc [For People with Intellectual and Developmental Disabilities] and AAIDD [American Association on Intellectual and Developmental Disabilities] *are opposed to all aversive procedures* [italics ours], such as electric shock, deprivation, seclusion and isolation. Interventions must not withhold essential food or drink, cause physical and/or psychological pain or result in humiliation or discomfort. (The Arc 2012)

Depending on how "discomfort" is defined, many early intervention strategies might produce it. For example, it is highly probable that at least some children with autism would indicate that they do not like to attend school or participate in discrete-trial training and they would not do so without inducement. Therefore, these activities, which are clearly intended to benefit the children, are aversive (i.e., the children would escape or avoid them if possible) and produce "discomfort" (because they maintain escape and avoidance responding and are labeled as "unliked," "unpleasant," or "uncomfortable"). Most people, including members of Arc and AAIDD, probably would not consider it to be unethical to require a child with autism to go to school or attend a well-designed training session at home, but this example illustrates the difficulties associated with blanket pronouncements regarding what is and is not proper, that is, ethical, treatment of children with autism or other developmental disabilities. Saying "please don't hit your sister" to a boy who strikes his sibling is punishment if the future probability of hitting is reduced, and so is using a cattle prod to produce the same outcome. That, however, is their sole commonality.

Perhaps unfortunately, the potential abuse of punishment and the negative connotations associated with the term often prevent researchers and practitioners from using what many view as mild and innocuous response-reduction procedures, like saying “No,” to reduce inappropriate responses. It is noteworthy that children with autism sometimes prefer response-deceleration procedures with a punishment component to alternative procedures not involving punishment (Hanley et al. 2005), punishment procedures are often effective in treating problem behaviors in children with autism (e.g., Campbell 2003; Matson and Taras 1989), and such procedures often do not produce undesirable side effects (e.g., Matson and Taras 1989). In view of these considerations, categorically refusing all punishment procedures from early intervention programs for all children with autism may do a disservice to some of those children. Ethical treatment requires individualization, that is, considering the goals, probable (and, eventually, obtained) effects, and procedures of alternative interventions being contemplated to benefit a particular child. In some cases, a procedure that can be accurately construed as involving punishment may be the best option for a child with autism. When punishment is used in a technical sense (i.e., as a description of a procedure in which the consequences of a particular response class reduce the probability of occurrence, or otherwise weaken, members of that response class), it is not inevitably unethical (see Cipani 2004). Certainly appropriate safeguards are needed when punishment is used, but the same is, or should be, true of all other behavior-change strategies.

Psychotropic drugs, which are medications prescribed with the intent of improving mood, cognitive status, or overt behavior, are a case in point. Such drugs are commonly prescribed for people with autism, including children (e.g., Poling et al. 2010), and in some cases certainly constitute an early intervention. It is widely recognized that all psychotropic drugs can produce adverse effects, although the nature and severity of these effects differ across medications and are influenced by many variables, including dose and patient characteristics. Risperidone (Risperdal), for example, is an atypical antipsychotic drug approved by the Food and Drug Administration (FDA) for treating “irritability” (which means reducing undesired behaviors such as stereotyped, aggressive, and destructive responding) in people with autism between 5 and 17 years of age (U.S. FDA 2006). The FDA does not regulate the practice of medicine, however, and physicians can and do prescribe risperidone to younger and older people.

Risperidone can produce a range of side effects, including tremors, drowsiness, fatigue, drooling, weight gain, and enuresis (e.g., Ghanizadeh and Kianpoor 2008; Scahill et al. 2007), but it is impossible to predict accurately which, if any, of these effects will appear in a given child. Anyone who supports early intervention with risperidone should be aware that such effects may occur. Moreover, she or he should be certain that provision is made to detect and deal appropriately with these and any other untoward effects that may occur in the course of treatment. Unfortunately, possible adverse effects of protracted exposure to risperidone begin early in life, which is certainly tenable in some cases, have not been evaluated, and it is possible that early intervention with risperidone exposes children to currently unknown risks. Be that as it may, careful consideration of the possible adverse effects of alternative treatments is an important part of ethical care provision. So, too, is careful monitoring to detect such effects. Poling (1994) contended, and we agree, that:

