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Parental Participation in Intellectual and Developmental Disability Research: A Review of Diversity

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disabilities

Review

Parallel Participation in Intellectual and Developmental Disability Research: A Review of Diversity

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Abstract: Parents provide important insights into the psychology, behaviors, and activities of themselves and their children with intellectual and developmental disabilities (IDD). However, it is unknown how prevalent parental participation in IDD research is in general, nor the diversity of geographical locations and research methods of these studies with parental participation. The current review screened 7845 published works in 7 IDD-focused journals between 2010 and 2019. A total of 1519 articles, accounting for 19.37% of all screened works, included at least one parental measure. For each parental article, we coded the country/continent of authors/participants, measurement tools used to obtain data from parents (e.g., questionnaire, interview), and the focus of the measurement (i.e., about parents, child, or both). We found an increasing number and proportion of studies involving parents between 2010 and 2019. Most studies (76%) came from North America and Europe, whereas other continents such as Africa and South America represented less than 1% of all studies reviewed. The predominant (88.0%) measurement tools were questionnaires and interviews. More studies were about both the children and the parents (42.6%) than either only the children (31.3%) or only the parents (26.1%). Together, our review showed a somewhat limited diversity in parental participation in IDD research and these findings have important implications for future research.

Keywords: review; parental participation; diversity; country; questionnaire; prevalence

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1. Introduction

Parents serve an active caregiving role in the lives of individuals with intellectual and developmental disabilities (IDD, [1]). While it is common for researchers to include parents as informants in research studies (e.g., [2]), the extent to which researchers utilize parental measures in the IDD field on a broader scale has not yet been empirically investigated. Here, we conducted a retrospective bibliometric and methodological review of parental participation in IDD research, focusing on the diversity of geographical locations and research methodologies.

1.1. Significance of Involving Parents in IDD Research

In the US, many individuals with IDD live with a family caregiver [1,3], and parents often provide lifelong support to their children with IDD [4,5]. It is therefore valuable for researchers to include parents' perspectives in research concerning individuals with IDD for several reasons. First, parents provide critical insights into the psychology, behaviors, and activities of their children with IDD [6,7]. In a recent review of measurement tools used to assess mental health functioning among youth with ID, Halvorsen and colleagues [2] found that most studies utilized informant-rated measures completed by the child's primary caregiver (i.e., parent). Moreover, best practice in the assessment of children and adolescents warrants the use of multiple informants (e.g., child and parent) to gather information about psychological functioning [8]. The value of gathering information via both self and caregiver report has also been recognized within the IDD literature [2,6,9]. Second, parents of children with IDD are worth studying in their own right. Caregivers of children with IDD often report higher rates of mental and physical health symptoms [10,11]. Knowledge acquired from parents about their unique caregiving needs can be used to guide future interventions and support services. Third, engaging caregivers in the research process may help to ensure that research aims better align with the needs of children and families and can inform future research practices [12].

While there are ample reasons for *why* it is valuable for researchers to include parents in their studies, it is unclear how much this belief translates into practice. No existing research has systematically examined how often researchers in the field include parents in their empirical studies nor the role that parents play when they are involved in research. Some reviews have examined parental involvement in IDD, but they have been content reviews, focusing on specific yet narrow topics such as stress (e.g., [13]). Here, we assessed the prevalence rate of including parents in research studies to provide actual, empirical data regarding the utilization of parents in IDD research on a broader scale. For instance, a 1% prevalence rate would indicate a serious under-utilization of parental measures in the field and would highlight an opportunity for future research. Alternatively, an 80% prevalence rate would indicate that including parental measures is common practice. This review provides a 'bird's-eye' view of the field's emphasis on parental involvement in research over the last decade to assess current practices. We anticipate that the findings from this review will be a useful tool to inform future research in the IDD field.

We conducted a methodological review examining articles containing parental measures published in seven well-known IDD journals during the last decade. Given that our primary aim was to assess the prevalence rate and diversity of parental measures in IDD research, conducting a systematic database review of parental involvement was deemed insufficient to answer our research questions. Rather, reviewing all published works within selected IDD journals allowed us to calculate the number of published articles that did and did not include parental measures within a designated time. In sum, we investigated how prevalent it was for researchers to include parental measures and the diversity of the geographic locations of these studies. We also examined the diversity of research methods used to gather information from parents. Attending to diversity issues has important implications for recognizing vital research limitations and promoting more diversity in research participation and methodological approaches for future research (e.g., [14]).

1.2. Diversity

1.2.1. Geographical Locations

Parents are important to IDD research, not only in western, wealthy countries, but also in other middle-to-lower-income countries [12,15]. However, much behavioral science has been conducted in Western and industrialized countries and, as a result, tends to include participants from these countries [16]. This has prompted calls for an increase in multicultural diversity and transnational representation in psychological research broadly, including in the IDD field [17,18]. Notably, parenting practices for children with IDD significantly differ across cultures [15,19]. Thus, the IDD field should consider global diversity to enhance the generalizability of research findings. Some content reviews have found less research attention on parents of children with IDD from middle-to-lower-income countries [11,15]. However, there are no detailed and comprehensive statistics on the extent to which participants and authors from these countries are genuinely underrepresented outside of these specific content areas. One goal of the current review is to answer this question.

1.2.2. Methodologies

Evaluating research methods plays an imperative role in assessing the focus and limitations of research [20,21]. The choice of research methods can shed light on what types of research questions are of interest. Scholtz and colleagues [22] found that the data collection method most often used in five general psychology journals between 2013 and

2017 were questionnaires (57%) followed by experimental tasks (16%). In IDD research, it is common to use questionnaires and interviews to collect data from parents, as questionnaires and interviews efficiently assess attitudes, behavior, and symptoms (e.g., [11]).

However, there are many other research methods available. For instance, reaction times and manual responses are commonly used to indicate cognitive and behavioral outcomes (e.g., [23]). Physiological responses and brain activities are typically collected to indicate physiological and neurological outcomes (e.g., [24]). Different methods are suited to answer different research questions and topics. Meanwhile, multiple methods can complement each other and provide information relevant to various aspects of the research question. Hence, it is likely worthwhile to adopt diverse measurement tools. However, it is unclear what kinds of research methods have been used in IDD research involving parents and whether there is an imbalance in using different methods or stagnation in adopting new research methods.

Another aspect of research methods is that parental measures can focus on parents, children, or both. For instance, a questionnaire could ask about parents' daily behaviors and emotional states (e.g., [25]) or ask parents to provide information about their child's daily behaviors (e.g., [7]). Whereas the former reflects an interest in the parents, the latter demonstrates an interest in the child. Knowing whether parental measures are focused on the child, the parent, or both will shed light on the purpose of the research and why researchers examined parents of children with IDD in the first place.

