

Title: Caregiver Involvement in Intellectual and Developmental Disability Research: A Systematic Analysis of Publication Diversity and Trends across the Decade

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Introduction: Caregivers play an important role in the social, emotional, and educational development of their children with research demonstrating that higher rates of parental involvement are associated with enhanced child outcomes across multiple domains (e.g., El Nokali et al., 2010). Given the role of parental involvement in child outcomes as well as the observed differences between caregivers of TD children and children with IDD, it is important that the experiences and perspectives of caregivers of children with IDDs be represented in developmental research. Though advancements have been made in exploring the specific experiences of caregivers of children with IDDs, the extent to which these caregivers are represented in the IDD literature in general has not been extensively explored. In other words, how common is it to employ a parent measure in the IDD literature? Moreover, studies involving parents of children with IDDs tend to be conducted in high-income countries with limited research occurring in developing, and non-Western countries (e.g., Scherer et al., 2019). This limits a multicultural understanding of parenting practices, stress, and coping among caregivers of children with IDDs, causing a significant deficit within the field. The primary aim of the current study was to investigate the rate of inclusion of parental measures in peer-reviewed publications in the IDD literature within the last decade. Moreover, we sought to examine trends in research methodology in terms of the type of parental measures used as well as diversity characteristics of the authors and participants represented in research.

Method: We reviewed publications from January 2010 to January 2020 across the following peer-reviewed journals: *American Journal of Intellectual and Developmental Disabilities*, *International Journal of Intellectual Disabilities*, *Journal of Applied Research in Intellectual Disabilities*, *Journal of Autism and Developmental Disorders*, *Journal of Intellectual and Developmental Disability*, *Journal of Intellectual Disabilities*, and *Research in Developmental Disabilities*. Parent involvement was defined as the inclusion of a caregiver measure in an empirical research study. The abstracts of all publications within the designated time frame were screened for the following keywords: *parent*, *caregiver*, *carer*, *mother*, *maternal*, and *father*. The method section of all papers meeting initial inclusion criteria were thoroughly reviewed. Papers were included for the final stage of coding and analysis if the following conditions were met: 1) Only empirical papers were included. We excluded non-empirical publications such as review papers, editorials, opinion papers, and book reviews. 2) The participant sample included individuals with IDDs and/or their primary caregiver. Studies involving only typically developing children were excluded. Papers that did not include caregivers of children with IDDs as participants were also excluded. 3) Papers were included if a caregiver measure (e.g., interview, self-report, parent-child observation) was utilized. All included papers were independently reviewed by two research assistants to ensure that each paper met final inclusion criteria. The final sample of papers were coded for the first author's affiliation and country, the participant's country, and the type (e.g., interview, self-report) of parent measure used. All papers were double coded for accuracy.

Results: In total, 7,908 abstracts were screened with 2,007 (25%) papers meeting initial inclusion criteria. After further review, the final sample included 1,605 (20%) papers. Table 1 shows the percentage of papers that included parental measures across each journal (Range; 14%-27%). A chi-square goodness of fit analysis indicated that the seven journals did not significantly differ from one another in terms of the percentage of papers that were included; however, a significantly higher (raw) number of papers were included from the Journal of Autism and Developmental Disorders. In terms of diversity characteristics, 39% of first author affiliations were located in the US followed by the UK (12%), Australia (8%), The Netherlands (5%), and Canada (5%). See figure 1 for percentages by continent. Similarly, 39% of participants were from the US followed by the UK (11%), Australia (7%), Canada (6%) and the Netherlands (5%). See figure 2 for percentages by continent. Additional analyses detailing parental measures and diversity characteristic as a function of year and journal will also be reported.

Discussion: We conducted an in-depth analysis of empirical papers published over the last decade in seven peer-reviewed journals specializing in research on intellectual and developmental disabilities. Across the 7,908 reviewed publications, 20% included parental measures for caregivers of children with IDD, which is a rather high rate. This may be because the field of IDD research has commonly used parental measures as a tradition and children with IDDs cannot properly report their own behavior/condition, among other factors. As anticipated, the overwhelming majority of research within the last 10 years has been conducted in Western, developed countries (e.g., US, UK) with a small proportion of research coming from developing countries. Moreover, our analyses indicate that caregivers of children with IDDs who reside in continents like Asia, Africa, and South America are significantly underrepresented in research. While researchers have emphasized the potential lack of diverse samples in developmental research, the current student provides the first in-depth examination of over fifteen hundred papers demonstrating an overall lack of diversity in the field in terms of including caregivers of children with IDDs from underrepresented countries. Our findings highlight the ongoing need for an increased focus on caregivers of children with IDDs in research from a multicultural perspective.

References:

El Nokali, N. E., Bachman, H. J., & Votruba-Drzal, E. (2010). Parent involvement and children's academic and social development in elementary school. *Child development, 81*(3), 988–1005. <https://doi.org/10.1111/j.1467-8624.2010.01447.x>

Scherer N, Verhey I, Kuper H (2019) Depression and anxiety in parents of children with intellectual and developmental disabilities: A systematic review and meta-analysis. *PLoS ONE 14*(7): e0219888. <https://doi.org/10.1371/journal.pone.0219888>

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Table 1

Percentage of Included Publications by Journal

Journal	Included	Reviewed	%
American Journal on Intellectual and Developmental Disabilities	98	357	27.45
International Journal of Developmental Disabilities	41	286	14.34
Journal of Applied Research in Intellectual Disabilities	125	731	17.10
Journal of Autism and Developmental Disorders	737	3108	23.71
Journal of Intellectual and Developmental Disability	82	419	19.57
Journal of Intellectual Disabilities	62	332	18.67
Research in Developmental Disabilities	460	2675	17.20
Total	1605	7908	20.30

Figure 1

FIRST AUTHOR CONTINENT

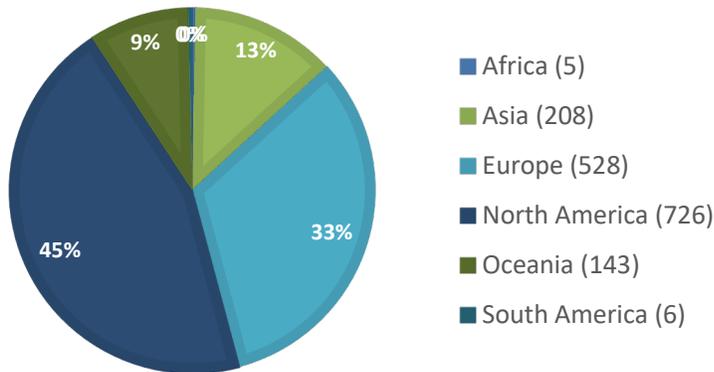


Figure 2

PARTICIPANT CONTINENT