> It is critical that decisions concerning [medication] use are individualized and data-based to the fullest extent possible. Because we can never know *a priori* how a given person will respond to medication, we must always determine what the medication is intended to do and whether this goal is accomplished. Moreover, we must take care to ensure that observed benefits are evaluated relative to real and possible costs to the patient, and that all decisions are made in her or his best interests. If this is done, treatment is rational and ethical as well. (p. 171)

The same points can be made with respect to all interventions, regardless of their modality or whether they are implemented early, late, or at the midpoint of a person’s life. The ethicality of early interventions for people with autism do, however, deserve particular scrutiny, because

Table 8.2 BACB requirements for responsible conduct state regarding treatment efficacy

2.10 Treatment efficacy	
(a)	The behavior analyst always has the responsibility to recommend scientifically supported most effective treatment procedures. Effective treatment procedures have been validated as having both long-term and short-term benefits to clients and society
(b)	Clients have a right to effective treatment (i.e., based on the research literature and adapted to the individual client)
(c)	Behavior analysts are responsible for review and appraisal of likely effects of all alternative treatments, including those provided by other disciplines and no intervention
(d)	In those instances where more than one scientifically supported treatment has been established, additional factors may be considered in selecting interventions, including, but not limited to, efficiency and cost-effectiveness, risks and side effects of the interventions, client preference, and practitioner experience and training

children may be unable to object to treatments to which they are exposed, even when they receive no benefit from or harm by those treatments. Greiner (1958) called attention to this issue more than 50 years ago in an early discussion of the use of psychotropic drugs to treat people with what was then termed mental retardation. He wrote:

> Sensible adult patients will usually balk when a drug is causing [negative] symptoms, but the very young and the very old are forced to take drugs, can't complain or stop on toxic symptoms, may not even connect them with the drug. The mentally deficient of any size or age cannot protect themselves either, and they also merit special care to avoid toxic doses. (p. 349)

Young children with autism are a highly vulnerable group. They do not have the capacity to consent voluntarily to early interventions of any type and it is imperative that (a) appropriate proxy consent be obtained before any such treatment is arranged and (b) the effects of any treatment are carefully monitored to prevent injury to and maximize benefit for the child.

Right to Effective Treatment and the Ethics of Evidence

Behavior analysts generally hold that their clients have a right to effective treatment (Van Houten et al.1988) and this belief is codified in section 2.0 of the *BACB Guidelines for Responsible Conduct* (Table 8.2), which deals with the effectiveness of treatment. From our perspective, arranging "effective" treatment means, first, that the initial selection of an intervention is based on scientific evidence indicating that the intervention is likely to produce the desired effects in any person exposed to it. That is, treatment selection is evidence based. "Effective" also means that the intervention actually produces the desired effects in the person exposed to it, without producing offsetting untoward effects, and that the desired effects are sufficiently large to be of clinical benefit to the client.

Deciding whether or not existing research indicates that a particular intervention is effective depends upon the type of research believed to provide admissible evidence and the findings of such research (Mesibov and Shea 2011). Behavior analysts typically employ small-N, repeated-measures experimental designs and are likely to consider a treatment effective if most individuals exposed to the treatment produce data that are indicative of an effect in the desired direction that is of sufficient magnitude to be clinically significant. They typically analyze data by visual inspection and do not rely heavily on inferential statistics. There are a number of compelling arguments supporting the use of these research methods (e.g., Horner et al. 2005; Poling et al. 1995). Outside of the field of behavior analysis, however, small-N, repeated-measures designs are often viewed with the same derision as case-study designs, and the distinction between the two seems to be poorly understood.