1.3. Current Study

Despite research evidence suggesting that parents are valuable informants and offer unique perspectives to advance IDD research, there is currently no empirical data to show the extent to which published studies in the IDD field include parental measures. Knowing this would shed light on the field's emphasis, or lack thereof, on parental involvement in research and can be leveraged to inform future research practices in the IDD field. Furthermore, despite a growing emphasis on authorship diversity and research methodology diversity (e.g., [22,26]), little research in IDD has specifically examined these diversity issues systematically. Our study aims to fill these gaps by examining the following questions: (1) How prevalent are parental measures in IDD research? (2) How diverse are the geographical locations of IDD research involving parents? (3) How diverse are the foci of the parental measures in this body of literature (e.g., on the child, parent, or both)? (4) How diverse are the measurement tools that have been used (e.g., questionnaires, interviews)? Findings from this review will highlight strengths and weaknesses of research involving parents within the IDD field, shed light on potential geographic biases in the current IDD literature, and examine what role parents serve in IDD research. It will also have significant implications for future research, such as revealing the utilization (or lack thereof) of parental measures in IDD research, encouraging publications from researchers from diverse backgrounds, and promoting the use of diversified and innovative parental measures.

2. Method

2.1. Inclusion Criteria

We selected a sample of well-known journals of IDD in the behavioral sciences (i.e., psychology). We selected journals based on a review of the journal's impact factor, specific aims and scope, and geographical location. We ultimately included the following seven journals:

1. *American Journal of Intellectual and Developmental Disabilities* (AJIDD);
2. *International Journal of Developmental Disabilities* (IJDD);
3. *Journal of Applied Research in Intellectual Disabilities* (JARID);
4. *Journal of Intellectual and Developmental Disability* (JIDD);
5. *Journal of Intellectual Disabilities* (JID);
6. *Research in Developmental Disabilities* (RIDD);
7. *Journal of Autism and Developmental Disorders* (JADD).

Due to feasibility and efficiency constraints, we acknowledge that there are other reputable IDD-focused journals which were not included in the current review. Nevertheless, the sample of journals selected are geographically diverse in terms of publisher location and editorial board composition and focus on a wide range of IDDs. For instance, the first five journals contain "intellectual disability(ies)" (ID) in their titles, aims, or scopes. RIDD mentioned developmental disabilities (DD) more broadly in their aims and scopes but has included many studies of ID. Lastly, JADD is a specialty journal of ASD research and has also included IDD research.

We screened all works in the seven journals published between January 2010 and December 2019 (initial screening began in March 2020). Given our primarily focus on parental participation in research for their children with IDD, our main inclusion criteria were that: (1) the study included primary caregivers (i.e., parents) of individuals with documented or suspected IDD diagnoses; and (2) the primary caregivers had completed at least one study measure, yielding identifiable data. Given our focus on parents rather than professional caregivers, we operationalized a primary caregiver as the biological or adoptive parent or another custodial family caregiver (e.g., sibling, grandparent) of an individual with IDD. We included all types of caregiver measures, except for demographic questionnaires or measures deemed insufficient for coding (e.g., caregiver verbally confirming the diagnosis).

2.2. Exclusion Criteria

We excluded review papers (e.g., meta-analyses, systematic reviews), editorials, opinion papers, book reviews, and all other non-empirical works. We used the definition of IDD set forth by the National Institute of Health [27] to guide our exclusion criteria. Because we were only in interested in children with documented or suspected IDD diagnoses, we excluded studies of only typically developing children or children deemed 'at-risk' (e.g., low birth weight, preterm birth) in the absence of a formal or suspected IDD diagnosis (e.g., population-based studies). Similarly, we also excluded studies of children with mental or behavioral health disorders without co-occurring IDD. Because we were only interested in primary caregivers, we excluded studies involving only professional caregivers such as health care staff or in-home aids without including data from primary caregivers (i.e., parents).

2.3. Literature Search

Trained research assistants (RAs) used each journal's primary website to screen all published works for the following keywords: "parent", "caregiver", "mother", "maternal", "father", and "carer". If RAs identified key terms in the abstract, keywords, or highlights, the article was retained for full-text review. In a few cases, open access articles were available on the same page as the abstract. If any of the keywords were found in the Method section of these open access articles, RAs retained the article for full-text review. This occurred in a small sample of cases. All other works were excluded at this stage. The first author randomly selected one year of each journal, double screened all published works, and found no errors warranting double screening. After initial screening, each full-text article was assessed for eligibility based on the inclusion criteria. See Figure 1 for PRISMA flowchart.

