

Declining high-impact clinical publication rate: A potential contributor to health disparities among persons with developmental and intellectual disabilities

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ABSTRACT

Background: Persons with intellectual and developmental disabilities (IDD) suffer from stark, well-documented health and healthcare disparities, despite data indicating that the majority see a healthcare provider at least annually. Multiple surveys have indicated that over 90% of physicians feel they have inadequate knowledge and skill in caring for those with IDD. This has been recognized as a key barrier to health equity. **Objective:** To evaluate the content of high-impact clinical literature for a potential cause of clinician knowledge deficits. **Methods:** We performed a bibliometric analysis of publications within major, high-impact general, and specialty clinical journals from 1946 to 2020 to determine the relative frequency of publications regarding IDD and publication rate. **Results:** We observed a significant decline in articles regarding IDD over the past 20 years within high-impact general medical journals, and a significant decline over the past 15 years within high-impact, specialty society-published journals of Psychiatry, Psychology, and Neurology. Furthermore, we observed that high-impact general medical journals devoted a significantly smaller proportion of publication space to articles regarding IDD than they did for conditions with similar prevalence such as HIV/AIDS, breast cancer, and drug abuse. **Conclusion:** The declining rate and low frequency of clinical publications regarding IDD within the major, respected clinical literature may be contributing to physicians' ability to source evidence-based information, thereby impacting perceptions of skill and knowledge deficits, and therefore may be contributing to healthcare disparities in this population. Well-designed clinical studies that engage persons with IDD may lead to an evidence base within the clinical literature that will improve physician confidence and care quality.

Keywords: Bibliometric analysis, developmental disabilities, health disparities, health equity, intellectual disabilities, medical education

Introduction

Persons with intellectual and developmental disabilities (IDD), who comprise 1–3% of the population, suffer from healthcare disparities so great that the American Medical Association has recommended that they be designated as a Medically

Underserved Population.^[1] Persons with IDD live 20 fewer years than the average person and more than a third of their deaths have been demonstrated as due to potentially preventable causes.^[2] They frequently suffer from missed diagnoses and consequent incorrect care.^[3] In addition, they have among the lowest provision of preventative care,^[4] and a higher prevalence of untreated chronic conditions such as obesity, dyslipidemia, diabetes, low bone density, and osteoporosis than the general population.^[5–8] This is the case despite the United States (U.S.) population surveys indicating that over 95% of persons with IDD have a primary care provider.^[9] Although numerous

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reasons for these disparities have been posited and have been the subject of two surgeon general reports,^[10,11] one key issue stands out as an important barrier to health equity: multiple surveys have shown that over 90% of healthcare practitioners feel that they do not have the proper knowledge to treat patients with IDD.^[12–14]

Clinicians usually find the knowledge to provide state-of-the-art care for their patients by consulting the peer-reviewed medical literature. For over 100 years, these medical journals have been the primary source of clinical practice knowledge, informing practitioners of cutting-edge research and state-of-the-art diagnostic and management methods.^[15] Publications in medical journals provide the evidence base for clinical practice guidelines,^[16,17] and clinicians look to high-impact medical journals (those with articles most frequently cited within a year) to learn about advances and priorities in general medicine and within their specialties.^[18]

We performed a bibliometric analysis of the high-impact general medical literature, as well as the journals of the specialty societies of family practice, internal medicine, neurology, and psychiatry to determine if potential information deficiencies in this medical literature (the source of evidence-based care practices and guidelines for most populations) may play a role in the perceived knowledge deficits of practitioners that, in turn, may contribute to the healthcare disparities suffered by persons with IDD.

Methods

Bibliometrics is the quantitative analysis of academic literature to evaluate publication trends in scientific activity over time within a field of study. It tracks citation quantity by predefined keywords.^[19] An OVID Medline search of all articles from the catalog inception of 1946 through 2020 was chosen as the database for this study because of its comprehensiveness, ease of use, and demonstrated equivalence to the PubMed database.^[20] The Ovid deduplication function was used to remove all duplicate records to assure accurate counts of each article type. The publisher and impact factor for each of the clinical journals that were studied is listed in Table 1. The general clinical journals were chosen, the New England Journal of Medicine, JAMA, and Lancet had the highest impact factor. In addition, the journals published by the respective professional societies of Internal Medicine, Family Medicine, Neurology, Psychiatry, and Psychology were also chosen for review because they are also often a source of specialty clinical guidelines. The sample size was determined using all publications in the journals listed for the given time. Sampling bias was avoided by accounting for all articles in the selected journals, and by selecting journals based on impact factors. The study was conducted in 2021.

