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Are the Majority of Children With Autism Mentally Retarded? A Systematic Evaluation of the Data

Meredyth Goldberg Edelson

There are frequent claims in the literature that a majority of children with autism are mentally retarded (MR). The present study examined the evidence used as the basis for these claims, reviewing 215 articles published between 1937 and 2003. Results indicated 74% of the claims came from nonempirical sources, 53% of which never traced back to empirical data. Most empirical evidence for the claims was published 25 to 45 years ago and was often obtained utilizing developmental or adaptive scales rather than measures of intelligence. Furthermore, significantly higher prevalence rates of MR were reported when these measures were used. Overall, the findings indicate that more empirical evidence is needed before conclusions can be made about the percentages of children with autism who are mentally retarded.

To be diagnosed with autism in the United States, a child must meet criteria as defined in the *Diagnostic and Statistical Manual of Mental Disorders (DSM)*. The child's cognitive ability has never been part of the diagnostic criteria for autism in any of the versions of the *DSM* in which autism has appeared (American Psychiatric Association [APA], 1980, 1987, 1994, 2000). However, the authors of the current manual, *DSM-IV-TR*, note that "in most cases, there is an associated diagnosis of mental retardation, which can range from mild to profound" (APA, 2000, p. 71). In fact, in each version of the *DSM*, mental retardation (MR) has been considered an associated condition of autism, and in some versions of the manual, it is noted that 70% to 75% of children with autism are also mentally retarded (APA, 1980, 1994).

Autism was first described by Kanner (1943), who maintained that children with autism had normal intellectual functioning; he stated that "even though most of these children were at one time or another looked upon as feebleminded, they are all unquestionably endowed with good *cognitive potentialities*" (p. 247; Kanner's emphasis). Kanner never systematically nor empirically assessed the intelligence of individuals with autism; his statements were made based on ob-

servations of 11 children. There were, however, early studies that did obtain empirical evidence regarding the intelligence of children with autism; rates of MR in samples of children with autism were typically between 30% and 40% in these reports (Pollack, 1958), much lower than the rates cited today. Questions arise as to when the assumptions about the rates of MR in children with autism changed and, more importantly, upon what evidence they changed.

Creak (1961) was the first author to make a claim that children with autism were likely to have MR. As part of a working group for establishing diagnostic criteria for autism in Great Britain, Creak described nine criteria for schizophrenic syndrome of childhood, one of which was "a background of serious retardation in which islets of normal, near normal, or exceptional functioning or skill may appear" (Creak, 1961, p. 818). In a subsequent paper, Creak (1963) again claimed that the psychotic child "is the most ineducable of any" (p. 88). The empirical evidence at the time, while scant, did not support Creak's assertions that there was *generally* a "background of serious retardation," and Creak herself never cited any evidence for her claims. However, shortly after Creak's publications, researchers began finding much higher rates of MR in children with autism, and this seemed to follow other nonempirical claims that could be traced back to Creak (e.g., Lockyer & Rutter, 1970; Rutter, 1974). Since then, hundreds of additional claims have been made, and currently it is commonly reported that between 67% and 90% of children with autism also have MR.

To date, no systematic examination of the evidence for the claims regarding the rates of MR in children with autism has been conducted. In view of this, the purpose of the present study was to examine the origin of the statistics regarding the high prevalence rates of MR in children with autism to ascertain the nature of the support for these statistics. Before this examination can take place, it is important first to understand how a diagnosis of MR is made and how intelligence level is typically assessed. A diagnosis of MR is based on three criteria: cognitive impairments defined by IQ scores less than 70,

adaptive skills deficits, and age of onset prior to 18 years (APA, 2000). Children who have autism will meet the latter two criteria as part of meeting the diagnostic criteria for autism (APA, 2000). However, because intelligence level is independent of a diagnosis of autism, the focus of the present examination is specifically on intelligence determination in children with autism.

In children without autism, standard measures of intelligence, such as the *Wechsler Intelligence Scale for Children—Third edition* (WISC-III; Wechsler, 1991) or the *Stanford-Binet* (Thorndike, Hagen, & Sattler, 1986), are frequently used. Although these and other intelligence tests were frequently used with children with autism in the 1960s and 1970s, this practice has been largely discontinued because of the acknowledgment that there are often language difficulties (see Tager-Flusberg, 1989; Rutter, 1978), attention deficits (see Burack, Enns, Stauder, Mottron, & Randolph, 1997; Dawson & Lewy, 1989), and processing delays and dysfunction (see Burack et al., 1997) that may make customary measures of intelligence challenging to use and, in some cases, inappropriate for children with autism. Language deficits, for example, may be independent of intelligence (Lord & Paul, 1997; Rutter, 1978), which may make verbal measures particularly troublesome for this population. For these reasons, some researchers, even in the early days of autism research, relied on subtests of intelligence tests or used alternative methods to assess the intelligence of children with autism.

Historically, alternative methods used to assess intelligence in children with autism included developmental measures such as the *Bayley Scales* (Bayley, 1969) or adaptive skills measures such as the *Vineland Social Maturity Scale* (Doll, 1965) or the *AAMD Adaptive Behavior Scale* (Fogelman, 1975). Although the use of these measures avoided some of the difficulties highlighted above, it is important to note that these are not measures of intelligence and do not provide the same kind of information as do intelligence tests. Developmental scales provide developmental quotient (DQ) scores, a reflection of the attainment of developmental milestones relative to same-age peers. Adaptive and social maturity scales provide social quotient (SQ) scores, a measure of the acquisition of social and adaptive behaviors also relative to one's cohort.