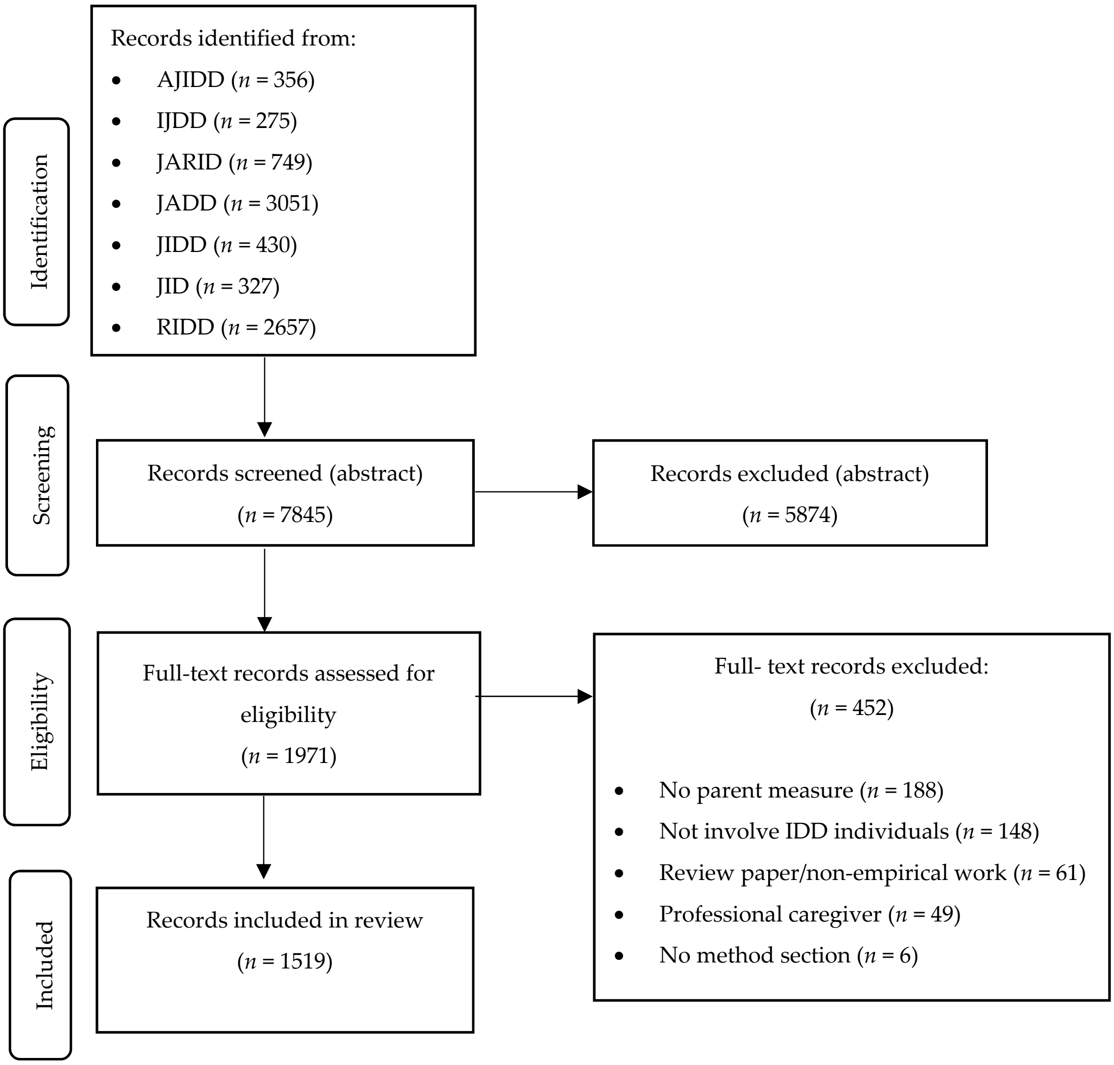

Figure 1. PRISMA flowchart of records.

2.4. Coding

We coded each article for: (1) first author affiliation(s), country, and continent; (2) participant country and continent; (3) the tools to collect caregiver data (e.g., questionnaire, interview, focus group, etc.); and (4) the focus of the caregiver measure (e.g., child, parent, both). Coding proceeded in three stages. First, trained RAs—forming the primary coding team—independently coded articles for their assigned coding section. The second stage consisted of double coding. The primary coding team double-coded author and participant data. The first and third authors independently double-coded all caregiver measures. Finally, the first author triple-coded all variables for a random 10% sample of articles (n = 151). Percent agreement for this sample was 96.03% for author affiliation, 98.68% for author country, 98.01% for participant country, 88.08 % for method type, 93.38% for child measures, and 96.69% for parent measures. All research team members met weekly to discuss progress and discrepancies throughout the screening, coding processes, etc. The first and third authors jointly made final screening and coding decisions in consultation with the second author.

2.4.1. Geographical Locations

Coders extracted the first author's affiliation(s) and country from the authors' information of each article. When a first author had more than one affiliation and associated country, or when participants come from more than one country, all countries were coded for the same article. Continents were then derived from the country information. Coders also coded the participants' countries and continents, extracted from the methods section. As expected, the results of participants' information were extremely similar to those of the authors' and are hence not presented further.

2.4.2. Parental Measures

We categorized parental measurement tools into questionnaires, interviews, observations, focus groups, biological measures, or other (e.g., record review, diary/log, experimental, due to their relatively small frequency). The categorization was based upon the authors' description in the article (e.g., "parents completed a structured interview") and/or the specific name of the measure (e.g., "Social Communication Questionnaire"). When clarification was needed, coders also referenced the website of the measure's publisher. One article could include multiple categories of caregiver measures. For measurement foci, coders indicated whether the parental measures were for or about the child, the parent, or both. Measures assessing family functioning were coded in the 'both' category.

3. Results

See Supplemental Data S1 for all parental articles and their applicable codes. For each dependent variable listed below, we first compared between different journals using one-way ANOVA and then examined its yearly trend using regression analyses.

3.1. Inclusion of Parental Articles

3.1.1. Count

Figure 2 shows the number of parental articles in each journal across the 10 years. The design included two factors: journal (7 levels) and year (10 levels). Each unique combination of the two factors was associated with one datum. Therefore, it was not appropriate to conduct ANOVA including both factors.

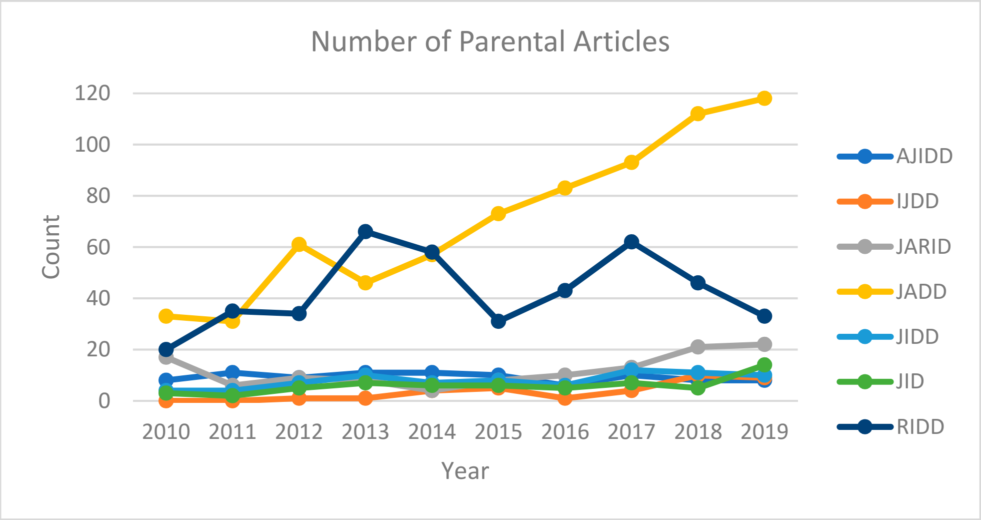

Figure 2. Number of parental articles in different journals in different years.