Searched keyword terms for IDD are listed in Table 2. The term, “learning disability” was included in the Lancet searches only, as this has been a term used synonymously with “intellectual and developmental disability” in the United Kingdom, but not in

the US. Keywords for genetic syndromes comprising 0.1% of the IDD population or greater were included in the search to optimize completeness. The comparison populations of those with breast cancer, HIV/AIDS, and drug abuse were chosen because they have similar prevalence with IDD within the US population.^[21–24] The purpose of this comparison is to assess the relative availability of literature in these journals that serve as the evolving evidence base for clinical care among similarly prevalent conditions. Search terms for HIV/AIDS, breast cancer, and drug abuse are listed in Table 3.

Statistical analysis: The significance of intra-journal article topic frequencies was assessed using paired *t*-tests. Article frequencies over time were analyzed using linear regression, quadratic, and piecewise segment regression models to determine the model that best fits the data. Slopes were then determined using the model in each analysis that yielded the highest R-square values. R software was used for all statistical analyses and frequency-over-time graphing (www.r-project.org).

Table 1: Characteristics of high-impact general and specialty journals chosen for analysis

Journal	Impact factor*	Year of first publication	Publisher
New England Journal of Medicine	91.2	1812	Massachusetts Medical Society
JAMA or the Journal of the American Medical Association	56.3	1883	The American Medical Association
Lancet	79.3	1823	Elsevier (since 1991)
Annals of Internal Medicine	25.4	1927	American College of Physicians
American Family Physician	0.7	1969	American Association of Family Physicians
American Journal of Psychiatry	18.1	1844	American Psychiatric Association
American Psychologist	10.9	1946	American Psychological Association
Neurology	9.9	1951	American Academy of Neurology

Table 2: Keyword search terms for articles containing intellectual and developmental disability

Developmental disability	Prader–Willi
Developmental disabilities	Smith–Magenis syndrome
Intellectual disability	Rett syndrome
Intellectual disabilities	Tuberous sclerosis
Mental retardation	Myotonic dystrophy
Autism	Smith–Lemli–Opitz
Down syndrome	Skraban–Deardorff
Down’s syndrome	Cohen syndrome
Fragile X	Rubinstein–Taybi
22q deletion	Sotos syndrome
Williams syndrome	Mirhosseini–Holmes–Walton syndrome
Angelman syndrome	Learning Disability (Lancet only)

Results

From a total of 348,672 articles in general medical journals (NEJM, JAMA, Lancet, Annals of Internal Medicine and American Family Physician) between 1946 and 2020, 2,248 articles were identified that included a discussion of IDD. Also, 1,325 articles referencing IDD were identified among the 57,280 articles published between 1946 and 2020 from the specialty journals, Neurology, American Journal of Psychiatry, and American Psychologist.

An analysis of annual total publications discussing IDD within high-impact clinical literature yielded noteworthy patterns. Annual

article counts noting IDD within the general high-impact medical literature rose steadily from 1946 but rose precipitously from 1962 until the early 1970s. This was followed by a steep decline in the mid-late 70s and stabilization of the publication rate until the early 2000s when publication rates declined steadily for the next 20 years [Figure 1]. A similar pattern occurs in the publication rate of articles regarding IDD in the high-impact specialty literature of psychiatry, neurology, and psychology [Figure 2]. Again, there was an increase in publication rate beginning in 1962, followed by a steadier rate between 1966 and 1994. There was, however, a precipitous rise from the mid-90s until the early 2000s, and then, similar to the pattern of general medical journal publication rate, publications fell steadily from about 2006 through 2020.