Research has shown that low scores on developmental scales do not predict subsequent development in children with autism as well as they predict development in typical children (Rogers, 2001) and that adaptive scales can underestimate the intelligence of children with autism (Fombonne, Siddons, Achard, Frith, & Happé, 1994). Developmental and adaptive scales may be particularly problematic for higher functioning children with autism, who may have a large discrepancy between their intelligence and what adaptive or developmental measures would predict (Liss et al., 2001). Therefore, the alternative methods used by some researchers to assess the intelligence of children with autism may also be problematic and should be examined systematically.

When evaluating the evidence supporting the claims regarding the rates of MR in children with autism, one must ex-

amine the source of the claims, the time when the studies were published, and the specific methods by which intelligence level was determined. The fact that the diagnostic criteria for autism have evolved since Kanner first identified the disorder cannot be ignored in the evaluation of the existing evidence. Because of this, the nature of the children comprising the samples in research has shifted over the years, and thus it could be argued that comparing prevalence rates across time may not make sense. It might also be argued that children with autism used in earlier studies may have had more severe autism than those assessed more recently. These issues are important to acknowledge. However, prevalence rates reported in the current literature cite past articles, often transcending periods during which various definitions of autism as well as diverse samples of children were used. Because of the use of prior research to support claims regarding the rates of MR in individuals with autism at the present, it is important to examine literature published across time frames regardless of the definition of autism or the nature of the sample utilized.

In the examination of the prevalence rates of MR in children with autism, three issues are important: (a) Do the prevalence rates reported in the literature derive from empirical sources? (b) Can nonempirical sources of these statistics be traced historically to valid empirical studies? and (c) When empirical studies have been conducted, are the methods by which intelligence is assessed appropriate?

Method

Attempts were made to obtain all articles written in English published through December 2003 that made claims or provided data in support of the claims concerning the rates of MR in children with autism. The initial step in the process of locating appropriate articles for review involved an online search of the literature from 1943 (when *autism* was first coined by Kanner) through December 2003 using the PsycINFO database. Because of the early use of the terms *childhood schizophrenia* and *early infantile autism* for what is now called "autism," the search included all three terms. A total of 6,876 articles were found as a result of the search for *autism*, *early infantile autism*, or *childhood schizophrenia*; 27,985 articles were found as a result of the search for *autism*, *early infantile autism*, or *childhood schizophrenia*; 27,985 articles were found as a result of the search for *mental retardation*. There were 842 articles that included the key terms *autism*, *early infantile autism*, or *childhood schizophrenia* and *mental retardation*. It should be noted that in the context of the present study, the term *article* refers to any published source, whether journal article, book, or chapter in an edited book.

Articles that (a) investigated levels of intelligence in children with autism; (b) discussed, in detail, the cognitive abilities of children with autism; or (c) cited a claim about the comorbidity between autism and MR served as the starting point for the present review. I examined the abstracts of the 842 articles to determine whether they met any of the criteria. If they did, they were considered for further review. Of the 842 reviewed, 145 met at least one of the three criteria.

Of these 145 articles, those that made specific claims about the prevalence of MR in children with autism or that provided data regarding the intelligence of children with autism that could be used to determine prevalence rates of MR were included in the present review. Also, a sample of recent child psychopathology, abnormal psychology, and general textbooks on autism was examined to determine if they made statements regarding the intelligence of children with autism. Any of these sources that made claims or provided data regarding the intelligence of children with autism were also included. Articles that provided support for any statistics or claims cited in articles already in the review were additionally examined and included if they met any of the three criteria outlined above. Finally, any additional articles of which the researcher was aware that made claims regarding the prevalence of MR in children with autism were included.

Once an article was chosen for inclusion in the present review, every reference cited by the authors of that article that was used to support the claim of MR was obtained and examined to determine the support for the original claim. These articles were then also included in the review if the reference also made specific statements concerning the prevalence of MR in children with autism or provided data in support of a claim. This practice of following a citation trail historically continued until the citation trail ended. Both peer-reviewed journal articles and non-peer-reviewed publications (e.g., chapters in edited books, claims in textbooks) were included in the sample, as both types of sources were frequently referenced by those making claims. It is recognized that, given the vast literature on autism, some articles making claims about the prevalence of MR in children with autism will have been missed, despite the measures taken to identify all such articles. However, given the size and scope of the sample of articles, it is believed that the sample is representative of the articles in the relevant literature.