We first conducted a one-way ANOVA comparing the seven journals. The main effect of journal was significant, $F(6,63) = 36.31$, $p < 0.001$, $\eta^2_p = 0.776$. Post hoc tests found the highest number of parental articles in JADD (M = 70.70), followed by RIDD (M = 42.80), $p < 0.001$. Both published significantly more parental articles than the other five ID journals, which did not differ from each other (AJIDD: M = 9.20, IJDD: M = 3.5; JARID: M = 11.80; JIDD: M = 7.9; JID: M = 6.0). However, this difference may be related to the higher total number of both parental and non-parental articles published in RIDD and JIDD. In fact, RIDD and JADD published 265.7 and 305.1 total articles each year on average, respectively, whereas the average yearly total articles ranged from 27.5–74.9 for the other five ID journals.

Next, we regressed the number of parental articles on year (disregarding the factor of journal). We first rescaled year by subtracting each year from 2009 so that the intercept could be easily interpreted. This rescaling was also done for all following regression analyses involving year. The overall regression model was marginally significant, y = 10.21 + 2.09Year (rescaled), $F(1,68) = 3.62$, $p = 0.061$, $R^2 = 0.051$. There was a 2.09 average increase in new parental articles published for each journal with each passing year. The regression model remained significant when we excluded JADD and RIDD from the analysis, y = 3.97 + 0.67Year (rescaled), $F(1,48) = 10.35$, $p = 0.002$, $R^2 = 0.177$.

3.1.2. Ratio

To account for different total articles in each journal and year, we calculated ratios by dividing the number of parental articles by the number of total articles (i.e., both parental and non-parental articles) for each journal in each year. These ratios showed the prevalence of parental studies in IDD research. Because one journal (IJDD) did not contain any parental articles in 2010 and 2011, the ratio would be $0 \div 0$ (i.e., indeterminate) and was hence treated as missing data.

Like the analyses above, we first compared the ratios of parental articles in different journals using one-way ANOVA. The main effect of journal was significant, $F(6,63) = 5.22$, $p < 0.001$, $\eta^2_p = 0.332$. Post hoc tests showed that AJIDD (M = 0.258) and JADD (M = 0.223) had the highest ratios of parental articles. Both journals published significantly higher ratios of parental articles than IJDD (M = 0.103), which had the lowest ratio, $p < 0.001$ and $p = 0.004$, respectively. AJIDD published a significantly higher ratio of parental articles than JARID (M = 0.163), which had the second-lowest ratio, $p = 0.050$. The ratios of the other three journals fell somewhere in between (JIDD: M = 0.184; JID: M = 0.178; RIDD: M = 0.175). On average, 0.183 or 18.3% of all articles in each journal in each year utilized at least one parental measure. These studies are called 'parental articles' hereafter.

Next, we regressed the ratios of parental articles on year. The regression model was significant, y = 0.124 + 0.011Year (rescaled), $F(1,68) = 12.72$, $p = 0.001$, $R^2 = 0.158$. Each passing year led to a 1.1% increase in the ratio of published parental articles.

3.2. Geographical Locations

3.2.1. Continent

Studies' geographical locations were categorized into six continents: North America, Europe, Oceania, Asia, Africa, and South America. Collapsing all journals across all years, 698 articles came from North America (45.5%), 474 from Europe (30.9%), 142 from Oceania (9.3%), 210 from Asia (13.7%), and 5 each from Africa and South America (0.3%).

To account for different total parental studies in each journal and year, we calculated ratios by dividing the frequency of each continent by the total number of continents for each journal in each year. For instance, in 2010, AJIDD published eight parental articles: seven from North America and one from Asia. Thus, the ratio of articles from North America for AJIDD in 2010 was 7/8, or 87.5%. The design included three factors: journal (7 levels), year (10 levels), and continents (6 levels). Again, because each unique combination of the three factors was associated with one datum, conducting a three-way ANOVA was not appropriate. We thus conducted three analyses. In the first analysis, we compared the six continents in a one-way ANOVA, including all journals. In the second analysis, we compared the six continents for each journal. In the third analysis, we examined the yearly trend for each continent. This approach was also adopted for analyses of countries, measurement foci, and measurement tools later.

A one-way ANOVA comparing the six continents including all journals yielded a significant main effect, $F(5,402) = 63.54$, $p < 0.001$, $\eta^2_p = 0.441$. Post hoc tests showed no difference between North America (M = 0.397) and Europe (M = 0.360), and both groups were greater than Oceania (M = 0.095) and Asia (M = 0.139), *p*s < 0.001, which did not differ from each other. The smallest ratios were observed for Africa (M = 0.008) and South America (M = 0.003), which did not differ from each other.

For each journal, we conducted a one-way ANOVA comparing the six continents. (see Figure 3). For more detailed results, see the Appendix A. To summarize, for AJIDD and JADD, the top continent was North America; for JARID, JID, and RIDD, the top continent was Europe; for JIDD, there were three top continents: North America, Europe, and Oceania. For IJDD, post hoc tests showed none of the comparisons to be significant.

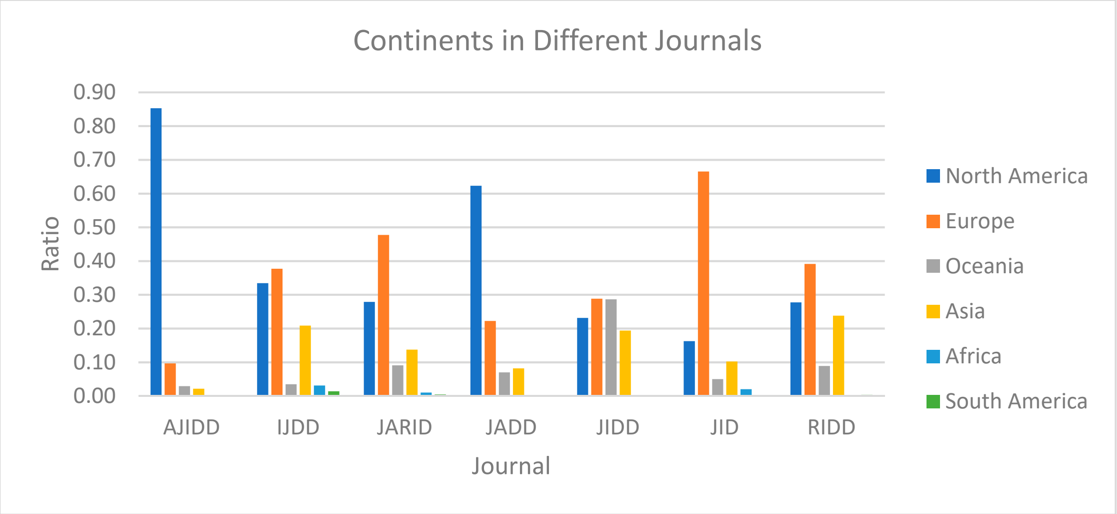

Figure 3. Ratio of articles from different continents in different journals.

