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## The Gender of Participants in Published Research Involving People with Autism Spectrum Disorders

Watkins

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THE GENDER OF PARTICIPANTS IN PUBLISHED RESEARCH  
INVOLVING PEOPLE WITH AUTISM  
SPECTRUM DISORDERS

by

Erin Watkins

A thesis submitted to the Graduate College  
in partial fulfillment of the requirements  
for the degree of Master of Arts  
Psychology  
Western Michigan University  
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INVOLVING PEOPLE WITH AUTISM  
SPECTRUM DISORDERS

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Western Michigan University, 2014

Research articles involving participants with an autism spectrum disorder and published from 2010-2012 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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Erin Watkins

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## INTRODUCTION

Girls and women make up slightly over half of the people on earth. Several studies reveal, however, that they make up far less than half of the participants in many kinds of psychological research. This is the case, for example, in school psychology (Holverstott, Ehrhardt, Parish, Ervin, & Poling, 2002), in organizational behavior management (Jarema, Snyckerski, Bagge, Austin, & Poling, 1999), in mental retardation (Porter, Christian, & Poling, 2003), and in psychopharmacology (Poling et al., 2009).

If results could be safely generalized from men and boys to women and girls, then the under-representation of females would be of no consequence from a scientific perspective. This was once believed to be the case, but it is now clear that the effects of many independent variables are to some extent gender-specific. Psychoactive drugs provide a clear example. Although it was once widely believed that findings of psychopharmacological studies involving only men could be safely generalized to women, and in fact Food and Drug Administration policies limited the participation of women in clinical trials, it has become increasingly clear that there are real, and sometimes clinically significant, gender differences in how people respond to a variety of drugs (e.g., Berlanga & Flores-Ramos, 2006; Franconi, Brunelleschi, Steardo & Cuomo, 2007; Legato et al., 2004).

In recent years, autism has generated much interest with respect to its proper diagnosis, its cause, and its treatment. The condition was first described by Kanner (1943), who reported on eight boys and three girls who exhibited “autistic disturbances of affective contact.” At present, “autism” and related conditions (i.e., Asperger’s syndrome, Rett’s syndrome, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified) are often grouped together under the diagnostic label of “Autism Spectrum Disorders” (ASD) in the

current, fifth edition, of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)* published by the American Psychiatric Association (2013). According to *DSM-5*, three categories of symptoms are characteristic of people with ASD. Such individuals have communication deficits and social difficulties, and exhibit restrictive and repetitive behavior. All of these behavioral deficiencies are present before three years of age, although the diagnosis of ASD may not occur until later in life.

There is debate about the true prevalence of ASD and whether the prevalence is actually increasing, in part because the condition is heterogeneous and there is no “gold standard” for its diagnosis (Hertz-Picciotto & Delwiche, 2009). The United States Center for Disease Control estimates that ASD is present in 1 of 88 children, although many other estimates are considerably lower (Baio, 2012).

An interesting finding of all epidemiological studies is that ASD is more common in boys than in girls (see Fombonne, 2003). Although the reported male:female ratio for ASD varies considerably across studies, ranging from 1.33 (McCarthy, Fitzgerald, & Smith, 1984) to 16 (Wing et al., 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). The exact male:female ratio is impossible to specify, but there is good reason to believe that ASD “is four to five times more common among boys than girls,” as Autism Speaks (2013) points out on its website.

Given that ASD is more common in males than in females, one would expect that the majority of participants with ASD in published studies in psychology journals are males. But it is not clear whether the proportion of male research participants is equal to, less than, or greater

than their representation in the population of people with autism. Data from one study, however suggests that it is greater. In 2012, Edwards, Watkins, Lotfizadeh, and Poling (2012) 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, “of the 1,644 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.

## **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 persons 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

analysis. 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 autism (a comparison group). If so, the numbers of males and females in the comparison group were recorded. 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.