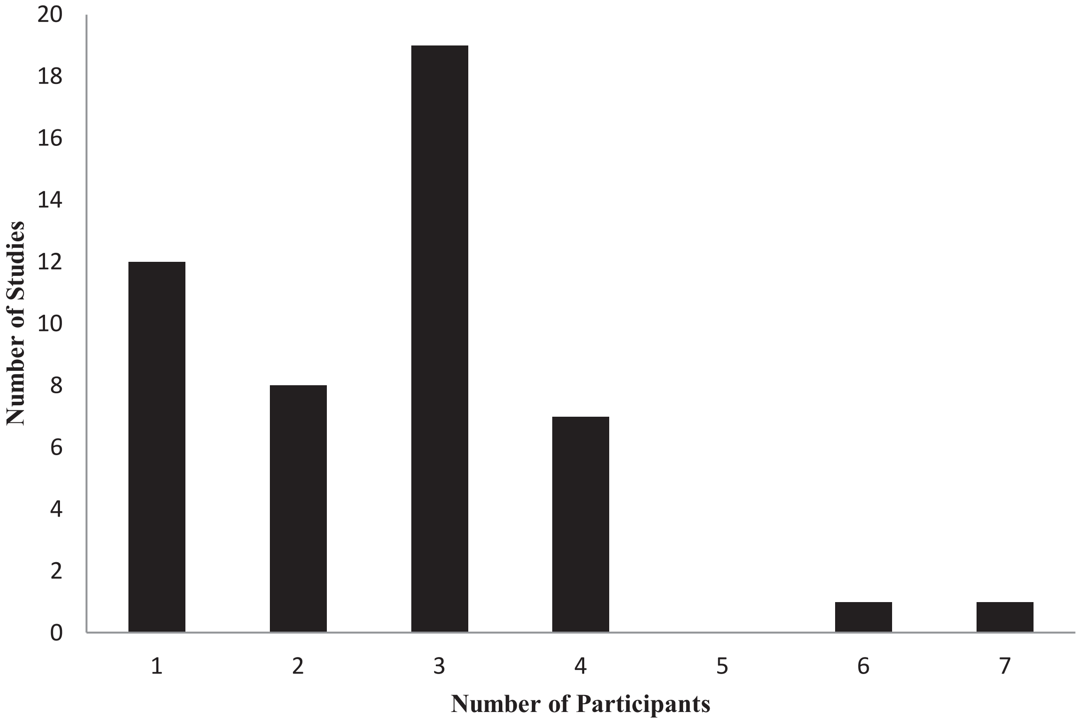

Fig. 8.1 Number of participants in the 48 studies exclusively examining individuals diagnosed with autism spectrum disorders published in the *Journal of Applied Behavior Analysis* from the summer 2010 issue to the spring 2012 issue. No study included more than seven participants

For most scientists, the gold standard for determining the effectiveness of an intervention is the randomized between-groups clinical trial, with statistical data analysis. As Smith (2012) noted in an article published in *The Behavior Analyst,* randomized clinical trials are regarded highly for many good reasons, including the fact that they are useful for performing large-scale evaluations of the efficacy of interventions, a point that is particularly important to funding agencies. He also mentioned that non-behavior analytic interventions are starting to gain approval as early intervention for children with autism because their efficacy is being demonstrated through randomized clinical trials rather than small-N research designs.

In the National Autism Center's (2009) evaluation of interventions for individuals diagnosed with autism, small-N, repeated-measures designs (single-subject designs) with at least 12 participants were included when determining which interventions could be considered to be "established" as effective (this is the best-documented category of interventions). Single-subject designs with at least six participants were considered when deciding which interventions were considered to be "emerging," but designs with fewer than six participants were not included in the evaluation. Figure 8.1 shows the number of participants with autism (or another autism spectrum disorder) studied in each of the 48 articles published in the *Journal of Applied Behavior Analysis* from the summer 2010 issue through the spring 2012 issue that studied only people with such a diagnosis. None of these studies involved 12 or more participants and only two studies (4 % of the total) involved six or more participants. Therefore, regardless of the treatment studied or its effects, none of these studies meet the National Autism Center's (2009) criterion for demonstrating that an intervention is "established" as effective and only two could provide evidence that an intervention is "emerging" with respect to effectiveness.

Children with autism are a vulnerable, protected group and serious ethical issues must be considered when evaluating any proposed study. For example, when randomized clinical trials are conducted, an untreated control group is needed to ascertain the true effectiveness of the early intervention of interest, but withholding treatment from children is difficult to justify ethically, especially when some clearly useful options are already available. Given this consideration, the proper design might compare the intervention of interest to the best possible alternative, perhaps EIBI. This arrangement would provide clinically useful but scientifically incomplete information. Reviews of early interventions commonly lament the paucity of well-controlled studies (e.g., Reichow and Wolery 2009; Rogers and Vismara 2008). That relatively few methodologically sound studies have appeared appears to primarily reflect the formidable ethical and practical challenges faced by researchers rather than a lack of skill or resources.