Next, we regressed ratios on year for each continent. The linear regressions were not significant for any continent except for South America, $y = -0.004 + 0.001\text{Year}$ (rescaled), $F(1,66) = 4.18$, $p = 0.045$, $R^2 = 0.060$. However, the extremely small score in each year may have biased the results. More specifically, for South America, only 2014 and 2019 had non-zero numbers (0.005 and 0.023 respectively), and the ratios were zero in all the other years.

3.2.2. Top Five Countries

We identified the five countries with the highest numbers of parental articles. More specifically, 613 authors (39.7%) were affiliated with institutions in the US, 187 authors (12.1%) from the UK, 135 (8.7%) authors from Australia, 86 (5.6%) from Canada, and 35 (2.3%) authors from China. These countries are collectively referred to as the 'top five countries' hereafter. Altogether, the top five countries appeared 1056 times among 1543 total countries. Hence, 68.4% of all authors came from only five countries. No other single country was associated with more than 2.3%.

Like the analyses of continents, we calculated ratios by dividing the frequency of each top five countries by the total number of countries for each journal in each year. We first conducted a one-way ANOVA comparing ratios between the top five countries, including all journals and years. The main effect was significant, $F(4, 335) = 34.07$, $p < 0.001$, $\eta^2_p = 0.289$. Post hoc tests showed the highest ratio in the US (33.13%), *ps* < 0.001, followed by the UK (15.44%) and Australia (9.06%), which did not differ from each other. The US and the UK were also significantly higher than Canada (6.45%) and China (1.49%), *ps* < 0.001, which did not differ from each other.

As in analyses of continents, we next explored differences between the ratios of the top five countries within each journal across all years (see Figure 4). To summarize, the US was the top country for three journals (i.e., AJIDD, JADD, RIDD). UK was the top country for two journals (JID and JARID). Australia was the top country for JIDD. Furthermore, we summed the ratios for the top five countries for each journal in each year. Higher ratios demonstrate a higher inclusion rate of the top five countries and hence fewer articles from other countries. A one-way ANOVA showed a significant main effect of journal,

$F(6,61) = 7.12$, $p < 0.001$, $\eta^2_p = 0.412$. Post hoc tests showed that AJIDD had a higher ratio (0.946) than four other journals (IJDD: 0.483; JIDD: 0.561; JID: 0.596, RIDD: 489), *p*s < 0.005. JADD contained the second-highest ratio (0.797), higher than two other journals (RIDD and IJDD), *p*s < 0.03. JARID (0.683) did not differ from any other journal.

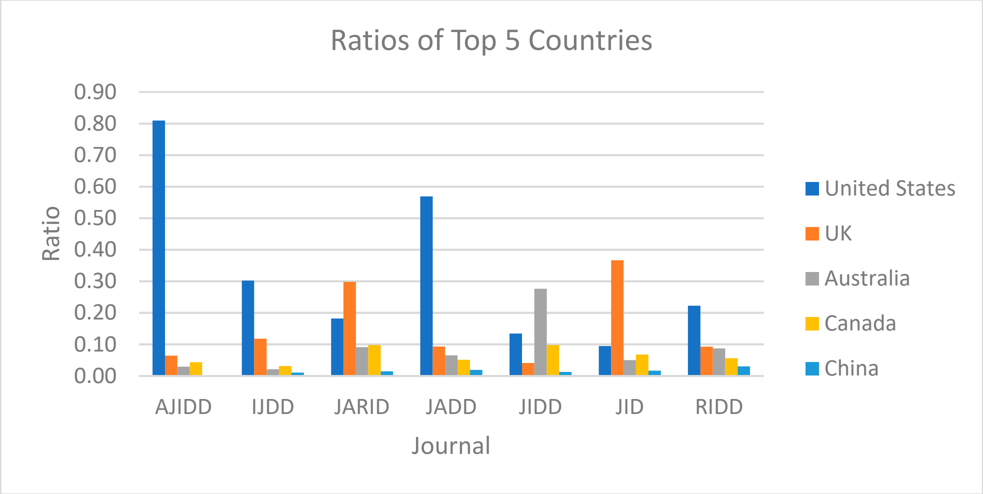

Figure 4. Ratios of the top five countries in different journals.

Are the observed differences in geographical diversity among journals related to the country where journals were published and/or to the journal editors' affiliations? It is fair to say that all seven journals have an international readership. Five journals (IJDD, JARID, JIDD, JID, and RIDD) explicitly describe themselves as "international" journals on their websites. No such explicit statements were found for JADD and AJIDD, the latter of which is one of the official journals of the American Association of Intellectual and Developmental Disabilities. For JADD, the publishing company is located in the US. For the nationality diversity of each journal's editors-in-chief, see Supplemental Data S2. In sum, AJIDD and JADD are American journals, had American editors-in-chief, and included fewer articles from countries (around or less than 20%) beyond the top five previously described. Other journals such as JIDD, JID, and IJDD are international journals, had editors-in-chief from institutions in non-US, developed countries (e.g., UK, Australia, Ireland, Singapore, Scotland), and included more parental articles (over 40%) from non-top-five countries.

Finally, we conducted linear regression analyses of ratios on year for each top-five country. The linear regressions were not significant for any country and were not reported here.

3.2.3. Number of Unique Countries

For each journal in each year, we obtained the number of unique countries. For instance, if there were 10 articles from the US, 5 from Canada, 1 from Ireland, and 1 from Australia, then there were 4 unique countries. We first compared the seven journals using a one-way ANOVA, across all years. The main effect of journal was significant, $F(6,63) = 27.34$, $p < 0.001$, $\eta^2_p = 0.723$. Post hoc tests showed higher numbers of unique countries for JADD (M = 12.6) and RIDD (M = 15.5) than the other five journals, *p*s $\leq$ 0.002. The other five journals (JARID: M = 7.0; JIDD: M = 5.4; JID: M = 4.1; IJDD: M = 3.2; AJIDD: M = 2.5) did not differ from each other with one exception: JARID was significantly higher than AJIDD, $p = 0.03$. The higher unique country count for JADD and RIDD may be because these journals had more parental articles overall.

Next, we regressed the number of unique countries on year. The overall model was significant, y = 4.25 + 0.534Year(rescaled), $F(1,68) = 5.91$, $p = 0.018$, $R^2 = 0.066$. On average, there were 0.534 more unique countries represented with each passing year. Next, we ran the regression excluding JADD and RIDD. The overall model was still significant, y = 2.15 + 0.417Year(rescaled), $F(1,48) = 11.45$, $p = 0.001$, $R^2 = 0.176$.

