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Is There a Hidden Population of Adults with Autism Spectrum Disorder?

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Abstract

Adaptive behavior measures were used to differentiate children who were diagnosed with autism spectrum disorder versus intellectual disability. The prediction formula derived from this analysis was then applied to a sample of 3028 adults who were being served within a statewide intellectual disabilities system. Application of the prediction equation suggested that as many as 1119 of the adults with intellectual disability presented adaptive behavior patterns similar to the children diagnosed with autism spectrum disorder. Only 126 of the 3028 adults had actually been classified with autism, suggesting the possibility of a hidden cluster of adults with autism spectrum disorder.

Keywords: Autism; Adults; Undiagnosed; Predicted

Introduction

Autism was once thought to affect about 4.5 of every 10,000 children. Recent studies, however, have yielded markedly higher estimates. An increasing prevalence rate is suggested by a number of repeat cross-sectional studies of autism prevalence [1-3]. A 1999 California study [4] reported rates as high as 20-40 per 10,000 children. Review articles regarding the apparent increase in autism [5,6] generally suggest that the incidence of autism has increased from around 5.2 per 10,000 births in 1966 to about 60 per 10,000 births in 2001. The Center for Disease Control [7], using a records review type of study, suggested that the incidence of autism/PDD may be as high as 1 in 150 (or about 67 per 10,000), and more recently, they have lowered that estimate to 1 in 88.

There appears to be no disagreement that the autism diagnosis is being used more frequently today than in the relatively recent past, however, the cause for this increase in prevalence of autism is open for discussion. Some [8] have sought to blame environmental causes, most frequently trying to attribute the apparent increase in autism to the use of mercury based preservatives in childhood vaccines. This argument has generally been refuted [9-11] although many still cling to this explanation.

Many professionals now consider the apparent increase in the prevalence of autism to be an artifact of an evolving definition applied to the condition, combined with greater public awareness and systemic improvement case finding. This evolution in the definition of autism derives from the recognition that the symptoms of autism can vary widely along the three primary diagnostic spectra. Autism is now generally recognized to be a spectrum disorder [12], in which symptoms may vary widely from mild to profound on the three primary diagnostic dimensions. This is in marked contrast to the more narrow diagnostic criteria proposed in the DSM-IV (American Psychiatric Association, 2000). This more traditional definition is now sometimes called "classical autism" [13]. An individual with "classical autism" presents as significantly withdrawn, uncommunicative and pronte to engaging in stereotypy for lengthy periods of time. There is also some evidence to suggest that the increase in the use of the autism diagnosis has been accompanied by a decrease in the use of the intellectual disability diagnosis [2]. This phenomenon is sometimes referred to as a diagnostic substitution.

If the actual diagnostic criteria for autism have broadened over time, surely one must wonder about people diagnosed prior to these changes. How many adults who were diagnosed with some form of mental illness or some degree of intellectual disability when they were children might today be classified as having autism spectrum disorder? In an early study, Shah et al. [14] reported that 38% of a population of adults with intellectual disability living in a mental hospital had the types of social impairment that could suggest what might now be called autism spectrum disorder. More recently Mandell (personal communication, 11/26/7) [15] reported that approximately 20% of residents in a state mental hospital scored in the diagnostic level on a scale to assess autism spectrum disorder. These two studies suggest the possibility of a hidden population of individuals with autism. Grinker [16] rhetorically asked where these individuals were; then, suggesting an answer to their own question, speculated that they existed, but without the diagnosis.

Prevalence cannot be accurately estimated if different diagnostic criteria are in use at different points in time. In particular, it seems reasonable that some people diagnosed with intellectual disability years ago when the more narrowly defined "classical autism" was the prevailing standard, might be diagnosed today with autism spectrum disorder. It is the intent of this exploratory study to attempt to ascertain whether there might be a population of adults being served within the intellectual disability service system who might also fit the relaxed contemporary diagnostic criteria for autism.