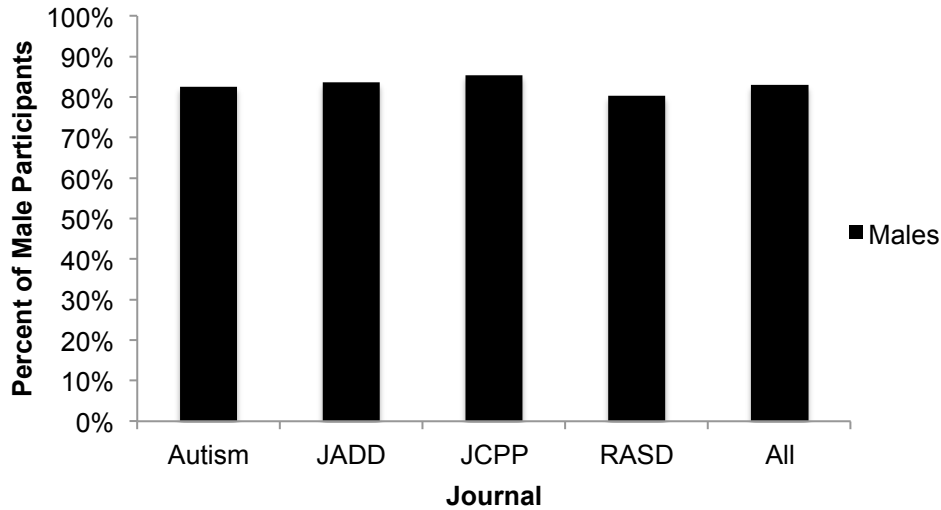
## **RESULTS**

The initial search revealed a total of 1,407 articles. Of them, 684 articles met our criteria for inclusion. *Autism*, *JADD*, *JCPP*, *RASD*, were the source of 62, 277, 26, and 242 articles, respectively. Seventy-seven, or 11.26%, of these articles failed to report the gender of the participants as shown in chart 1. The remaining 607 articles included a total of 52,033 participants. Figure 1 shows the overall percentage of participants who were male in each journal and in all four journals combined. The overall percentage of male participants with ASD in articles published in *Autism*, *JADD*, *JCPP*, *RASD* was 82.60, 83.57, 85.44, and 80.28%, respectively. Across all journals, 81.82% of the participants with an ASD were male.

Table 1

*Total Number of Articles that Failed to Report Gender Across Journals*

<u>Journal</u>	<u>Gender Reported</u>	<u>Gender Not Reported</u>	<u>%</u>
<i>Autism</i>	62	12	16.22
<i>JADD</i>	277	41	12.89
<i>JCPP</i>	26	3	10.34
<i>RASD</i>	242	21	8.00
Total	607	77	11.26



*Figure 1.* Percent of male participants with ASD across articles. This figure illustrates the percent of male participants across articles in each journal.

Across all years and journals, as shown in Figure 2, 82.21% of the articles included both male and female participants, 17.30 percent included only male participants, and 0.49 percent (3 articles) included only female participants. The percentage of articles with both male and female participants, male only participants, and female only participants was 80.65, 17.74, and 1.61; 83.75, 16.34, and 0; 92.31, 7.69, and 0; 79.75, 19.42, and 0.83, and; 82.21, 17.30, and 0.49 for *Autism, JADD, JCPP, RASD*, respectively.

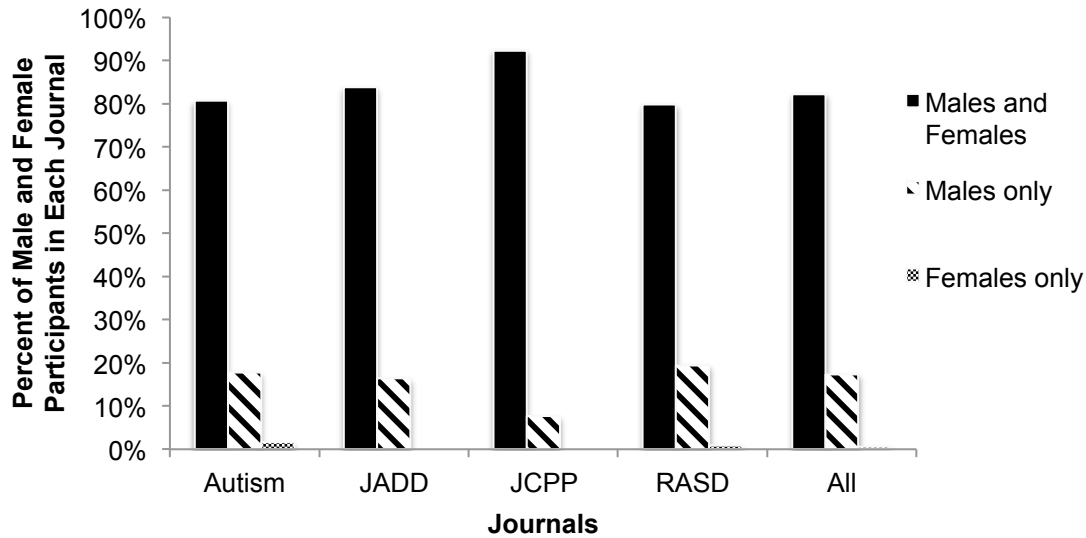


Figure 2. Percent of male and female participants with ASD in each journal. This figure illustrates the percent of both male and female, just male, and just female participants across journals.