3.3. Measurement Foci

We again calculated ratios by dividing the frequency of each measurement focus (child, parent, both) by the total number of all measurement foci for each journal in each year. We first compared three measurement foci in a one-way ANOVA, disregarding the factors of journal and year. The main effect of measurement foci was significant, $F(2,201) = 10.35$, $p < 0.001$, $\eta^2{}_p = 0.093$. Post hoc tests found a significantly higher ratio for both (M = 0.425) compared to parents only (M = 0.262) and child only (M = 0.313), $ps \leq 0.01$, whereas the latter two did not differ from each other, $p = 0.511$.

As in analyses of continents, we compared the ratios between different measurement foci within each journal, across all years (see Figure 5). To summarize, for all seven journals, a relatively high proportion of studies utilized measures for both parents and children. However, the comparisons between parent only and child only differed among journals. Four journals (AJIDD, IJDD, JADD, RIDD) contained more child only than parent only studies, whereas the reverse pattern was found in the other three journals (JARID, JIDD, JID). Next, we conducted linear regression analyses of ratios on year for each measurement focus. None of them were significant, indicating that the ratios of each measurement focus did not change over the years and hence were not reported.

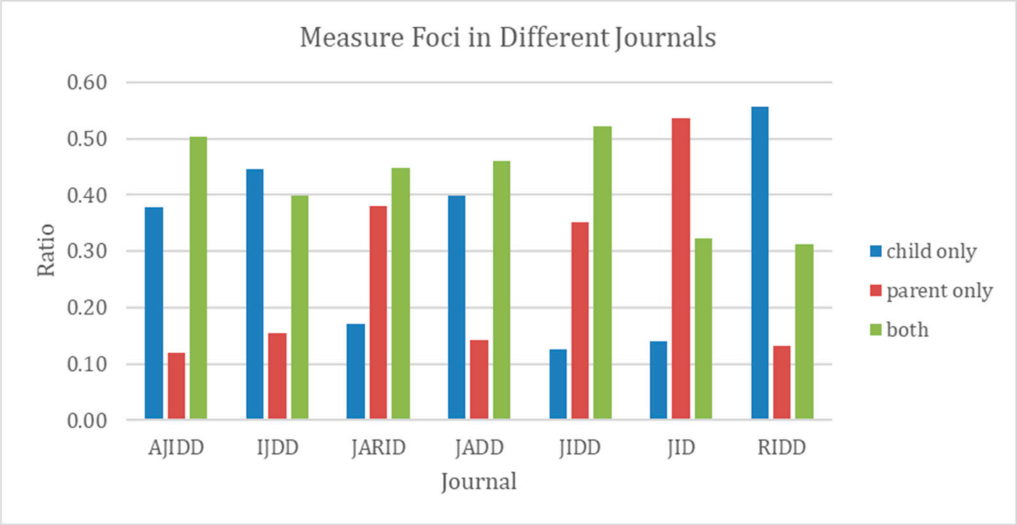

Figure 5. Ratios of different measurement foci in different journals.

3.4. Measurement Tools

We identified six measurement tools: questionnaire, interview, observation, focus group, biological/medical record, and other. Again, we obtained ratios by dividing the frequency of each measurement tool by the total number of all measurement tools for each journal in each year. The one-way ANOVA showed a significant main effect of measurement tool, $F(5,402) = 235.34$, $p < 0.001$, $\eta^2{}_p = 0.745$. Post hoc tests showed a significantly higher ratio for questionnaires (M = 0.568) than interviews (M = 0.312), $p < 0.001$. Both measure types were significantly higher than any of the other four types, $ps < 0.001$ (M = 0.037 for observation, M = 0.045 for focus group, M = 0.007 for biological/medical record, M = 0.032 for other)

As in the analyses of continents, we compared the ratios between different measurement tools for each journal across all years (see Figure 6). Overall, the pattern of results in each journal was consistent with the overall trend. There were higher ratios of questionnaires and interviews and lower ratios of the other four measurement tools. We also conducted linear regressions, regressing ratios on year for each measurement tool. None of them were significant, indicating that the ratios for each measurement tool did not change over the years and hence were not reported.

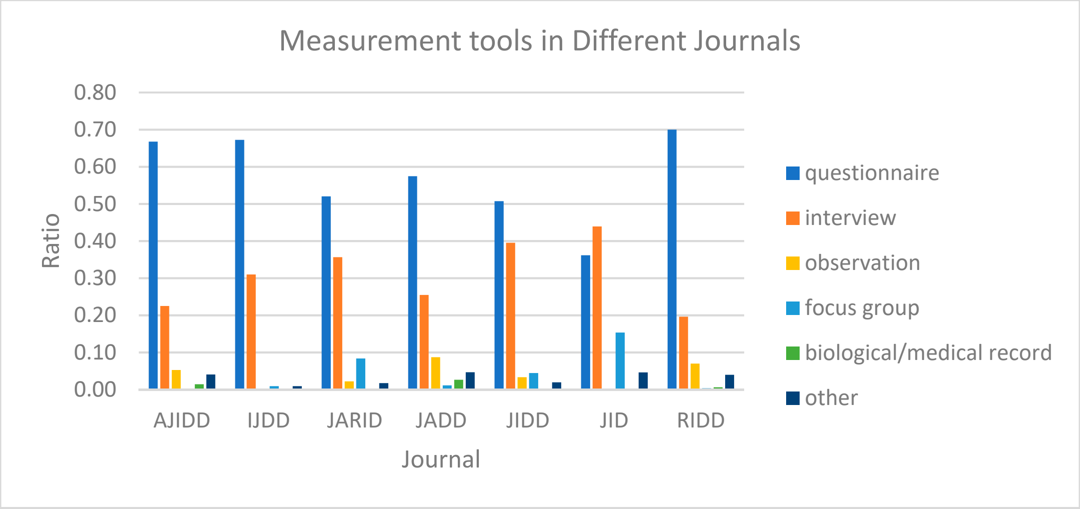

Figure 6. Ratio of measurement tools in different journals.