After examination, only articles that either made specific claims concerning the occurrence of MR in children with autism or that reported data that could be used by others as support for claims were included in the final sample. Some articles screened for inclusion in the present review ultimately were not included. For example, some articles implied a relationship between intelligence level and autism. The title of one of these articles illustrates this occurrence: "Long-Term Follow-up of 100 'Atypical' Children of Normal Intelligence" (Brown, 1978). These articles were not included in the final sample because they made no explicit prevalence claims. Some articles reported prevalence rates of children with autism who scored above and below an IQ of 50 (e.g., Lewis, 2003; Sponheim & Skjeldal, 1998). These articles distinguished what the authors often termed "low-functioning" children with autism (those scoring in the severe and profound categories of MR) from "high-functioning" children with autism (those scoring in the moderate range of MR or above). Because it was not possible to tease apart the percentages of children scoring above and below the actual cutoff for MR, an IQ of 70, these

studies also were not included in the present review. Finally, articles including children with Asperger syndrome or other autism spectrum disorders (ASD) were specifically excluded from the review, as the purpose of the current research was to examine the evidence for MR claims specifically in individuals with autism.

The final sample consisted of 215 articles that were classified into two types: (a) those that provided data regarding the prevalence rates of children with autism who also had MR (labeled "empirical articles") and (b) those that made claims in the absence of empirical evidence (labeled "nonempirical articles"). Articles that both provided empirical data and made nonempirical claims were considered in both categories. Whether an article was classified as empirical or nonempirical was determined solely with regard to the claim made about the prevalence of children with autism who had MR, not whether the article reported the results of an empirical study. Of the 215 articles in the final sample, 58 made empirically based claims, and 165 made nonempirical claims; 8 of the 215 articles were considered in both the empirical and nonempirical article categories. Thus, 223 total claims were evaluated spanning 1937 to 2003. The one article published prior to Kanner's label of autism in 1943 (Piotrowski, 1937) was obtained when following the citation trail of another article (Pollack, 1958).

Separate examinations of the empirical and nonempirical articles were conducted. Specific findings will be discussed, and some of the articles reviewed will be used as illustrations of particular results. However, due to the amount of data collected for each article, it is not possible to discuss, in detail, each article included in the review. The interested reader is referred to the author's Web site, which offers detailed tables summarizing the information about each nonempirical and empirical article reviewed (www.willamette.edu/~medelson/). An alphabetical reference list of all articles included in the review is included in the appendix.

Results

Because the vast majority of the claims regarding the prevalence of MR in children with autism originated from nonempirical sources, these results will be presented first.

Results From Nonempirical Articles

Seventy-four percent of the claims about the prevalence of MR in individuals with autism came from nonempirical articles; 26% derived from empirical studies. Of the nonempirical articles, 36% never provided a citation in support of the claim. Of the 106 nonempirical articles that did make citations, 8% of the citations failed to provide supporting evidence for the claim, and 21% reported higher prevalence rates than those reported in the articles that the authors cited. Finally, of the 165 nonempirical articles that made claims about the prevalence of

MR in individuals with autism, 88 (53%) of the citations never traced back to empirical data when the reference trail was followed historically.

Of the nonempirical articles, 104 cited specific percentages of individuals with autism who had MR. The remainder of the nonempirical articles made such statements as “a majority of children with autism are also mentally retarded” (e.g., Gillberg & Coleman, 2000, p. 10). For analysis purposes, if an article cited a percentage range, the highest end of the range was considered, as the current review determined that this was most likely the percentage to be cited by subsequent authors. The average prevalence rate reported in the 104 articles citing specific rates was 77.83%, the median prevalence rate reported was 75% MR, and the modal prevalence rate of MR in individuals with autism that was reported was also 75% (reported 45 times); the second most frequently reported prevalence rate was 80% (reported 23 times).

Prevalence rates reported in the nonempirical articles varied by decade of publication. The average rates reported in the nonempirical articles were 40% for the 1 article published prior to 1960; 75% for the 1 article published between 1960 and 1969; 79.39% for the 13 articles published between 1970 and 1979; 75.56% for the 27 articles published between 1980 and 1989; and 79.15% for the 62 articles published since 1990. A one-way analysis of variance (ANOVA) and subsequent Bonferroni post hoc analysis indicated that there was a significant difference between the prevalence rate reported in the 1 article published prior to 1960 and the average prevalence rates reported since then, $F(4, 99) = 8.683, p < .001$. However, this finding should be interpreted with caution as only 1 nonempirical article reported a specific prevalence rate of MR in children with autism prior to 1960.

When all of the nonempirical articles are considered together, not just those reporting specific prevalence rates, a consistent increase is evident over the years in the number of articles making claims that a majority of children with autism have MR. Of all 165 nonempirical articles reviewed, 1 article made this claim prior to 1960 (1% of the nonempirical articles); 4 articles made claims between 1960 and 1969 (2.5% of the articles); 32 articles made claims between 1970 and 1979 (19% of the articles); 47 articles made claims between 1980 and 1989 (28.5% of the articles); and 81 articles have made claims since 1990 (49% of the articles). A chi-square analysis indicated that the number of nonempirical articles claiming that children with autism have MR differed across decades, $\chi^2(4) = 132.30, p < .001$.

One hundred seventeen empirical citations were offered as direct evidence by the authors of the 106 nonempirical articles that made citations for their claims, and they were examined to determine when the empirical data used in support of the nonempirical claims were obtained. For this analysis, only the original empirical citations were considered; nonempirical citation trails were not followed historically as it would be expected that the more the citation trail is traced back, the less recent the studies would be.