One hundred thirteen of the 607 articles (18.62%) were rated as intervention articles. The 113 intervention articles comprised a total of 1,661 participants with an ASD, with a mean of 14.70 participants per article, whereas the 494 other articles comprised a total of 48,420 participants with an ASD, with a mean of 98.02 participants per article. Across all articles, 39,811 of the 48,420 participants with an ASD, 82.22%, were male. For intervention articles, of the 1,661 participants with an ASD, 1,426, 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 an 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  $\alpha$  level.

Overall, 336 of the 607 rated articles (55.35%) contained both a group with an ASD and a comparison group, comprising participants not diagnosed with an 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 (S = 0.21) for groups with an ASD and for control groups, respectively. A *t*-test revealed that the 22.08% difference in means is significantly different at the .01  $\alpha$  level ( $t = 7.44$ ,  $df = 670$ ,  $p < .01$ ). Figure 3 represents the percent of male participants with ASD and in a comparison group in an average article.

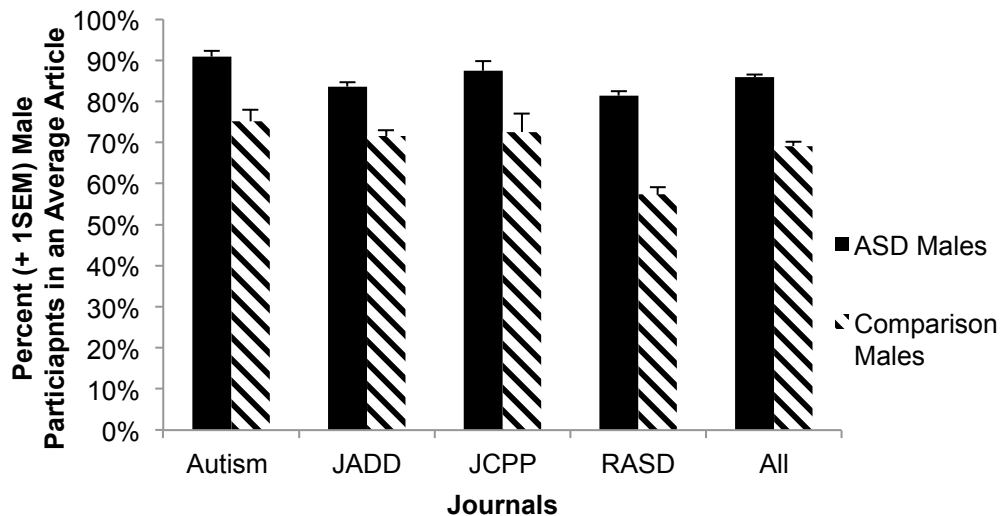


Figure 3. Percent of male ASD and comparison group participants in an average article. This figure illustrates the percent of male participants with ASD and comparison males in an average article across journals.

## DISCUSSION

Edwards et al. (2012) recently reported that 85.8% of the 1,644 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 represents 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 these studies relative to their abundance in the general population of people with an ASD. They did not, however, examine other kinds of studies.

In the present study, 85.85% of the participants with an ASD who took part in intervention research published in *Autism*, *JADD*, *JCPP*, and *RASD* from 2010 through 2012 were male. This value, which is equivalent to a male:female ratio of 6.07, is very similar to the value reported by Edwards et al. and is significantly higher than the percentage of participants with an ASD who were male in other kinds of research published in those journals over this period. Therefore, the present findings suggest that males with an ASD are over-represented in intervention studies relative to other kinds of studies.

It is not clear why males are over-represented in the intervention studies examined by Edwards et al. (2012) and by us. An obvious possibility is that males with ASD behave differently than females with ASD, and the difference is such that a greater proportion of males require a treatment worthy of describing in print. Some studies suggest that there are characteristic differences in the symptomatology of ASD in boys and girls (Lord, Schopler, & Revicki, 1982; Hartley & Sikora, 2009; Rivet & Matson, 2011). For example, in a study of toddlers (1.5-3.9 years of age) Hartley and Sikora (2009) compared 157 boys and 42 girls with ASD. They found substantial similarity in developmental profiles, autism symptoms, and

coexisting behavior problems, although: “Girls with ASD evidenced greater communication deficits than boys and boys evidenced more restricted, repetitive, and stereotyped behavior than girls. Girls exhibited more sleep problems and anxious or depressed affect than boys” (p. 1715). There is nothing in this pattern of results to suggest that boys are more deserving candidates for treatment than are girls.