4. Discussion

To our knowledge, this is the first methodological review concerning the prevalence of parental involvement in IDD research with an emphasis on diversity issues. After screening a total of 7,844 published works in seven journals between 2010 and 2019, 1519 studies (19.37%) included at least one parental measure. Another major contribution of this review is to use statistical measures including regression and ANOVA analyses to examine the yearly trend and differences between different journals regarding parental involvement in IDD research. The regression analysis showed an increase in parental articles published each year, suggesting greater involvement of parents in IDD research over the past decade. Authors from North America and Europe published 76.4% of all parental articles reviewed. By comparison, less than 1% were published by authors from Africa and South America. Most studies measured both parent and child attributes (42.6%). The overwhelming majority of measurement tools were questionnaires and interviews, with a combined ratio of 88.0%. Our review provides a 'bird's-eye' view of the field by examining the prevalence, geographical diversity, and methodology diversity of articles involving parental measures IDD journals. While anecdotal evidence and individual studies suggest that parents' perspectives are valuable to include in research, our review provides empirical data regarding the actual utilization of parental measures in practice. Moreover, while there was some diversity in geographical locations and research methodology in the articles reviewed, we believe that more can be done to increase diversity in the IDD field.

4.1. Geographical Locations

Consistent with prior research in behavioral science [16,18], our results showed an overall high concentration of IDD research involving parental measures from North America and Europe. The countries with the highest number of parental articles were the US, UK, Australia, Canada, and China (i.e., the top five countries). One could argue that these five countries are more affluent and have greater access to resources to research than do lower-income countries. However, it is still interesting that these top five ranks are not necessarily consistent with GDP rankings: US, China, Japan, Germany, and the UK in 2021 [26]. However, we did limit our literature search to studies published in English, which may have limited the input from researchers from non-English speaking countries. Research published by authors outside of the top five countries was still relatively limited. The US and the UK alone accounted for over 50% of all countries represented in the parental articles reviewed, although these two countries only comprise less than 10% of the world's population [28]. One implication of our results is that many existing research conclusions about parental involvement in IDD research might have been about western, wealthy countries, and that researchers should exercise caution in accepting these conclusions, especially if they are examining participants from non-western, developing countries.

More geographical diversity in parental research in the field of IDD will better highlight how culture shapes parental behaviors and will better serve people with IDD and their families from diverse backgrounds [17,29,30]. Indeed, lately, more and more IDD research has adopted transnational and global perspectives (e.g., [15,17,29,30]). In a recent special issue on parental participation in RIDD [14], particular interest was placed on underrepresented communities (e.g., Africa, Asia, and South America) and/or ethnic minorities. One contribution of our review is to provide actual data on the extent to which research had been underrepresented in specific geographic locations. It is somewhat encouraging that our regression analyses showed there were, on average, 0.54 new unique countries with each passing year. This implied that more researchers from non-top-five countries included parental participation in their IDD research over the last decade. However, this still seems slow, especially compared with 2.09 new parental articles per journal and year. The number of new parental articles far outpaced the number of unique countries by about 4-fold. Furthermore, the yearly trend of continents and top five countries showed almost no variation over the past decade, again corroborating the slow progress of diversity. Therefore, we should ask: is the lack of research from non-top-five countries because researchers from these countries do not think parents are important to IDD research? We highly doubt it. Rather, researchers from low-income, developing countries may lack the necessary resources (infrastructure, facilitates) to conduct research involving parents of children with IDD, or face certain publication barriers. This lack of diversity may not be limited to IDD research but applies to psychology research in general [16]. Nevertheless, systematically documenting it may serve as an essential first step for future structural changes.

4.2. Research Methods Diversity

Our results showed a relatively even distribution of measurement foci on parents and children (26.2% vs. 31.3%). Most measures focused on both the child and parent (42.6%). Therefore, our findings suggest that researchers involve parents as informants for their children with IDD and also seek to learn about parental perspectives, behavior, and psychology. Overall, the research of parental participation typically centers around the social role of parenting and the parent–child dyadic relationship [31].

Approximately 88% of the parental studies we reviewed used questionnaires and interviews to gather information from parents. Furthermore, ratios of different research methods remained remarkably stable over the past decade, as shown by the regression analyses. Although it is expected that questionnaires and interviews would make up the majority of research methods, it is still somewhat surprising to see the extent to which these methods have dominated the field over the last decade. Questionnaires and interviews are particularly effective for probing attitudes, symptoms, daily activities, and behaviors. However, they are also prone to bias [32]. For instance, respondents may not understand particular questions, interpret a question differently than other respondents, or avoid extreme answers. Therefore, sometimes, many different research methods can complement each other and provide a more complete picture of the human behavior and psychology of interest (e.g., [24]). According to a recent large-scale survey, over 80% of parents of children with IDD deemed it acceptable to collect parental data using a variety of measurement tools such as DNA sampling, blood sample, video observations, medical records, ability tests, and eye tracking, among others [12]. Therefore, parents' lack of willingness should not be an obstacle for researchers to utilize various measurement tools. Different research methods also offer opportunities to study research questions that questionnaires and interviews cannot investigate. For instance, Gokcen et al. [33] administered neurocognitive and social cognition tests to parents of children with ASD, which contributed to identifying potential genetic susceptibility factors of unaffected family members, hence endophenotype marker of autism. Taken together, the field appears homogeneous when it comes to research methods. One implication is that the field may benefit from more diverse research methods, which would then afford the ability to answer more questions from different perspectives.

4.3. Differences between Journals

Our analysis indicated significant differences in the prevalence rate of parental studies and geographical diversity among the seven journals. RIDD and JADD published significantly more articles than the other five journals. As a result, they also contained more parental articles and more unique countries than the other journals. Our observation showed journals such as JIDD, JID, and IJDD labeled themselves as international journals, had editors-in-chief from institutions in non-US, albeit developed countries, and included more parental articles from non-top-five countries. Therefore, it is reasonable to hypothesize that diversifying the editorial board may help attract and retain high-quality research by researchers from diverse backgrounds [34]. Nevertheless, future research may further explore this issue.

Additionally, our analysis showed a fundamental similarity in research methods among the seven journals. They all showed higher ratios for studying both parent and child and using questionnaires and interviews. This may reflect an implicit consensus in the IDD field regarding how parental participation research should or can be conducted. Recognizing this implicit consensus may motivate the field to take a critical look at the 'old ways' of doing things, which encourages more innovative research methods that can help answer pressing research questions more creatively.

5. Limitations

Our findings are limited to the seven journals reviewed between 2010 and 2019 and may not generalize to other journals in the IDD field or during a different time period. Due to the large-scale nature of the review, it was not feasible to include all the possible IDD journals across all these years that may include parental studies. While efforts were made to include journals based on predetermined criteria, we acknowledge that reviewing other journals may add additional information pertinent to our research questions and, thus, represents an area for future research. In addition, articles were retained based on screening the abstract, keywords, and highlights of the article for eligible terms. It is possible that some articles included parental measures which were not otherwise indicated, which may have resulted in exclusion from our review. The large sample of articles reviewed is nevertheless useful in providing a glimpse into current research practices involving parents in the IDD field. Finally, we were not able to conduct analyses including both year and journal at the same time, which may seemingly have overlooked the interaction between journal and year. However, because there was one datum for each journal in each year, it was not appropriate to conduct such analyses including both factors. Nevertheless, we provided data visualization such as graphs (e.g., Figure 2) in some conditions, which may aid understanding.