Table 3: Keyword search terms for articles containing breast cancer, HIV/AIDS, and drug abuse

Condition	Search terms
Breast cancer	Breast cancer Breast neoplasm
HIV/AIDS	HIV AIDS
Drug abuse	Illicit drugs Drug abuse Opioid abuse Opioid-related disorders Drug addiction Street drugs

The percentage of articles within general medical journals referencing IDD compared to condition types with similar prevalence such as HIV/AIDS, breast cancer, and drug abuse are presented in Figure 3. Among high-impact general medical journals, a significantly smaller percentage of publication space was devoted to articles discussing IDD compared to the percentage of each journal’s articles devoted to HIV/AIDS, breast cancer, or drug abuse. In addition, the mean value of the proportion of IDD articles within all high-impact journals (0.6%) was significantly lower than the proportion of articles discussing HIV/AIDS, breast cancer, and drug abuse. Of note, publications regarding HIV/AIDS did not occur until the early 1980s and still demonstrated a far higher overall

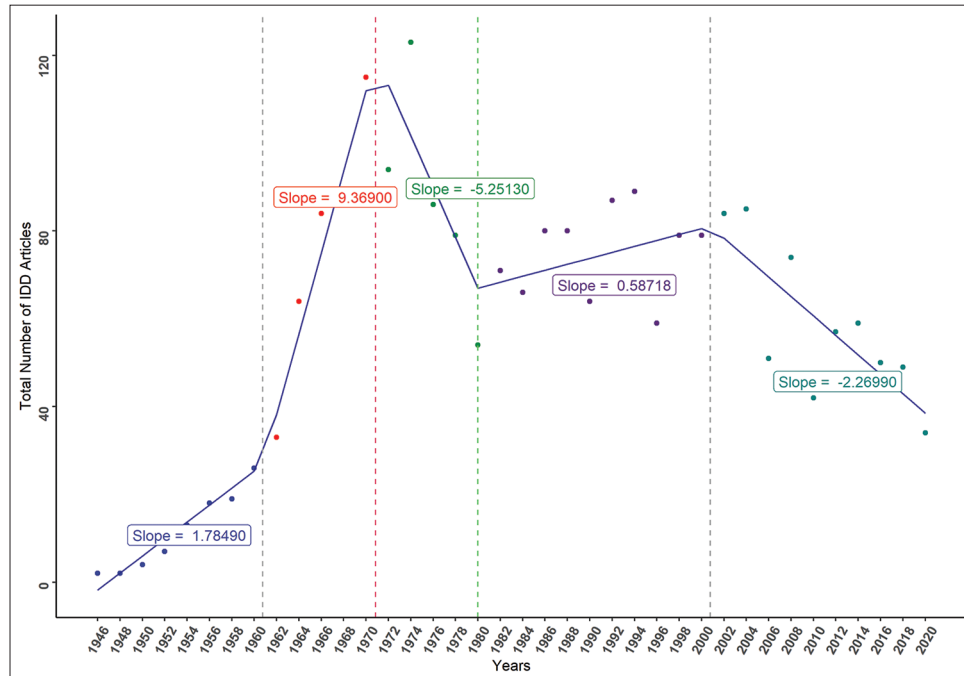


Figure 1: Publication frequency analysis by IDD article count during the period 1946–2020 in high-impact general medical journals (New England Journal of Medicine, JAMA, Annals of Internal Medicine, and American Family Physician). The annual number of publications was analyzed using multiple techniques of Linear Regression, Quadratic models, and Piecewise Segmented Regression on overall data. The Piecewise Segmented Regression model had the best fit for the data with an R-squared value of 0.885 and a residual standard error of 10.7, whereas Linear Regression and Quadratic model has R-squared values of 0.1466 and 0.6929, respectively. The IDD publication count annual time series was explained in five segments: the first segment (1946–1960) had a growth rate of 1.78 articles/year, the second segment, coincident with the 1962 establishment of the NICHD (1960–1970), had a growth rate of 9.36, the third segment (1971–1980) had a decline rate of 5.25, the fourth segment (1981–2001) had a growth rate of 0.58, and the fifth segment (2001–2020) had a decline rate of 2.26 articles/year