The purpose of this study is to attempt to provide policy makers and program designers with gross estimates of autism prevalence among adults currently diagnosed with intellectual disability. To do this, we will first seek to develop a mathematical representation of the contemporary diagnostic process with respect to autism spectrum disorder. A mathematical representation as proposed doesn't so much replicate the actual diagnostic process as it presents a mathematical model that can effectively describe the process and predict diagnostic outcomes via application [17]. We will then apply the derived mathematical representation of the autism spectrum disorder diagnostic process to a large sample of adults in the intellectual disability service system. This will enable us to ascertain whether some portion of that adult sample might, under contemporary diagnostic practices, be classified as having autism spectrum disorder.

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Method

Participants

Two independent data sets were employed in this study. A group of school age children in an Approved Private School in Pennsylvania were used to derive the autism spectrum disorder prediction equations. The resultant equations were then applied to a large sample of persons in a statewide intellectual disabilities service system. Each group is described below.

Group one consisted of 156 children who lived in a residential Approved Private School serving individuals with significant developmental disabilities concomitant with the presence of challenging behaviors. There were 123 males and 33 females. The average age was 16.1 (SD=2.52); all were under 21 years of age. A review of records at the program revealed that 97 of the 156 children had diagnoses of autism and/or Pervasive Developmental Disorders. All of these diagnoses fell within the realm of autism spectrum disorder. Note that most of these diagnoses had been established prior to the individual's admission to the Approved Private School, but they were confirmed by a staff psychiatrist at the Approved Private School shortly after admission. A breakdown by level of intellectual disability revealed the following: 7.1% without intellectual disability; 33.3% with mild intellectual disability; 22.4% with moderate intellectual disability; 18.6% with severe intellectual disability; and 3.2% with profound intellectual disability. Approximately 15.3% of the individuals for who level of intellectual disability were not classified.

Group two consisted of 3028 adults who had intellectual disability and were receiving state-supported residential services from the statewide intellectual disabilities system. These individuals were routinely monitored by an independent program evaluator who reviewed annual data regarding their inclusion and adaptation. At the time of data collection, approximately 66.5% lived in group homes or similarly integrated community settings, and 33.5% lived in various congregate care alternatives. The average age was 44.98 (SD=15.45), and all were over 21 years of age. There were 1631 males and 1397 females. A breakdown by level of intellectual disability revealed the following: 2.1% without intellectual disability; 28.9% with mild intellectual disability; 17.6% with moderate intellectual disability; 15.1% with severe intellectual disability; and 21.9% with profound intellectual disability. No indication of level of intellectual disability was listed on the charts of 14.3% of the individuals. It was noted that 126 (4.2%) of these individuals also had a diagnosis of autism listed in their charts.

The differences between the children's derivation sample and the adult's application sample are both strikingly evident and completely essential to the task at hand. A contemporary prediction equation can only be derived from a sample that had been diagnosed relatively recently. That would preclude most adult samples because the diagnosis of autism tends to occur relatively early in life. On the other hand, to capture a sample of individuals whose diagnosis would predate the more relaxed contemporary diagnostic standards will result in a significantly older group.

Instrumentation

Both groups were administered the Behavior Development Survey [18]. This is a shortened version of the American Association on Mental Retardation's Adaptive Behavior Scale [19]. It consists of 32 items, and it yields raw scores that range from 0 to 129, with lower scores indicating increasingly diminished levels of adaptive behavior. It is administered by interviewing a third party who is familiar with the person whose adaptive behavior is being assessed. Pawlarczyk and Schumacher [20] reported that the Behavior Development Survey is a concurrently valid method of assessing adaptive behavior, based on a review of correlation matrices from simultaneous administrations of the Behavior Development Survey, the AAMD Adaptive Behavior Scale, and the Vineland Social Maturity Scale. An unpublished study [21] revealed an inter-rater reliability of .91 for the Behavior Development Survey, a figure that is consistent with report on the longer version of the scale [22]. Data collection for the children's group (Group one) occurred during the summer of 2007, and it employed direct care staff as informants. Data collection for the adult group (Group two) occurred in 2000, and it also involved direct care staff as primary informants.