None of the empirical citations were to studies published prior to 1960. Forty-four citations (38%) were to empirical articles published from 1960 to 1969; 32 citations (27%) were to empirical articles published from 1970 to 1979; 26 citations (22%) were to empirical articles published from 1980 to 1989; and 15 citations (13%) were to empirical articles published between 1990 and 2003. A chi-square analysis indicated that there were significant differences in the number of citations across decades, $\chi^2(3) = 14.885, p < .01$. Overall, nearly two thirds of the empirical citations were to articles published 25–45 years ago. Figure 1 presents a comparison of the dates of publication of the articles making nonempirical claims that a majority of children with autism are MR and the dates of publication of the empirical data used to support these claims.

Results From Empirical Articles

Of the 58 empirical articles included in the current review, 53 had data for which prevalence rates of MR could be determined (the remaining 5 were included because they were cited by nonempirical articles as empirical support for their claims). The average prevalence rate for these 53 empirical articles was 75.28%, similar to the median and modal prevalence rates reported in the nonempirical articles.

Of these 53 empirical articles, 3 articles (6%) were published prior to 1950; 10 articles (19%) were published from 1960 to 1969; 9 articles (17%) were published from 1970 to 1979; 14 articles (26%) were published from 1980 to 1989; and 17 articles (32%) were published from 1990 to 2003. There was a significant difference in the numbers of empirical articles published across decades, $\chi^2(4) = 4.0, p < .05$. The results suggest a slight increase in data speaking to the prevalence rates of MR in children with autism over the years, which

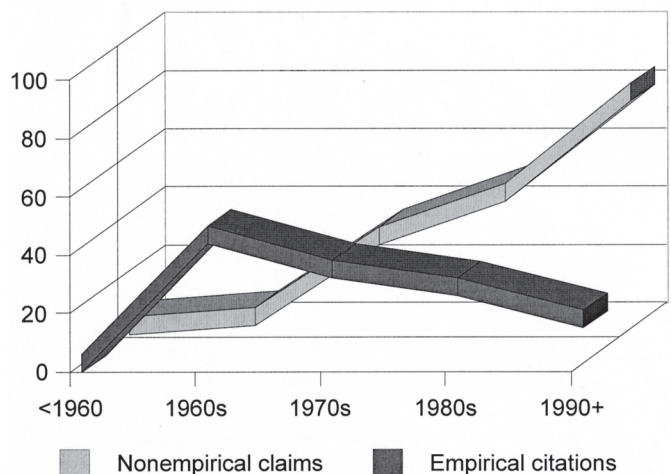


FIGURE 1. Numbers of nonempirical claims and direct empirical citations in support of the claims by decade of publication.

is interesting given that the authors of most nonempirical articles cited less recent empirical studies as support for their claims.

The average prevalence rates were also calculated separately by the decade in which they were published, and a one-way ANOVA was conducted to determine whether the percentages differed across the decades. As can be seen in Figure 2, there was a significant difference in prevalence rates across the years, $F(4, 48) = 7.231, p < .001$. The average prevalence rates reported were 34.33% for the 3 studies conducted prior to 1960; 66.9% for the 10 studies conducted from 1960 to 1969; 86.78% for the 9 studies conducted from 1970 to 1979; 78.29% for the 14 studies conducted from 1980 to 1989; and 78.88% for the 17 studies conducted since 1990.

Bonferroni post hoc comparisons determined that the results were due to significant differences in prevalence rates reported between studies published prior to 1960 and studies published later. Thus, the empirical data show that the reported prevalence rates of individuals with autism determined to be MR increased from prior to 1960 to the 1970s, where peak prevalence rates were reported (averaging approximately 86%), and have remained fairly consistent since then.

Of the 53 empirical articles providing data regarding prevalence rates of MR, 51 could be evaluated with regard to the methodologies they used to determine intelligence (2 articles were reviews of epidemiological surveys previously conducted; see Fombonne, 1998; Wing, 1993). Thirty-five of these 51 articles described the specific methodologies by which the researchers determined intelligence in their samples of children with autism. Thus, of the 223 total claims evaluated, only 35 (15.7%) were both empirical and of such a design that they allowed for an examination of the specific methods used to determine the prevalence rates of MR in children with autism. Although there was not a statistically significant difference between rates of MR reported in articles that did and did not de-

scribe their methodology, the mean prevalence rate of MR in the studies that described their methodology was 71.89% compared with 82.88% for the studies that did not describe how intelligence was assessed, $t(49) = 1.88, ns$.

Analyzing the Effects of Individual Methods Used to Determine Intelligence. The types of methods described in the 35 articles varied, and most articles reported utilizing more than one type of measure. *T* tests were utilized to assess differences between empirical studies that did and did not rely on specific methodologies to determine intelligence. When the standard deviations of the two groups were similar, the *t* tests were based on pooled variances; otherwise, separate variances were used.

Two types of measures of intelligence were used: verbal measures or timed (performance) measures. There were no significant differences in prevalence rates depending on whether the study employed one of these methods or not, and the majority of studies that described their methodology employed both of these measures. Furthermore, most studies that used these measures of intelligence used subtests rather than the full scales. The average prevalence rate of the 8 studies not utilizing verbal measures was 77.25%, compared with a mean prevalence rate of 70.3% for the 27 studies that did use these measures, $t(9.3) = .486, ns$. The average prevalence rate of the 5 studies that did not use timed measures was 73.4%, compared with an average prevalence rate of 71.63% for the 30 studies that did use this method, $t(4.4) = .121, ns$.

