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The gender of participants in published research involving people with autism spectrum disorders



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ABSTRACT

Research articles involving participants with an autism spectrum disorder and published from 2010 through 2012 in *Autism*, *Journal of Autism and Developmental Disorders*, *Journal of Child Psychology and Child Psychiatry*, and *Research in Autism Spectrum Disorders* were examined to determine the reported gender of participants. The overall male:female ratio was 4.62, which is similar to that reported in epidemiological studies, but the ratio was 6.07 in intervention studies. These findings suggesting that males were in a statistical sense over-represented in intervention studies, but not in other kinds of research. Most (82.21%) of these studies included both male and female participants, but direct comparisons of males and females with an autism spectrum disorder are scarce. Few of the articles we examined, 0.49% of the total, involved only female participants. Roughly half of the articles included comparison groups without an autism spectrum disorder. The percentage of male participants in these comparison groups was substantially and significantly lower than the percentage of males in groups with an autism spectrum disorder, which may in some cases constitute a methodological confound. We encourage researchers to carefully consider the gender of participants as both an extraneous variable and as an independent variable in future investigations.

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1. Introduction

In 1943, Kanner described eight boys and three girls who exhibited “autistic disturbances of affective contact.” Since that time, epidemiological studies have confirmed that the condition now known as “autism,” and similar conditions which, with autism, constitute “autism spectrum disorders” (ASD), is more common in boys than in girls (see Fombonne, 2003). Although the reported male:female ratio for ASD varied considerably across studies, ranging from 1.33 (McCarthy, Fitzgerald, & Smith, 1984) to 16 (Wing, Yeates, Brierly, & Gould, 1976) in the 29 studies reviewed by Fombonne, the mean male:female ratio was 4.3, which is similar to the 4.6 value evident in 2008 data reported by the 14 sites comprised by the Autism and Developmental Disabilities Monitoring Network (Baio, 2012). Although the exact male:female ratio is impossible to specify, there is good reason to believe that autism “is four to five times more common among boys than girls,” as Autism Speaks (2013) points out on its website.

Edwards, Watkins, Lotfizadeh, and Poling (2012) recently reported on the ages of participants with autism in intervention studies published in *Autism*, *Focus on Autism and other Developmental Disabilities*, *Journal of Autism and Developmental Disorders (JADD)*, and *Research in Autism Spectrum Disorders (RASD)* from 2009 through early 2012 and noted in passing that,

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“of the 1644 participants whose sex was reported, 85.8% were male” (p. 997). This percentage is equivalent to a male:female ratio of about 6, which suggests that males are in a statistical sense over-represented as participants in intervention studies. It is not clear whether males are similarly over-represented in the literature at large. The purpose of this study was to examine all recent published research articles in four prominent autism journals to provide further information on the gender of people with ASD who serve as research participants.

2. Methods

In determining which journals to evaluate, the *PsycINFO* data base was searched using “autism” as the sole search term and limiting the search to 2010 through 2012. This strategy located articles involving the full spectrum of autism spectrum disorders (ASDs), not just autism. Therefore, the focus is on participants with ASDs. The four journals with the most relevant articles were *Autism*, *JADD*, *Journal of Child Psychology and Psychiatry (JCPP)*, and *RASD*. An online or paper copy of each of these articles was perused by one author to determine whether one or more person diagnosed with an ASD was the focus of the article. If so, the article was a candidate for inclusion. Because participants from different diagnostic categories were often included in the same study and data were grouped across categories, no attempt was made to record data separately for different ASD categories. Each candidate article was evaluated to determine if it was a review article or meta-analysis and, if so, it was excluded from participation. For all other articles, one author recorded (a) whether the gender of participants was reported, and, if so, (b) the number of males and (c) the number of females. She or he also determined if each study involved comparing one or more characteristic in people diagnosed with ASD and in people not diagnosed with ASD (a comparison group). If so, the numbers of males and females in the comparison group were recorded, as were the numbers of males and females in the group with ASD. When multiple comparison groups were included in a single article, data were summed and a single value was reported for each gender. Finally, the rater reported whether each article was an intervention article as defined by Edwards et al. (2012), that is, whether it: “. . . described an intervention (treatment) intended to benefit directly some (as in a group study with an untreated control group) or all (as in a single-case experiment) of the participants. ‘Benefit’ was broadly construed to include any desired change in overt behavior, cognitive status, or subject state (e.g. affect)” (p. 997). It was impossible to determine the number of people who served as participants in more than one article because relevant information was not reported.

3. Results

Our initial search revealed a total of 1407 articles. Of them, 684 articles met our criteria for inclusion. *Autism*, *JADD*, *JCPP*, and *RASD* were the sources of 62, 277, 26, and 242 articles, respectively. Findings were similar across years and across journals, therefore, only summary data are reported. Seventy-seven, or 11.26%, of the 684 articles failed to report the gender of the participants and were not included in the data analysis. Of the 607 included articles, 82.21% included both male and female participants, 17.30% included only male participants, and 0.49% (3 articles) included only female participants.

One hundred thirteen of the 607 articles (18.62%) were rated as intervention articles. The 113 intervention articles comprised a total of 1661 participants with ASD, with a mean of 14.70 participants per article, whereas the 494 other articles comprised a total of 48,420 participants with ASD, with a mean of 98.02 participants per article. Across all articles, 39,811 of the 48,420 participants with ASD, 82.22%, were male. For intervention articles, of the 1661 participants with ASD, 1426, or 85.85%, were male, whereas 38,385 of the 46,759 participants in other articles, or 82.09%, were male. The un-weighted mean percentage of male participants with ASD in intervention articles was 85.85 (SD = 0.19), whereas the mean value for other articles was 82.09 (SD = 0.14). A *t*-test revealed a significant difference in these means ($t = 5.86$, $df = 511$, $p < .01$) at the .01 α level.

Overall, 336 of the 607 rated articles (55.35%) contained both a group with ASD and a comparison group, comprising participants not diagnosed with ASD. There were 18,527 people in the groups with ASD and 45,413 people in the comparison groups. Across all studies, the un-weighted mean percentages of participants who were male were 81.47 (SD = 0.14) and 59.39 (SD = 0.21) for groups with ASD and for control groups, respectively. A *t*-test revealed that the 22.08% difference in means is significantly different at the .01 α level ($t = 7.44$, $df = 670$, $p < .01$).

4. Discussion

Edwards et al. (2012) reported that 85.8% of the 1644 people with ASD who participated in recent intervention studies published in *Autism*, *Focus on Autism and other Developmental Disabilities*, *JADD*, and *RASD* were male. This value represent a male:female ratio of 6:1, which is substantially higher than the mean value of 4.3 obtained by Fombonne (2003) when the results of 29 epidemiological studies were combined and the 4.6 value evident in 2008 data reported by the 14 sites comprised by the Autism and Developmental Disabilities Monitoring Network (Baio, 2012). With a male:female ratio of 4.3:1, 81.13% of the participants are male, whereas 82.14% are female with a ratio of 4.6:1. Because the male:female ratio was substantially higher in the intervention studies they examined than in large epidemiological studies, Edwards et al. suggested that males were over-represented in intervention studies relative to their abundance in the general population of people with ASD. They did not, however, examine other kinds of studies.

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