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Intervention research to benefit people with autism: How old are the participants?

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ABSTRACT

We determined the reported ages of participants with autism (or autism spectrum disorders) in 146 intervention research studies published recently in four prominent journals. Most participants were between two and eight years of age and only 1.7% of them were 20 or more years of age. These findings suggest that the special needs of older people with autism have generated little interest among researchers, which is arguably an unfortunate oversight.

1. Introduction

Kanner (1943) called attention to autism nearly 70 years ago and since that time interest in the condition has increased exponentially. Much of this interest has involved attempts to develop systematic interventions that improve the lives of people diagnosed with the condition, and with the related conditions comprised by the broader diagnostic category of "autism spectrum disorders" (henceforth, "autism" will be used in this broader sense). Autism emerges in childhood and there is good evidence that early intervention is key to maximizing the quality of life of people with autism (e.g., Harris & Handelman, 2000; Lovaas, 1987; Sheinkopf & Siegel, 1998). Corsella (2005) clearly makes this point in a review of the relevant literature, beginning her conclusion thusly: "The available evidence from a variety of programs and studies suggests that early intervention leads to better outcomes" (p. 82). She cautions, however, that "It is important that professionals and parents are informed about the progress they can expect for their child, as well as remain aware that most research does not support a 'cure' or 'recovery' from autism" (p. 83). That being the case, it is reasonable to assume that many people with autism will have special needs, and hence potentially benefit from therapeutic interventions, throughout their lifespan.

This point was made compellingly by Shattuck et al. (2007). Those authors reported that the specific symptoms of autism and the maladaptive behaviors emitted by people diagnosed with autism changed as people aged, and typically became milder, but most individuals in their sample "remain significantly impaired and dependent on the assistance of others for daily living" (p. 1746). "Therefore," they wrote, "our findings should give greater impetus to extending interventions and services for this population across the life course" (p. 1746). Taking a different tack, Ganz (2007) estimated the age-specific use and financial costs of nonmedical and medical care of people with autism and noted "although autism is typically thought of as a disorder of childhood, its costs can be felt well into adulthood" (p. 343). Interestingly, he estimated the average per capita cost of behavioral therapies as $32,501, $4033, $3479, and $1235 for the age groups 3–7, 8–12, 13–17, and

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18–22 years, respectively, and as $0 for all older age groups. These data suggest that most adults with autism receive no behavioral therapy, even though Shattuck et al.'s findings suggest that many such individuals experience significant behavioral challenges.

Although it is apparent that much of the intervention research involving people with autism involves treatment arranged in childhood, to our knowledge no one has examined the relative number of studies that focus on people with autism in various age groups. The purpose of the present study was to provide such information for a substantial number of recent publications in four prominent autism journals.

2. Materials and methods

To determine the journals with the highest number of intervention studies, we searched the *PsychINFO* database using "autism" and "intervention" as the search terms and limiting the search to article titles. This database was used because it includes a large number of journals devoted to autism. To provide a meaningful but manageable sample, we examined articles that appeared in the four journals with the highest number of relevant articles published from 2009 to the present time. Those journals are *Autism*, *Focus on Autism and Other Developmental Disabilities (FADD)*, *Journal of Autism and Developmental Disorders (JADD)*, and *Research in Autism Spectrum Disorders (RASD)*.

Articles published in these journals and revealed by our search were evaluated by a single person who determined whether each article described an intervention (i.e., 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 subjective state (e.g., affect). Articles with these characteristics were further evaluated to determine the reported (a) number of participants, (b) sex of participants, and (c) age of participants. If information was provided about the age of each participant, that information was recorded. When summary information was provided for a group of individuals, we recorded all of the information provided in the article. If the article included no age-related information or only included information about educational level (e.g., grade in school), it was not considered further.

3. Results

A total of 1167 articles were published in the four journals during the period we examined. Of them, 148 described an intervention as we defined it. We evaluated a total of 146 of these articles; the other two did not include information about participants' actual ages. *Autism*, *FADD*, *JADD*, and *RASD* were the sources of 12, 21, 53, and 60 of the evaluated articles, respectively. The studies described in these articles collectively involved 2144 participants. Of the 1644 participants whose sex was reported, 85.8% were male. The mean age of the participants for whom sufficient information was provided to allow for calculation (2063 people) was 6.89 years. Fig. 1 shows the percentage of studies that included at least one participant in the 0–5 (not including 5), 5–10, 10–15, 15–20, and 20+ year-old categories. Because more than one age category could be included in an article, the cumulative percentage in Fig. 1 exceeds 100. For articles that did not include data on individual

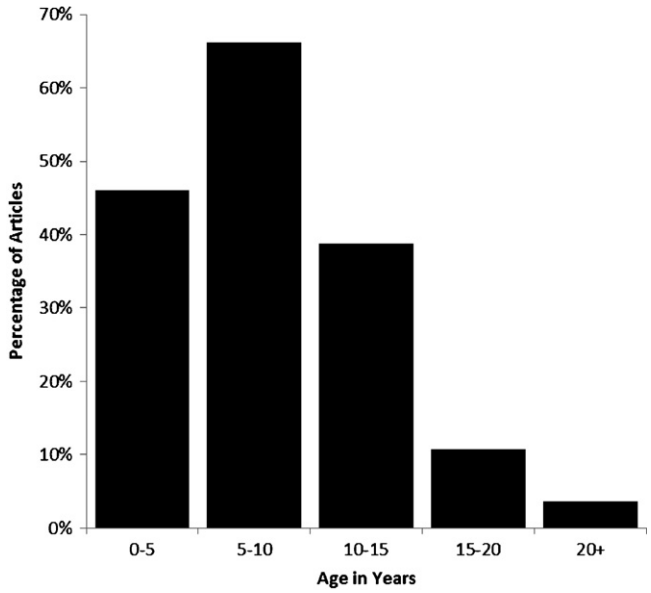

Fig. 1. Percentage of articles that included participants in each specified age category (data based on 146 articles that included sufficient information to calculate the range of participants' ages).