Many studies used developmental scales, adaptive scales, or other alternative measures of intelligence. Developmental scales were used in 16 studies, and the average reported prevalence rate of MR in individuals with autism for these studies was 80.25%, compared with an average rate of 64.68% for the 19 studies not utilizing developmental scales, $t(33) = 2.495, p < .05$. A similar finding was obtained for the use of adaptive scales as measures of intelligence. For the 13 studies using adaptive scales as measures of intelligence, the average prevalence rate reported was 79.46%, compared with the mean prevalence rate of 67.27% for the 22 studies that did not use adaptive scales; this difference, however, was not statistically significant, $t(33) = 1.824, ns$. Finally, there was a nonsignificant difference in the prevalence rates of MR reported in studies that used estimates or observations of intelligence (average rate for the 7 studies was 77.71%) compared with those that did not (average rate for the 28 studies was 70.43%, $t(11.7) = 1.013, ns$).

In the 1960s and 1970s, some researchers assumed that children who were "untestable" had MR. These researchers assigned untestable children to the severe or profound MR category and then reported prevalence rates incorporating the "data" from these children (e.g., Kolvin, Humphrey, & McNay, 1971; Rutter, 1966a; Rutter & Lockyer, 1967). Although not statistically significant, there were higher prevalence rates of MR reported for studies that equated untestability with MR. The average prevalence rate for the 8 studies utilizing this practice was 80.5%, compared with the average

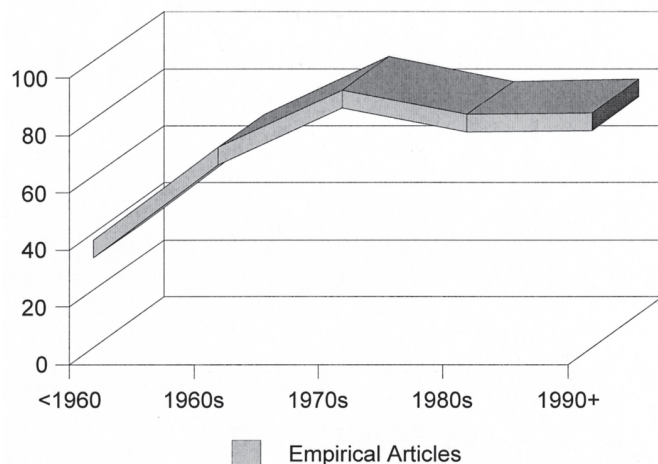


FIGURE 2. Mean prevalence rates of MR reported for children with autism in empirical articles by decade of publication.

prevalence rate of 69.33% for the 27 studies that did not utilize this practice, $t(23.4) = 1.971$, *ns*.

Analyzing the Effects of the Combined Use of Alternative Measures of Intelligence. Most studies utilized at least one alternative measure of intelligence, and the majority of these used more than one such measure. Table 1 presents the findings for the combined use of methods other than true measures of intelligence. It should be noted that the total number of empirical studies included in these analyses exceeds 35 because if an article did not describe a specific method used to determine intelligence but made general statements that allowed for a classification regarding whether a general type of method was employed, the article was included.

As can be seen in Table 1, when studies used either developmental or adaptive measures of intelligence, higher average prevalence rates of MR were obtained; there was a mean prevalence rate of 79.85% for the 20 studies using at least one of these methods, compared with an average rate of 63.75% for the 16 studies that used neither method, $t(34) = 2.576$, $p < .05$. The 28 studies that used developmental or adaptive scales or that relied on observations or estimates of intelligence reported an average prevalence rate of MR of 80.96%, compared with a rate of 57.17% for the 12 studies that did not utilize any of these methods, $t(38) = 4.274$, $p < .001$. Finally, the 30 studies that used at least one of these three methods or that assigned untestable children to the MR category had an average prevalence rate of MR of 80.53%, compared with an average rate of 55.91% for the 11 studies that did not utilize any of these four methods, $t(39) = 4.101$, $p < .001$.

An Examination of DeMyer et al. (1974). Only one study used an unstandardized measure of intelligence, a study conducted by DeMyer et al. (1974), who used the *Vineland Social Maturity Scale* or the *DeMyer Profile Test* as measures of performance IQ in children with autism. The *Vineland* is an

adaptive behavior scale, and a Social Quotient (SQ), not an IQ, is obtained. The *DeMyer Profile Test* is an unstandardized test created by the authors and for which there is no normative nor psychometric data. DeMyer et al. measured verbal IQ either by “estimating” verbal age through an interview with their 115 participants, 78 of whom had no speech or echolalic speech only, or by again using the *DeMyer Profile Test*. In most cases, general IQ was obtained by averaging the performance and verbal IQs. Thus, this study used an unstandardized measure of intelligence with no psychometric data speaking to its reliability or validity, a measure of adaptive skills, and an interview of predominantly nonverbal participants. DeMyer et al. reported that 94% of their sample had MR. Despite the poor methodology and the fact that the article is 30 years old, this study is still being cited as *direct* evidence that a majority of children with autism have MR in sources as recent as the late 1990s and the early 21st century (e.g., deBildt et al., 2003; Erickson, 1998; Prior & Ozonoff, 1998; Sigman, Dissanayake, Arbelle, & Ruskin, 1997; Zelazo, Burack, Boseovski, Jacques, & Frye, 2001). Furthermore, of the 77 nonempirical articles that traced to empirical data, 26 (34%) of these traced either directly or indirectly to this one study.