Results

The initial step in the data analysis involved the development of a mathematical equation that might adequately predict the diagnosis of autism spectrum disorder. To do this, Behavior Development Survey data from the children's group were submitted to discriminant function analysis. The individual Behavior Development Survey items were submitted to stepwise analysis in an effort to predict membership in either the autism group or the non-autism group. In this initial analysis, a stepwise procedure was employed so that we might empirically ascertain the best predictors for future use.

The initial step in a discriminant function analysis involves determining whether there is an overall between groups difference on the predictor variables. A Wilks lambda of .66, approximately equivalent to an F ratio of 25.42 (df=3/146, p<.001), indicated that the group centroids were indeed different with respect to the Behavior Development Survey. Continued analysis was warranted.

The stepwise analysis retained three predictor variables. They were, in order of entry, Use of Sentences, Ordering Meals in Public Settings, and Paying Attention to Tasks and Activities. The standardized discriminant function coefficients were .805, -.446, and .500 respectively. The single derived discriminant function was found to be statistically significant (Chi-Square of 61.57, with three degrees of freedom, p<.0001). The Wilks lambda, which is an inverse measure of R square, revealed that this linear equation was able to explain approximately 34.31% of the variance in diagnostic group membership. These findings were generally supported by a supplemental stepwise logistic regression analysis, in which the same three predictor variables were identified. Statistical significance was again achieved (Chi-Square [3]=59.09, p<.001), and a Nagelkerke r-square value of .444 was determined. The Nagelkerke value is not directly comparable with a Wilks value or a traditional R square value.

Having determined that one can predict membership in the autism spectrum disorder diagnostic group, the next step in the analysis was to apply the derived equations to a different group of individuals. While it is recognized that there will be some shrinkage in the predictive utility of the equation in doing this, it was hoped that we might derive a general estimate of the number of persons in a large intellectual disability sample who might also be diagnosed with autism spectrum disorder under contemporary practices.

The discriminant function analysis yielded Fisher's classification equations that were applied to the adult group in an effort to determine probable group membership, given the adult's set of scores on the selected predictor variables. Two equations, one for each group (Autism Spectrum Disorder/ not Autism Spectrum Disorder) were calculated to provide unique solutions for each adult study participant. An individual

was classified as a member of the group associated with the algebraic solution resulting in the largest score. Thus, if an individual's Autism Spectrum Disorder equation score exceeded his/her non-Autism Spectrum Disorder score, he/she was classified in the autism spectrum disorder group. Similarly, if the Autism Spectrum Disorder score was less than the non-Autism Spectrum Disorder score, that individual was classified in the non-autism spectrum disorder group. Use of this procedure identified 1119 adults (about 37% of the sample) as being potentially diagnosable with autism spectrum disorder. It should be noted that the use of this prediction equation was able to identify 75 of the 126 adults (59%) who already had an autism diagnosis in their record.

Discussion

Our findings suggest that children with autism spectrum disorder can be adequately differentiated in the basis of just three adaptive behavior items. Two of these items clearly relate to the use of language (Use of Sentences and Ordering Meals in Public), while the third (and weakest) item is related to the ability to Pay Attention to Tasks and Activities. The linear combination of the three items resulted in a statistically significant prediction equation; however, the amount of explained variance clearly indicates that other factors are in play. Of course, it must be recognized that our use of a stepwise entry procedure in the discriminant function analysis might capitalize on error; however, the typically high intercorrelation among adaptive behavior items would seem to minimize this concern. One must simply recognize that there are other adaptive behavior items that might predict diagnosis almost as well. The ability to predict a diagnosis of autism spectrum disorder from just three adaptive behavior items, while interesting, becomes of policy level interest if the resultant prediction equation can be applied to other populations.

The application of the prediction equation to a statewide intellectual disability service system suggested that many adults in that system might be classified with autism spectrum disorder under contemporary diagnostic practices and standards. While our findings are clearly not definitive, they are at least suggestive of the possibility a hidden autism cluster. Our empirically derived prediction equation yielded an estimate of 1119 such individuals when applied to a sample of 3028 adults in a statewide intellectual disability service system, a figure that is about nine times greater than the actual number of adults in that sample already diagnosed with autism. This prediction also exceeds the estimates derived from a psychiatric hospital by Mandell (2007, personal communication, 11/26/7), [15] but is interestingly congruent with early work by Shah et al. [14] who studied individuals within the intellectual disabilities system.