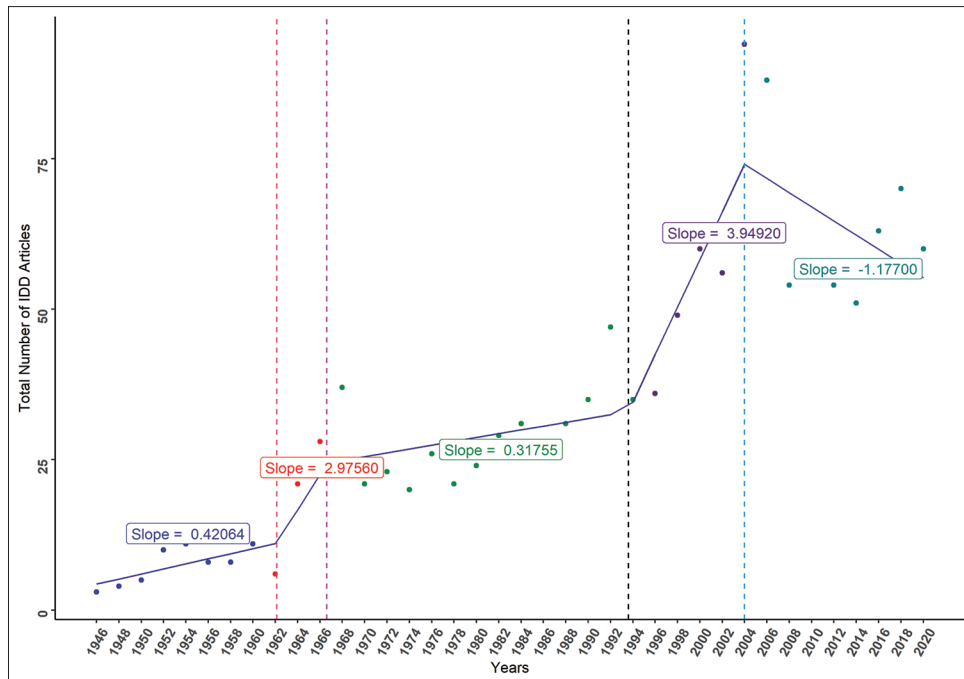


Figure 2: Publication frequency analysis by IDD article count during the period 1946–2020 in high-impact, specialty society clinical journals (Neurology, American Journal of Psychiatry, American Journal of Psychology). The annual number of publications was analyzed using multiple techniques of Linear Regression, Quadratic models, and Piecewise Segmented Regression on overall data. The best fit for the data was the Piecewise Segmented Regression model (R-squared = 0.855, residual standard error = 8.87) compared to linear regression (R-squared = 0.7902) and quadratic model (R-squared = 0.7916). The IDD publication count annual time series was explained in five segments. The first (1946–1960) had a growth rate of 0.42 articles/year. The second (1961–1967) segment, coincident with the 1962 establishment of the NICHHD, had a growth rate of 2.97. The third segment (1967–1994) and the fourth segment (1995–2004) had growth rates of 0.31 and 3.94 articles/year, respectively. The fifth segment (2005–2020) declined by 1.17 articles/year