Discussion

An Examination of the Three Issues

The results from the analyses of nonempirical and empirical articles are considered together to address the three issues put forth at the beginning of the paper.

Did the Prevalence Rates Reported Derive From Empirical Sources? Seventy-four percent of the articles making claims about the prevalence of MR in children with autism came from nonempirical articles; only 26% derived from empirical studies. Of the 165 nonempirical claims made, 36%

TABLE 1
Differences in the Reported Prevalence Rates of Mental Retardation in Children With Autism in Empirical Articles:
A Combined Examination of the Use of Alternative Measures of Intelligence

| Method | Mean prevalence rate | | | | p value of difference (using t test) |
|---|-----------------------|----|---------------------------|----|---|
| | Studies using methods | | Studies not using methods | | |
| | % | n | % | n | |
| Developmental or adaptive skills measures | 79.85 | 20 | 63.75 | 16 | < .05 |
| Developmental or adaptive skills measures or estimates of intelligence | 80.96 | 28 | 57.17 | 12 | < .001 |
| Developmental or adaptive skills measures, estimates of intelligence, or assuming untestable children are mentally retarded | 80.53 | 30 | 55.91 | 11 | < .001 |

Note. The total number of studies for these analyses exceeds 35 because some empirical articles that did not describe specific methodologies did make general statements about the types of measures used. Therefore, if it could be determined whether a particular article did or did not use one of the general combined methods being analyzed, it was included in the analysis.

never gave a citation in support of the claim; an additional 8% gave a citation that did not provide evidence to support the claim; and a surprising number of nonempirical articles (21%) claimed that a higher percentage of children with autism had MR than was claimed in the citation used to support the percentage (e.g., Asarnow, Tanguay, Bott, & Freeman, 1987; Burack, 1992, 1994; Burack & Volkmar, 1992; DeMyer, 1979; Gillberg, 1993; Myers, 1989; Prior & Werry, 1986; Rutter, 1974; Rutter, Bartak, & Newman, 1971; Seligman, Walker, & Rosenhan, 2001; Volkmar & Cohen, 1988; Wing, 1974, 1976). This latter finding indicates a practice of inflating the prevalence rates, which in turn can result in these higher percentages being cited by subsequent authors.

Could Nonempirical Sources of the Prevalence Rates of MR in Children With Autism Be Traced Historically to Valid Empirical Studies? A total of 53% of the nonempirical articles making claims about the prevalence of MR in children with autism never traced back to an empirical source when the citation trail was followed historically. However, some authors making nonempirical claims made specific reference to data supporting their claims even though their claims never traced back to empirical evidence. For example, Schreibman (1988) stated that “the *data* acquired to date indicate that the majority of autistic children are mentally retarded” (p. 25, emphasis added). Yet, the citation Schreibman provided in support of this statement was a nonempirical article (Ritvo & Freeman, 1978). Although Ritvo and Freeman (1978) claimed that 80% of children with autism were MR, they did not provide a citation in support of their own claim. Thus, neither Schreibman’s citation nor the citation trail derived from it provided the “data” she asserted in her claim. The practice of using nonempirical citations to support nonempirical claims was fairly widespread, but most readers would not be cognizant of the fact that, over half the time, the citation trail ended before leading to empirical data.

Were the Methods by Which Intelligence Was Assessed in the Empirical Studies Valid Given the Interference of Autism on the Process of Intellectual Assessment? Empirical evidence for the high prevalence of MR in children with autism came from two sources: epidemiological studies and empirical investigations. A significant number of the recent empirical articles were epidemiological studies investigating the prevalence of autism in various communities (e.g., Arvidsson, Danielsson, Forsberg, Gillberg, Johansson, & Kjellgren, 1997; Fombonne & du Mazaubrun, 1992; Fombonne, du Mazaubrun, Cans, & Grandjean, 1997; Gillberg, Steffenburg, & Schaumann, 1991; Honda, Shimizu, Misumi, Niimi, & Ohashi, 1996; Magnússon & Sæmundsen, 2001; Wignyosumarto, Mukhlas, & Shirataki, 1992). These studies frequently reported prevalence rates of MR based on intelligence assessments that were obtained prior to the study by individuals other than the researchers. Because of this, there was little detail reported about the specific measures of intelligence and methods of administration used in these studies.

Only 8% of the empirical articles published prior to 1980 were epidemiological studies compared with 60% of the empirical articles published since 1980, $\chi^2(1) = 6.96, p < .01$.

The first empirical study of the intelligence of children with autism was conducted by Piotrowski (1937), who found that 30% of individuals with “childhood schizophrenia” had MR. Other early reports describe similar prevalence rates (see Pollack, 1958). The first reports that a majority of children with autism also had MR occurred in the mid to late 1960s (e.g., Gibson, 1968; Gillies, 1965; Gittelman & Birch, 1967; Lotter, 1966a, 1966b; Rutter, 1966a; Rutter & Lockyer, 1967; Wing, 1969). These studies reported prevalence rates of MR in children with autism ranging from 56% to 100%. High prevalence rates of MR in children with autism continued to be reported in the 1970s, where the average prevalence rates of MR in children with autism peaked at over 86%, and the prevalence rates reported since then seem to have stabilized at approximately 78%.