Studies like this should come with warning labels or at least an admonition encouraging caution in drawing conclusions. Let us stipulate that the individuals within the entire state-wide adult sample were diagnosed years ago. We do not have specific information about the date of the initial diagnosis, but Mandell et al. [23] noted that the diagnosis of autism tends to occur prior to school age, and the average age of our adult group was about 45 in 2000. It is certainly not unreasonable to speculate that most of the 126 diagnoses of autism predated the recognition of autism as a spectrum disorder, i.e., the "modern" definition. Another warning must be applied to our effort to project autism classification onto adult using a formula derived from children. Ideally, we would use another adult grouping from which to derive the prediction equation, but with the evolution of the diagnostic criteria, such a group is simply not available. Hence, the reliance on a children's sample.

The projection of 1119 cases of adult autism spectrum disorder within our sample is staggeringly large and strongly suggestive of a hidden autism cluster within public intellectual disabilities service systems. Even if our prediction is off by as much as 50%, it still suggests that there may be 4-5 times as many individuals in these systems with autism spectrum disorder than the records would suggest. Because there is evidence that some relinquish the label as they mature [24], more conservative estimates might be more realistic. The finding of the possible existence of a hidden autism cluster also would seem to support the refutation of any model that seeks to explain the apparent increase in autism prevalence as being of epidemic proportion. If the increasing numbers of people identified with autism truly were attributable to the addition of thimerosol to vaccine, it seems unlikely that we would have been able to find such a large number of adults displaying symptomatology similar to children in contemporary studies of autism spectrum disorder. While our findings cannot prove that the increase in autism spectrum disorder is attributable to diagnostic spread, they certainly offer indirect support for that argument. Ultimately, our findings tend to concur with the observation of Grinker [16] that 1 in 150 adults with these characteristics are indeed out there; they just don't carry the diagnosis of autism spectrum disorder.

Policy implications

What does it mean if the prevalence of adults with autism spectrum disorders is really much greater than assumed, perhaps even equivalent in proportion to that for children? Does it change the way we look at service delivery for adults with autism spectrum disorder? Is there potential for individual growth and remediation that might justify extraordinary expenditures for services for these people? Are strategies and approaches used with children with autism spectrum disorders also effective with adults with similar symptomatology?

In general, the service model for children with autism spectrum disorders appear to be characterized by the use of the term, "treat". Services and supports are typically designed to treat, or minimize, deficiencies that are presumed to reside within the child. Consistent with the diagnostic criteria, these would include limited or atypical communication and socialization skills. As noted in the National Autism Association's mission statement, "the search for a 'cure' for this disorder remains primary, and that the autism community must never give up its search to help loved ones achieve their full potential" (National Autism Association, 12/27/7) [25]. Clearly, the efforts of the organization are being directed towards changing the person in order to eliminate barriers to societal inclusion.

In contrast, the intellectual disabilities field has gradually come to recognize disability as the product of the interaction of people and the social and physical environment in which they live [26]. They are disabled to the degree defined by the social and physical context in which they live. This social constructivist approach to disability emphasizes the acceptance and accommodation of individuals rather than specific treatment efforts to change them. It is possible to minimize the problems associated with disability by removing numerous social or environmental barriers. For example, it has been argued that if access to all buildings was unfettered, the impairment requiring the use of a wheelchair would no longer be considered a disability. "Treat" is perceived by some as something one does to "sick" people to ameliorate a condition and, it is believed, should not be used synonymously with "educate" or "rehabilitate". Some disability advocates have even argued that efforts to correct an individual's impairment may functionally serve to devalue that person. While this is perhaps an extreme perspective, it is clear that the intellectual disabilities field has moved from the medically

influenced model of the 1970s (focused intervention in order to fix the broken individual) to one that more closely embraces the notions of choice, self determination, quality of life, and inclusion.