It is obvious, but worth noting, that nothing prevents researchers and research consumers from establishing criteria for determining the effectiveness of particular interventions based on data from small-N, within-subject experiments. Odom et al. (2003) attempted to develop a methodology for doing so and used that methodology to characterize intervention practices as "well established," "emerging and effective," and "probably efficacious." Based on a review of 37 articles published from 1990 to 2002, they reported that "adult-directed interventions," and "differential reinforcement of desired behavior" were well established and that "peer-mediated interventions," "visual supports," "self-monitoring," and "involving families," were "emerging and effective." These categories differ substantially from and are more narrow than those used in other reviews (e.g., National Autism Center 2009; Rogers and Vismara 2008), the methods used to assign interventions to categories (e.g., as well established vs. emerging and effective) are neither clear nor obviously objective, and the procedures used by Odom et al. have not been widely adopted. At present, it appears that there is no good and accepted method for determining general treatment effectiveness based on the results of within-subject experiments.

Therefore, one must ask: Is it ethical to recommend as effective a treatment that has not been shown to be effective in a large-N, between-groups study? And is one such study sufficient? Or two? There is at present no clear evidential standard for determining when an intervention is and is not effective (Mesibov and Shea 2011) and it appears that the best one can do is to be aware of the evidence regarding the effects of a given intervention, to describe that evidence as accurately as possible to people with a legitimate interest in the child who may be exposed to that intervention (e.g., the child's parents), and to make decisions based on the best evidence available. Regardless of the evidence supporting the general effectiveness of an intervention, it is essential to evaluate the effects of that intervention in the individual child. Only in that way can one ensure that the intervention does no harm and at least some good, which is the crux of an ethical intervention.

Behavior analysts performing research on early interventions for children diagnosed with autism should consider employing randomized clinical trials whenever feasible, especially when single-subject data can be collected simultaneously (see Poling et al. 1995, pp. 103–127). Experimental designs that provide information about an intervention's influence at the group as well as the individual level are a compromise in that some participants are not exposed to the intervention until later in the study, if at all, and independent variables generally cannot be adjusted based on individual outcomes. These are certainly undesirable features of those designs. Nonetheless, failure to conduct randomized clinical trials and appropriate statistical analyses could result in the exclusion of many effective behavior-analytic interventions from lists of empirically validated interventions for children diagnosed with autism. When examining new interventions or when doing applied work, small-N, repeated-measures studies might be the only realistic option, but when there is good evidence that an intervention shows promise, we should take the final step and test the intervention via randomized clinical trial. Additionally, when analyzing treatment options, although proper precautions must be taken, an intervention should not be disregarded just because its validation is based on randomized clinical trials. As Mesibov and Shea (2011) point out:

> [The concept of evidenced-based-practice has] significant financial and legal implications. An unfortunate recent trend is for approaches to claim that they are the 'only' evidence-based or scientifically-proven approach and to encourage parents to demand that public funds be used to support the approach in question. (p. 125)

People who advocate for EIBI do so for good reason, but stating their case too strongly is unwise and may border on unethical.

It is noteworthy that the *BCBA Guidelines* require behavior analysts to recommend "the most effective treatment procedures" and to review and appraise "likely effects of all alternative treatments, including those provided by other disciplines and no intervention." These are tall orders, easily voiced but nearly impossible to follow. In many cases, there are no direct comparisons of alternative intervention. For instance, as Weeden et al. (2010a) point out, both risperidone (Risperdal) and behavior-analytic interventions are used to reduce problem behavior in children with autism and there are published data indicating the value of both.

There are, however, no direct comparisons and the research methods used to evaluate the effects of risperidone and behavior-analytic interventions differ sufficiently to make cross-study comparisons problematic. In addition, a wide variety of behavior-analytic procedures are used to reduce undesired behavior, making it nearly meaningless to compare "risperidone" to "behavior analysis." Finally, as noted previously, the long-term effects of exposure to risperidone are unknown. Even if a behavior analyst is fully knowledgeable with respect to published studies, she or he will be hard pressed to say whether risperidone or a given behavior-analytic procedure is "most effective." Moreover, it is not realistic to expect most practitioners to be conversant with research outside their area of expertise, or to have the skills or time to evaluate this research. If they do not, are they irresponsible or unethical? We think not.