Where the Empirical Support Originated and the Quality of the Data

Most (65%) of the empirical citations provided for nonempirical claims came from studies conducted in the 1960s and 1970s, and 87% were prior to 1990. Of the sample of empirical articles reviewed, 55% of the empirical studies were conducted prior to 1980; 75% were conducted prior to 1990. Thus, most of the empirical data used in support of the prevalence claims are not recent.

In all likelihood, early empirical studies followed the established standards of practice for testing at the time. However, less was known about autism and the possible interfering effects of autism on the assessment of intelligence. Because of this, few if any modifications were made in determining the intelligence of children with autism; only a handful of authors acknowledged the possible interference of autistic symptomatology on the assessment process (e.g., Lotter, 1966a; Mittler, 1966; Viitamaki, 1964; Vorster, 1960). Moreover, there was little or no discussion of whether the examiners administering the measures of intelligence even had experience in working with children with autism.

Mittler (1966) was one of the first authors to acknowledge the possible adverse affects of autistic symptomatology on intelligence testing. He noted that intelligence scores of individuals with autism may be inaccurate, especially when refused items are counted as failures, as they are on most performance scales. Mittler also stated that verbal measures of intelligence may be inappropriate because of the language deficits often present in children with autism. Other early researchers agreed on this latter point, including Rutter (1966b), who stated that many commonly used measures of intelligence are “usually unsuitable” (p. 91) for children with autism given their reliance on verbal subtests. However, in another chapter *in the same book*, Rutter (1966a) reported that 71% of children with autism in his sample had MR, a statistic obtained in a study

that utilized the *Wechsler Intelligence Scale for Children*, a commonly used measure of intelligence with many verbal subtests (see Rutter & Lockyer, 1967, which is a report of the same study). Thus, despite the recognition that certain methods of intelligence determination were inappropriate for children with autism, they were still used; and data from these studies were then cited by subsequent authors.

The current standards of practice for testing suggest that modifications need to be made in the assessment of individuals with a disability; the standards state that (a) testers must select appropriate tests and make test accommodations when necessary given the disability; (b) testers must recognize the effects of the environment in which the person is assessed and the demands of the tests themselves on the performance of individuals with disabilities; and (c) testers must ensure that test scores are accurate indicators of the construct being measured rather than reflecting “construct-irrelevant characteristics associated with the disability” (Turner, DeMers, Roberts Fox, & Reed, 2001, p. 1104).

It is important to recognize that most of the empirical articles reporting rates of MR in children with autism made no mention of the experience of the examiner in working with individuals with autism or whether any modifications were made in the testing given the interference of autistic symptoms on the process of assessment. Freeman and Ritvo (1976) noted that the particular test used to assess intelligence and the skill of the examiner are important contributors to test outcome. Ironically, it was DeMyer (1979) who acknowledged that “few clinicians, even psychologists, are familiar with the techniques of reliably estimating the intelligence of an autistic child” (p. 133).

Because the early empirical research “establishing” the prevalence of MR in children with autism did not take into account these issues when using standard measures of intelligence with children with autism, the validity of the data obtained from these early studies is called into question. However, perhaps a greater concern is that researchers frequently utilized methods to determine intelligence level that were not actual measures of intelligence.

The most commonly used alternative methods of determining intelligence were developmental and adaptive scales. Developmental scale scores are not meant to reflect the intelligence of children but rather whether children have obtained skills normative for their chronological age (Goldman et al., 1983). Adaptive scale scores reflect the attainment of social milestones and adaptive behaviors. Both types of scores are based on observer reports of a child’s behavior and are not comparable to IQ scores, which require responses from the person being assessed (Goldman et al., 1983). Moreover, recent research has indicated that these measures may be particularly poor substitutes for measures of intelligence in samples of children with autism (Fombonne et al., 1994; Rogers, 2001).

The results from the analyses of the empirical articles demonstrated that significantly higher prevalence rates of MR

were found in children with autism when developmental or adaptive scales were used as measures of intelligence than when these scales were not utilized. In fact, there was a difference of nearly 25% in reported average prevalence rates of MR if studies used developmental measures, used adaptive skills measures, made estimates of intelligence, or assumed that untestable children had MR. Thus, much of the data supporting the high prevalence rates of MR in children with autism was obtained using measures that were not designed to assess intelligence and that were likely to inflate these percentages.

It is important to note that nearly all of the empirical studies utilized more than one method of determining intelligence. Therefore, even if some measures of intelligence were used that were appropriate given the symptoms of autism, it was not possible to determine which scores of intelligence were obtained on which measures. An example of this occurred in a study by Rutter and Lockyer (1967). Only 3 of the 63 children in their study were administered the *Leiter International Performance Scale* (Leiter), a nonverbal measure of intelligence. Research has indicated that the same children with autism have been shown to score significantly better on the Leiter than on the *Wechsler Intelligence Scale for Children—Revised* (WISC-R; see Shah & Holmes, 1985). In Rutter and Lockyer’s study, 10 of the children were deemed untestable and were arbitrarily assigned an IQ of 25, and the remainder were assessed using verbal measures of intelligence, adaptive scales, or projective measures of personality. The way in which Rutter and Lockyer (1967) reported their data does not allow the reader to know how rates of MR varied depending on the measure used, and this was true of virtually all empirical studies reviewed. Thus, the fact that nearly all studies employed at least some inappropriate measures may account for why the prevalence rates were generally high across all studies even when individual methods were considered separately.