The pressing question may be whether adults with Autism Spectrum Disorder should be treated under a variant of the model used with children who have autism or supported via the accommodation and support model used with many adults who have intellectual disabilities. It is tempting to suggest that the most effective strategy be adopted; however, that depends upon desired outcomes. Neither the autism literature nor the intellectual disabilities literature offers great encouragement for the significant remediation of either disability in adulthood [27]. While some isolated examples can be noted in both areas [28-30], the potential for additional improvement in the underlying symptomatology by adults within either class of diagnoses seems limited. Since these conditions are enduring, decisions about adult services require analysis taking into consideration all the factors previously contributing to a well-formed IEP offset by the potential for funding of services.

Quality autism services are expensive-even more expensive than intellectual disability services. Evidence based practices like discrete trial training generally require 1:1 staffing with skilled personnel, and even the less rigorous behavioral approaches are typically labor intensive. While a compelling argument may be made for parity in specialty services for both children and adults [31-35], fiscal realities and priorities will significantly impose limitations on the intensity of offerings for adults. If adults are identified as having autism spectrum disorder, and if more expensive autism treatments are offered to help address their needs, the impact is likely to be felt in other components of the intellectual disabilities system. Spreat and Conroy [32] reported that class action litigation could result in a two-tiered service system in which some people, by virtue of class membership, could receive more services than others. With most states already experiencing extensive waiting lists for intellectual disability services, the impact of increased allocation request for autism services intensifies the competition for funding. Not only are costs likely to increase, there is the challenge of resource availability. Consider the communication aspect of autism spectrum disorder, where speech services are practically routine components of Individual Education Plans of children with autism spectrum disorder. If added to the individual support plans for adults, how many more speech pathologists will be needed? There is already a shortage of such professionals, and the recognition of enhanced need will only drive the costs of such services higher.

Candidly, it would be difficult to justify policy changes based on this study alone. Pennsylvania has recently undertaken a census of persons with autism, and as part of this process, it commissioned research on autism prevalence among persons in state mental health institutions. Pennsylvania's approach to estimating the magnitude of the problem before trying to solve it seems warranted. It is hoped that this study will lead to additional research on the prevalence of autism spectrum disorder among persons currently diagnosed with intellectual disability.

Limitations

Of primary import is the recognition that our mathematical representation of the diagnostic process is simply that-a representation. The Behavior Development Survey is not proposed for use in diagnosing or classifying autism spectrum disorder. The mathematical model does not reflect how clinicians actually reach their diagnoses; it merely describes it. Clearly, the study would have been enhanced by formally reassessing every individual within the intellectual disabilities system. This would have been an expensive undertaking, especially for an exploratory type of study. Our model, similar to the approach used by many college admission committees to predict freshman grades for the incoming class based on the grades and predictors of other classes, was inexpensive and appropriate for a first-level analysis. This study employed available existing data in an effort to ascertain whether there is a population of adults with intellectual disability who might be classified as having autism spectrum disorder under contemporary diagnostic practices. The preliminary nature of our project must be stressed, and it must be recognized that a more definitive answer can only come from the actual re-diagnosis of adults with intellectual disability.

While the prediction equation achieved statistical significance, it explained less than half of the variance in diagnostic categories. Clearly other factors, items, and dimensions would have enhanced the prediction process. Despite this limitation, it should be recognized that the three item prediction equation was able to correct classify approximately 80% of the individuals in the derivation sample.

We reported that our derived prediction equation was able to identify only about 75% of the adults whose records indicated a diagnosis of autism. Were we treating this analysis as a validity study, accepting the existing diagnoses are presumptively valid; our findings would indeed be discouraging. Our concern, however, is that the diagnostic process has evolved over time, and that diagnoses contained in records may not be presumed to be valid under contemporary diagnostic practices. While the reliability of psychiatric diagnoses has long been questioned, that reliability is of less concern in this study. Our question is focused on the impact of contemporary diagnostic practices on previously diagnosed individual.

It is suggested that Type I error may have played a factor in these findings, leading to the misclassification of individuals as having autism spectrum disorder. While Type I error is potentially a threat to any study, the usual correction for Type I error is replication, and the findings of our study essentially replicate those of Shah et al. [14]. This is not to suggest that our study is devoid of error, but rather to suggest that there is need for definitive research on an adult population.

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