Many interventions for individuals diagnosed with autism originate outside of the field of behavior analysis. As we emphasized previously, non-behavior-analytic interventions should not be dismissed out of hand, and some are of documented value. Nonetheless, many of them have no supporting evidence, have been demonstrated to be ineffective, or have been shown to be harmful. It is not a practitioner's obligation to be aware of all alternative therapeutic interventions and the status of those interventions, but situations can arise in which an individual with whom a practitioner is working might be exposed to questionable or potentially dangerous interventions. If, for example, a practitioner discovers that a child with whom she or he is working will be exposed to chelation therapy, what action, if any, should the practitioner take? Chelation therapy is used appropriately to remove heavy metals, such as lead and mercury, from the body (Klassen 2006), but there is no evidence that lead, mercury, or any other heavy metal causes autism, there is no evidence that chelation therapy benefits children (or adults) with autism, and there is clear evidence that such therapy is dangerous (Weber and Newmark 2007). Therefore, its use to treat children with autism appears to be unethical.

Because chelation therapy is dangerous (and potentially lethal) does a behavior-analytic practitioner have an obligation to inform the guardian of a child with autism who is a candidate for chelation therapy about the status of research on chelation therapy and the potential for harm to the child even if that practitioner has no direct role in the treatment? In our view, he/she probably does. There is a risk, however, of such a practitioner voicing opinions regarding that which she or he has no real expertise, and in so doing venturing onto shaky ground. Standard 1.02 (Competence) of the *BACB Guidelines* (2010) specifies that:

> (a) Behavior analysts provide services, teach, and conduct research only within the boundaries of their competence, based on their education,

> training, supervised experience, or appropriate professional experience.
>
> (b) Behavior analysts provide services, teach, or conduct research in new areas or involving new techniques only after first undertaking appropriate study, training, supervision, and/or consultation from persons who are competent in those areas or techniques.

Most behavior analysts are not trained in psychopharmacology, medicine, or occupational therapy. If that is the case, is it ethical for them to provide information to parents or guardians of children with autism regarding the nature or probable effects of psychotropic medications, chelation therapy, or sensory integration? And how does the ethical obligation for competence prior to service delivery relate to the ethical obligation to review and appraise "likely effects of all alternative treatments, including those provided by other disciplines and no intervention?"

Another significant issue regards how a practitioner should proceed when it appears that a child with autism is a candidate for treatment with an intervention that is apparently harmless but also useless that is, of no benefit to the child. In such cases, it appears to be good practice to inform the child's guardian of the relevant research findings and suggest in a tactful way that the proposed treatment is highly unlikely to be of benefit. In the event that the child's guardian still wants to continue with the intervention, the practitioner could offer to take data to determine whether or not the intervention actually is effective if doing so is tenable, or offer a suggestion as to how others could collect and interpret relevant data.

When dealing with "harmless but ineffective" interventions, such as requiring children to wear weighted vests (for a review see Stephenson and Carter 2008), practitioners, parents, and other individuals concerned with the child's well-being should be made aware that these interventions are often costly and time consuming and may cut into resources that could be allocated to effective therapy. In addition to their opportunity cost, interventions that are not obviously harmful may in fact have unintended negative consequences that are real but difficult to quantify. For example, requiring a child with autism to wear a weighted vest may be socially stigmatizing and negatively affect interactions with other children.

If there are no compelling data indicating whether an intervention is harmful in children with autism, but there is reason to believe that this may be the case, practitioners should proceed cautiously in making recommendations and base those recommendations on whatever evidence is available, being sure to relate the nature of that evidence to others with a legitimate interest in the quality of life of the child in question, such as her or his parents. For example, we have noted that risperidone is FDA approved for the treatment of irritability in children with autism and that there are data indicating that it can be effective for this purpose. As we have also indicated, the drug is known to produce a range of untoward short-term effects, but its long-term effects in children with autism are unclear and the likelihood that a given child will experience adverse reactions cannot be confidently specified *a priori*.