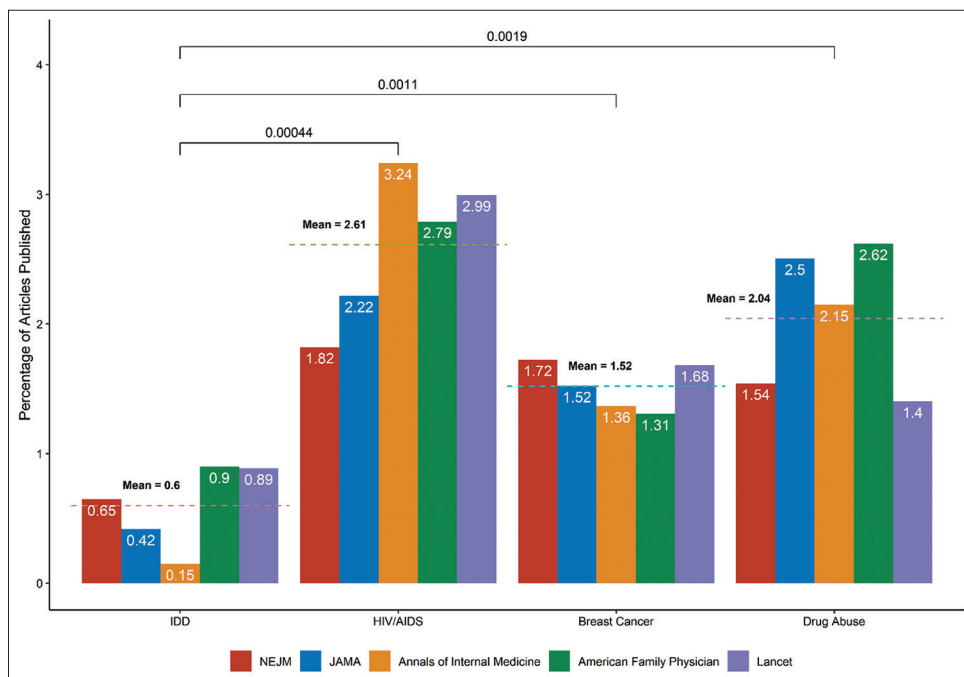


Figure 3: Percentage of articles regarding IDD within high-impact medical journals compared to percentages of those regarding HIV/AIDS, breast cancer, and drug abuse between 1946 and 2020. Comparative analysis of 92,232 articles shows that the mean value of the proportion of publications discussing IDD (mean = 0.6%) is significantly lower than the other three conditions including HIV/AIDS (2.61%), breast cancer (mean = 1.52%), and drug abuse (mean = 2.04%) with *P* values of 0.00044, 0.0011, and 0.0019, respectively. Within each journal the proportion of IDD articles in the New England Journal of Medicine, JAMA, Annals of Internal Medicine, American Family Physician, and Lancet (0.65%, 0.42%, 0.15%, 0.9%, and 0.89%, respectively) was lower compared to each of the other three conditions

prevalence compared to those discussing IDD. In addition, each of these general medical journals published significantly fewer articles regarding IDD than they did for each of the other three conditions [Figure 4].

Discussion

This analysis indicates that high-impact medical journals have published far fewer articles about intellectual and developmental disabilities than they have for other major conditions affecting similar or smaller proportions of the population, and the number of articles published in these journals has declined significantly, particularly over the past 15 years. This may be contributing to physicians' lack of confidence, evident in multiple surveys and across multiple specialties such as family medicine, internal medicine and psychiatry, specifically regarding whether physicians have adequate knowledge of proper diagnosis and treatment of issues affecting the IDD community.^[12-14]

We have observed that over the past 74 years, there have been up to 500% more publications regarding HIV/AIDS, a condition not recognized until the 1980s and affecting approximately 10 times fewer persons in the US^[21,22] than articles concerning IDD. The data show that the Annals of Internal Medicine, the high-impact journal of the American College of Physicians that is relied upon by all medical specialties, has published 20 times more HIV/AIDS than IDD articles. The publication rate regarding conditions such

as drug abuse, affecting 7.5 million people in the US^[23] and breast cancer, affecting approximately 4 million,^[24] was also far higher than that of IDD.

Publication rates of IDD articles in the major medical journals increased significantly from 1946 to the early 1970s, possibly due to increased scientific activity after the establishment of the US National Institute of Child Health and Development (NICHD) in 1962, and the Eunice Kennedy Shriver Intellectual and Developmental Disabilities Research Centers (EKS-IDDRCs) in 1963. However, from the mid-1960s to the early 2000s, there was a significant decline in publication rates in these journals and a much steeper decline over the past 15 years. It is noteworthy that this publication rate decline has occurred despite major US initiatives to improve the health of persons with IDD such as the passing of the Developmental Disabilities Assistance and Bill of Rights Act of 2000, which funded 67 University Centers for Excellence in Developmental Disabilities Education, Research and Service (UCEDDs) across the US,^[25] and a landmark Surgeon General Report in 2002 that outlined both health disparities in persons with IDD and set goals for improving health quality that included a strong research agenda to improve IDD healthcare and create care standards.^[10] Therefore, although one robust US government initiative, the development of NICHD, showed proof of advancing an evidence base for IDD, subsequent initiatives have been largely unsuccessful in supporting a research base for decreasing health and healthcare disparities among those with IDD.