Acceptance in the Field That a Majority of Children With Autism Have MR

According to Rutter (1999), researchers in the field of autism research long ago determined that most children with autism were, in fact, mentally retarded. In a lecture on the evolution of research and clinical practice related to autism from the 1950s through 1998, Rutter (1999) discussed the focus of autism research across four time frames. He stated that in the 1950s and 1960s, there were many comparative studies focusing on the differentiation of autism from MR. By the 1970s, Rutter noted that it was already believed to be the case the most children with autism had MR. In the 1970s through mid-1980s, the cognition research shifted to understanding the particulars of reported cognitive deficits in individuals with autism. According to Rutter’s report, after the mid-1980s, few research studies focused on determining the intelligence level of children with autism; this might, in part, explain why a greater percentage of recent empirical articles were epidemio-

logical surveys of the prevalence of autism rather than empirical studies assessing the intelligence of children with autism.

Historically, our knowledge of autism, as reflected in what is cited in the literature, has transformed slowly. For example, Bettelheim (1967) asserted that autism was caused by psychogenic factors, specifically “refrigerator mothers” who coldly rejected their children. It took many years before authors stopped citing Bettelheim’s theory as fact, even in the absence of supporting data and even after there was ample evidence refuting his theory. The unfortunate consequences of this slow transition in the literature was that there was a continued practice of blaming mothers of children with autism long after it was clear that they were not the cause of their child’s condition.

Similarly, authors may continue to cite high prevalence rates of MR in these children long after it has been shown that the data are not present to support these claims. An unfortunate consequence of this may be the failure to provide the most effective interventions due to incorrect assumptions about the intelligence of these children. Yet, it is likely that most individuals reading the high prevalence claims in the literature are unaware of the state of the evidence used to support the claims. Most readers of the research likely accept the citations given for a claim without checking the strength of the evidence provided by the citation. Moreover, given the frequency with which claims of MR are made, it seems probable that readers of the literature assume that it is an established fact that children with autism have MR. This may also explain why many nonempirical claims about the prevalence of MR in individuals with autism do not have a supporting citation.

Conclusions and Implications

In view of the present findings on these three issues, the conclusion that the majority of children with autism also have MR does not seem warranted. Most of the claims originate from nonempirical sources that (a) do not trace to empirical data, (b) cite empirical research that is 25 to 45 years old, (c) used inappropriate measures, or (d) typically failed to acknowledge the possible interference of autism on the assessment of intelligence. Furthermore, only 15.7% of all claims made actually traced to empirical data that were obtained from studies whose authors described specific methods used to assess intelligence. Thus, only a small percentage of studies reported methods that could be evaluated with regard to their validity.

Although recent data have shown that some children with autism do, in fact, have MR, the rates are much lower than the high prevalence rates cited in the past. Recent epidemiological surveys have shown that the prevalence rates of MR in children with autism is between 40% and 55% (e.g., Chakrabarti & Fombonne, 2001), much lower than the typical rates cited in the literature. Recent empirical studies indicate that when appropriate measures of intelligence are used—those that take into account the interference of autism—a significantly lower prevalence rate of MR is found relative to the rates typically re-

ported in the literature (see Edelson, Schubert, & Edelson, 1998; Koegel, Koegel, & Smith, 1997).

However, the practice of claiming that a majority of children with autism are mentally retarded continues largely unabated. These claims can be found in recent journal articles (e.g., Bodfish, Symons, Parker, & Lewis, 2000; Dennis, Lockyer, Lazenby, Donnelly, Wilkinson, & Schoonheydt, 1999; Happé, 1999; Ruble & Dalrymple, 2003); chapters on autism in edited books, many of which are still in books on MR (e.g., Kasari, Freeman, & Paparella, 2001; Minschew, Johnson, & Luna, 2001; Volkmar & Klin, 2001); chapters on autism from child psychopathology textbooks (e.g., Mash & Wolfe, 2002; Wicks-Nelson & Israel, 2000); chapters in abnormal psychology textbooks (e.g., Davison & Neale, 2003; Seligman, Walker, & Rosenhan, 2001); “ask the editor” columns in journals on autism (Volkmar, 2003); and in the most recent edition of the *Diagnostic and Statistical Manual of Mental Disorders* (American Psychiatric Association, 2000).

Given the present results, it seems prudent to obtain additional empirical evidence before making any definitive conclusions regarding the prevalence rates of MR in children with autism. Empirical studies need to be conducted in which measures of intelligence take into account the interfering symptoms of autism on the process of assessment, examiners are knowledgeable about and have experience in assessing children with autism, and modifications to the testing situation are made to minimize the “construct-irrelevant” error in test outcome. Until that time, researchers in the autism field should use caution when making assumptions or citing claims about the rates of MR in children with autism.

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NOTES

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APPENDIX

Alphabetical list of the complete references for articles included in the present review (articles published 1937–2003)

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