6. Conclusions

Parents serve a vital role in IDD research. Our review showed a relatively high prevalence rate of engaging parents in IDD research (19.36%) within the last decade. Furthermore, geographical locations and research methods among these parental articles are somewhat diverse, but still limited. Although the findings are somewhat expected, by providing detailed, actual data, our study was able to pinpoint exactly where diversity is lacking, how much it is lacking, and its trend over the past decade. This information may guide future research to advance diversity of the field. More specifically, to increase participants and methodological diversity, the field should encourage research from under-represented countries and studies using innovative research methods to understand parents' unique perspectives and experiences. For instance, journals may host special issues focusing on lower income, developing countries. Researchers from high-income and low-income countries may seek collaborations with each other more. Regarding methodological diversity, conferences can host methodological workshops that teach innovative, cutting-edge research methods and demystify the notion that the only way to study parents is through questionnaires and interviews. Nobel Prize Laureate, Dr. Sydney Brenner once said:

"Progress in science depends on new techniques, new discoveries and new ideas, probably in that order."

Fortunately, lately there have been more studies utilizing diverse, non-traditional methods studying parents of children with IDD. We hope more future studies can follow. Diversity brings new ideas, experiences, and perspectives [35]. Greater diversity may bring better solutions to old and new research questions and help us better understand and serve people with IDD and their families.

Supplementary Materials: The following supporting information can be downloaded at: https://digitalcommons.montclair.edu/psychology-facpubs/608 (accessed on 11 August 2021), Supplemental Data S1, Supplemental Data S2.

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Appendix A

Table A1. Comparisons within each journal.

	Continents	Top Country	Measurement Focus	Measurement Tool
AJIDD	$F(5,54) = 235.06$, $p < 0.001$, $\eta^{2}_{p} = 0.956$ North America > all the other four, $ps < 0.001$	$F(4,45) = 186.99$, $p < 0.001$, $\eta^{2}_{p} = 0.943$ US > the other four, $ps < 0.001$	$F(2,27) = 19.764$, $p < 0.001$, $\eta^{2}_{p} = 0.594$ (Both, child) > parent, $ps \leq 0.001$	$F(5,54) = 118.56$, $p < 0.001$, $\eta^{2}_{p} = 0.917$; Questionnaire > interview > the other four, $ps < 0.001$
IJDD	$F(5,42) = 3.71$, $p = 0.007$, $\eta^{2}_{p} = 0.307$ Post hoc tests showed no significant difference at 0.05 level (bonferroni)	$F(4,35) = 2.57$, $p = 0.055$, $\eta^{2}_{p} = 0.227$ No differences, $ps \geq 0.10$	$F(2,21) = 2.24$, $p = 0.131$. (may be due to n = 8, ratio = 0/0 in the 2010 and 2011	$F(5,42) = 14.11$, $p < 0.001$, $\eta^{2}_{p} = 0.627$; Questionnaire > the other five, $ps \leq 0.017$
JARID	$F(5,54) = 25.21$, $p < 0.001$, $\eta^{2}_{p} = 0.70$ Europe > all the other four, $ps \leq 0.005$	$F(4,45) = 8.76$, $p < 0.001$, $\eta^{2}_{p} = 0.438$ UK > (Canada, Australia, China), $ps \leq 0.003$	$F(2,27) = 10.25$, $p = 0.001$, $\eta^{2}_{p} = 0.431$; (Both, parent) > child, $ps \leq 0.009$	$F(5,54) = 66.14$, $p < 0.001$, $\eta^{2}_{p} = 0.860$; Questionnaire > interview > the other four, $ps \leq 0.002$

Table A1. *Cont.*

	Continents	Top Country	Measurement Focus	Measurement Tool
JADD	$F(5,54) = 205.14$, $p < 0.001$, $\eta^2_p = 0.950$ North America > Europe > all the other three, $ps < 0.001$	$F(4,45) = 196.50$, $p < 0.001$, $\eta^2_p = 0.946$ US > the other four, $ps < 0.001$	$F(2,27) = 70.33$, $p < 0.001$, $\eta^2_p = 0.839$; (Both = child) > parent, $ps \leq 0.001$	$F(5,54) = 541.94$, $p < 0.001$, $\eta^2_p = 0.980$; Questionnaire > interview > the other four, $ps < 0.001$
JIDD	$F(5,54) = 8.40$, $p < 0.001$, $\eta^2_p = 0.437$ (North America, Europe, Oceania) > (Africa, South America), $ps \leq 0.012$	$F(4,45) = 7.80$, $p < 0.001$, $\eta^2_p = 0.410$ Australia > (Canada, UK, China), $ps < 0.013$	$F(2, 27) = 18.83$, $p < 0.001$, $\eta^2_p = 0.582$; both > parent > child, $ps < 0.05$	$F(5,54) = 56.44$, $p < 0.001$, $\eta^2_p = 0.839$; (Questionnaire, interview) > the other four, $ps < 0.001$
JID	$F(5,54) = 29.23$, $p < 0.001$, $\eta^2_p = 0.730$ Europe > all the other, $ps < 0.001$	$F(4,45) = 7.80$, $p > 0.001$, $\eta^2_p = 0.409$ UK > all the other four, $ps \leq 0.004$	$F(2,27) = 6.62$, $p = 0.005$, $\eta^2_p = 0.329$; parent > child, $p = 0.003$	$F(5,54) = 15.65$, $p < 0.001$, $\eta^2_p = 0.592$; (Questionnaire, interview) > the others, $ps \leq 0.054$
RIDD	$F(5,54) = 50.98$, $p < 0.001$, $\eta^2_p = 0.825$. Europe > (North America, Asia) > the other three, $ps < 0.011$	$F(4,45) = 38.61$, $p < 0.001$, $\eta^2_p = 0.774$ US > all the other four, $ps < 0.001$	$F(2,27) = 52.89$, $p < 0.001$, $\eta^2_p = 0.797$; child > both > parent, $ps \leq 0.001$	$F(5,54) = 559.61$, $p < 0.001$, $\eta^2_p = 0.981$; Questionnaire > interview > the others, $ps < 0.001$

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