It is noteworthy that the makers of Risperdal (the trade name of risperidone) were recently fined about US$ 1.2 billion by the state of Arkansas for downplaying the negative side-effects of the drug (Muskal 2012, April 11). Although the efficacy of the drug has been validated through clinical trials, this news seems to suggest that many parents and guardians decided to expose the children in their care to Risperdal without full knowledge of its potential to do harm and that the children were harmed by that exposure. Is a behavior analyst working with parents or guardians whose children are, or might soon be, exposed to Risperdal ethically obligated to inform them of the recent developments regarding Risperdal noted above, even though the behavior analysts is not expert with respect to psychopharmacology or law and is not legally empowered to administer the drug?

The Need for Intervention

So far, this chapter has been written under the working assumption that children diagnosed with autism should be exposed to interventions designed to help them behave similarly to their typically developing peers, but this assumption may merit scrutiny. In this section, we examine arguments for and against the implementation of interventions intended to change the behavior of people diagnosed with autism.

Some representatives of autism rights groups argue that autism is an example of “neurodiversity” and that attempting to “normalize” individuals who have been diagnosed with autism is a violation of their rights. Advocates of this perspective see autism as a defining and fundamental aspect of an “autistic” individual and promote the acceptance of autism rather than attempts to “cure” autism, which, they argue, is not a disease or disorder (Harmon 2004). In an extreme example of this perspective, Dawson (2004) decries EIBI as a gross violation of numerous ethical standards and the basic rights of children diagnosed with autism. One of her major gripes with behavior-analytic interventions is that they are intended to change individuals by making them “less autistic,” which implies that autism is an undesirable condition. It is abundantly clear that *people with autism* are in no sense undesirable and have precisely the same rights and prerogatives as people without the diagnosis. Moreover, discriminating against such people in any way is unethical and promoting the full acceptance of people with autism, despite their unique characteristics, is highly desirable. Nonetheless, the behavioral characteristics exhibited by children with autism that lead to their diagnosis are less than desirable in that their occurrence limits opportunities for reinforcement in the everyday world and therefore the quality of their present and future lives. Changing these behaviors early in life to the fullest extent possible appears to be in the best interest of the children and in our view arguments against early interventions in general are both few in number and misguided.

In fact, a reasonable argument could be made that it is unethical to withhold early interventions from a child diagnosed with autism. In pursuing this point, Moon (2010) describes a scenario in which a medical doctor identifies clear autistic behavioral characteristics in a young patient and asks the child’s parents about the interventions he has received, to which the parents reply that he does not need therapy because his differences are simply an example of neurodiversity and there is nothing wrong with him. The doctor, who works at an autism clinic, feels conflicted about her responsibilities. She is obligated to respect the parents’ decisions as caregivers, but she also has a responsibility to help the child develop into a healthy, autonomous individual. Moon suggests that the doctor should refer to the guidelines outlined by Diekema (2004, p. 252) and base her actions on answers to the following questions:

1. By refusing to consent are the parents placing the child at significant risk of serious harm?
2. Is the harm imminent, requiring immediate action to prevent it?
3. Is the intervention that has been refused necessary to prevent the serious harm?
4. Is the intervention that has been refused of proven efficacy, and therefore, likely to prevent the harm?
5. Does the intervention that has been refused by the parents not also place the child at significant risk of serious harm, and do its projected benefits outweigh its projected burdens significantly more favorably than the option chosen by the parents?
6. Would any other option prevent serious harm to the child in a way that is less intrusive to parental autonomy and more acceptable to the parents?
7. Can the state intervention be generalized to all other similar situations?
8. Would most parents agree that the state intervention was reasonable?

If the answer to all questions save number 6 is “yes” and the answer to Question 6 is “no,” then withholding treatment is unethical. Therefore, the doctor in our scenario should respect the parents’ decision and take no forceful action against them because the child is not in immediate danger of significant harm.

Although the strategy proposed by Diekema (2004) for evaluating the ethicality of withholding treatment relies on subjective evaluation and is not universally accepted, it does appear to align well with legal opinion. For example, Diekema (2004) recounts a case in which the parents of a child with Burkitt’s Lymphoma refused to expose him to chemotherapy, which offered a 40 % chance of survival. The court ruled in favor of the parents' decision because, although the alternative to the treatment was certain death, "[chemotherapy] is extremely risky, toxic, and dangerously life-threatening" (p. 256).