It is, however, clear that there are often differences in the behavior of boys and girls with ASD, and those differences are sufficiently important that some professionals have criticized the assessment devices used to screen for early autism on the basis that those devices were based largely on the behavioral characteristics of boys and hence miss many cases of ASD in young girls (Koenig & Tsatsanis, 2005). Among the assessments subject to this criticism are the Childhood Autism Rating Scale (Schopler, Reichler, De Vellis, & Daly, 1980), the Autism Diagnostic Observation Schedule – G (Lord et al., 2000), and the Autism Diagnostic Interview – R (Lord, Rutter, & LeCouteur, 1994). ASD as currently defined is remarkably heterogeneous – so heterogeneous that some have questioned whether it is even a useful diagnostic category, save for gaining access to early and effective behavioral interventions (e.g., Poling & Edwards, in press). Given that such interventions are key to positive outcomes for people with a wide range of behavioral challenges, it and it is indeed unfortunate if gender bias in developing instruments commonly used early screens for ASD discriminate against girls.

Be that as it may, as evident in the findings of two reviews (Koenig & Tsatsanis, 2005; Rivet & Matson, 2011), few studies have actually compared important characteristics of males and females diagnosed with an ASD, methodological problems are common in the studies that have appeared, and results are often variable and inconsistent. Therefore, there is no compelling evidence to suggest that behavioral differences in males and females are responsible for the over-

representation of males in intervention studies, although this possibility appears to merit attention. So do other potential explanations, such as different family or teacher expectations for boys and girls.

Although males with an ASD are in a statistical sense over-represented in the intervention studies examined to date, they are not over-represented in the wide range of other kinds of research examined in the present study, for those studies considered in combination with the intervention studies. This pattern is different from that observed in several other areas of psychological research, where males are over-represented (e.g., Holwerstott et al., 2002; Jarema et al., 1999; Poling et al., 2009; Porter et al., 2003). Across all of the articles examined in the present study, 82.22% of the participants with an ASD were male and 82.09% were male in the non-intervention articles. These values represent male:female ratios of 4.62 and 4.34, respectively, which are similar to the 4.3 ratio 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).

Most of the articles evaluated in the present study, 82.21% of the total, included both male and female participants. Therefore, if data were compared for males and females, they could provide information about the influence of gender on whatever variables were of interest. No attempt was made to determine how many articles directly compared males and females with ASD but, as noted previously, others have reported that few studies do so (Koenig & Tsatsanis, 2005; Rivet & Matson, 2011). This is seemingly due in part to the small number of females in many studies, which reduces statistical power. At present, surprisingly little is known about gender differences in ASD, and it appears that Koenig and Tsatsanis and Rivet and Matson argue

rightly in contending that that further research examining possible differences is sorely needed. It is noteworthy that very few studies we examined, 0.49% of the total, involved only females with ASD, and a case could be made that this population has been largely ignored by researchers. Given the scarcity of research involving anyone with ASD more than 20 years of age (Edwards et al., 2012), and the paucity of research specifically targeting women, it is probable that middle-aged and older women with an ASD have been almost entirely neglected by researchers, which is a serious oversight.

An interesting and novel finding of the present study concerns the significant gender difference evident in groups with an ASD and in comparison groups. For all articles combined, the mean percentage of male participants was substantially higher in groups with ASD than in comparison groups, and the absolute difference exceeded 20%. With some outcome measures, this may be a significant confound given that there are many well documented differences in the behavior and physiology of males and females with and without diagnosed psychological problems (e.g., Bell, Foster, & Mash, 2005; Hyde, 2007). If gender influences the outcome measure in a particular study in which gender ratios are substantially different in a group with ASD and in a comparison group, it is impossible to ascertain how or if diagnostic status alone affects that measure. It was beyond the purpose of the present study to examine whether the gender make-up of comparison groups versus groups with an ASD was an obvious confound in particular studies and our findings should not be construed as a criticism of any of the articles we examined. Nonetheless, researchers should carefully consider the gender of participants as both an extraneous variable and as an independent variable in future investigations. They also should routinely report the gender of participants, which was not done in over 10% of the articles we examined. Unless gender is reported, it is obviously impossible to ascertain whether that variable

influenced findings. Of course, there may be good reasons not to report gender, or it may be impossible to determine gender in some data sets, and no attempt was made in the present study to determine whether gender could or should have been reported in individual articles that did not do so. This issue, like the gender of comparison groups, merits further attention.

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