In most cases, children who meet the diagnostic criteria for autism are not in immediate danger of significant harm and, therefore, it is unlikely that courts would require exposure to EIBI or any other early intervention. In cases involving serious self-injurious behavior or other life-threatening behavior, however, the court might rule in favor of forced intervention despite parental objections. In such cases, the intervention must be "proven to be effective," which raises issues concerning the standards of evidence required for demonstrating effectiveness. These issues were discussed previously.

Many autism rights activists agree that people who have been diagnosed with autism should be exposed to education and therapy (e.g., Sinclair 1998), but due to their perception of "autistic" individuals as fundamentally and permanently different from "non-autistic" individuals, they argue that the methods and goals of education for "autistics" should also be fundamentally different from the methods and goals for "non-autistics." Ignoring for a moment the implicit assumption that autism is an all-or-none condition, which appears to be in conflict with data suggesting that "autistic" behavioral characteristics are normally distributed, the meat of the argument could be rephrased as a question: Do learning mechanisms for "autistic" individuals differ significantly from learning mechanisms for "non-autistic" individuals? Some autism rights activists say the answer is "yes" and, like Dawson (2004), contend that EIBI does not take these differences into account. Moreover, they believe that the methods employed in typical EIBI are inappropriately directed at normalization ("in the sense of making children with autism normal," that is, like other children) rather than habilitation of children with autism. In sum, according to this argument, EIBI is suboptimal and misguided. Although part of the foundation for this argument, regarding the nature of autism, appears to be on shaky ground, the accusations are serious and should be addressed.

As discussed in the context of "the right to effective treatment," if one type of treatment is found to be more effective than another type, with few exceptions (e.g., the alternative treatment is also dangerous), the more effective treatment should be pursued. Without evidence for a more effective method of education, criticism of EIBI as suboptimal falls flat. EIBI is founded on principles of learning that transcend race, strain, species, and diagnosis. It is unlikely that a certain subset of the human population is exempt from the orderly influence of the environment on their behavior, and there is much evidence documenting the effectiveness of behavior analytic methods in changing the behavior of children diagnosed with autism. Additionally, unlike many alternative interventions, EIBI is highly individualized in that the strengths and weaknesses of individual children are taken into account throughout the educational process. This personalized approach is particularly important for individuals diagnosed with autism given that their behavior and its controlling variables sometimes differs significantly from that of typically developing individuals.

Although EIBI is individualized, the National Academy of Sciences National Research Council recognized that effective programs have certain general features. For example, they start early in life (by 2–3 years of age), run each weekday year round for at least 25 h a week, have a low (1 or 2 to 1) teacher (or therapist-) to child ratio, utilize structured (rather than unstructured or discovery based) programs, are conducted in quiet and non-distracting environments, emphasize developing communication and social skills, prevent the emergence of challenging behaviors, involve parents, and arrange interactions with typically developing peers (Thompson 2007). If EIBI did not have unifying characteristics, it would be impossible to evaluate its general effectiveness or to disseminate it widely to serve the interests of children with autism.

Concluding Comments

We have introduced a substantial range of issues under the guise of ethics. Whether those issues are, in fact, ethical issues depends solely on one's perspective. All of the issues, however, are relevant to the well-being of children who may be diagnosed with autism and exposed to early interventions intended to deal with the behavioral excesses and deficits that are the basis of the diagnosis. For that reason, they are important issues. Many of them also are complex. "Autism" is a broad, heterogeneous, and murky diagnostic category and the specific needs of children who receive this diagnosis differ substantially. Further research is needed to ascertain the etiology of those needs and the best tactics and strategies to meet them. As Rogers and Vismara (2008) point out:

> It is clear that the field is still very early in the process of of determining (a) what kinds of interventions are most efficacious in early autism, (b) what variables moderate and mediate treatment gains and improved outcomes following intervention, and (c) the degree of both short-term and long-term improvements that can reasonably be expected. (p. 8)

Ethical conduct requires practitioners to do their best to stay abreast of the research literature and consistently endeavor to implement best practices for children with autism. At present, EIBI as initially developed by Lovaas is the sole comprehensive treatment generally recognized as "well established" (Rogers and Vismara 2008) and it is certainly appropriate for behavior analysts to advocate for and consistently utilize it.

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