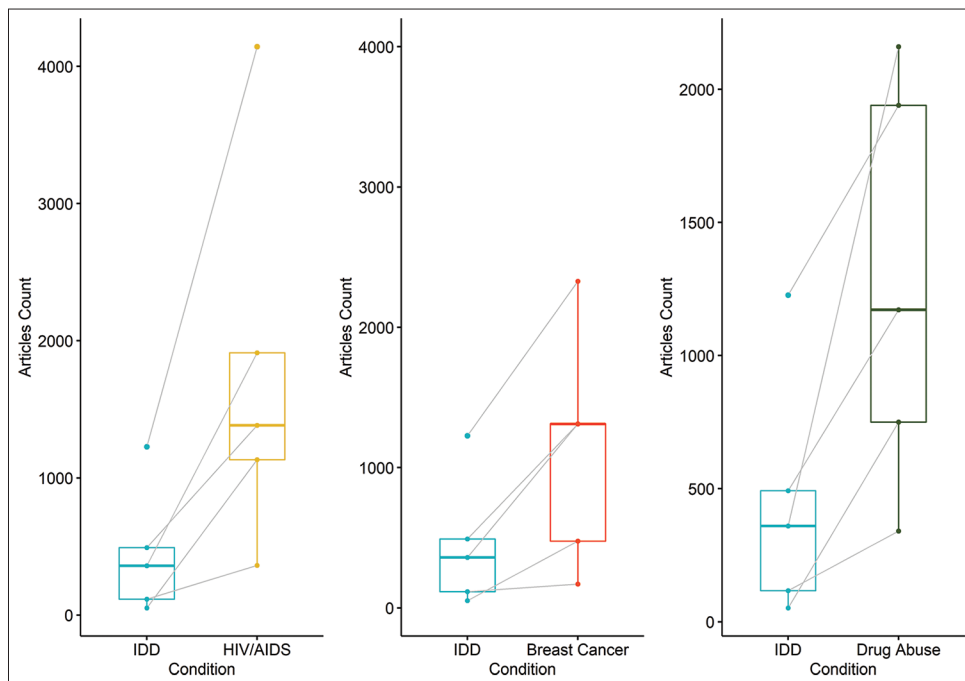


Figure 4: Comparative analysis of the publication count of articles discussing IDD to those regarding HIV/AIDS, breast cancer, and drug abuse within general medical journals from 1946–2020. Paired *t*-test was performed to compare publication counts of articles regarding IDD to those regarding conditions with similar prevalence (HIV/AIDS, breast cancer, and drug abuse) within general medical journals (New England Journal of Medicine, JAMA, Annals of Internal Medicine, and American Family Physician). Results demonstrate that each journal published significantly fewer articles discussing IDD compared to those regarding HIV/AIDS, breast cancer, and drug abuse with *P* values of 0.04, 0.025, and 0.034, respectively

The number of IDD articles increased in the 1990s in high-impact specialty journals. This may be coincident with the development of the Diagnostic Manual for ID, DM-ID,^[26] a standardized textbook for diagnosing psychiatric illness in persons with IDD, as well as the increased off-label use of atypical antipsychotic agents in persons with IDD. Over this time, there was also the discovery of new genetic and molecular markers for neurodevelopmental disorders, as well as advances in the management of seizure disorders common in persons with IDD. However, the increased publication rate was short-lived and was followed by a continuous decline over the last 15 years.

The cause of the relative paucity and most importantly, the recent decline in IDD publications in the major medical journals is unclear. Most clinical information regarding IDD is observational and comes from small convenience samples.^[27] High-impact clinical journals are far more likely to publish larger studies with evidence-based interventions tested by randomized-controlled or other methodologically sound approaches.^[28] Large population studies of persons with IDD are rare but are becoming more common. There have been recent advances in the mining of large datasets to improve the health surveillance of those with IDD; however, these approaches have been hampered by the lack of a standard method of identifying all persons with IDD in each dataset.^[29] Further, although the analysis of datasets, such as Medicare, Medicaid, or medical record information has been helpful, for example, in demonstrating that the IDD population has among the highest mortality risk from SARS-CoV-2 infection,^[30] this observational approach is not designed to increase the evidence base for effective diagnosis and intervention.

Impact

Despite the reasons, the lack of well-researched, trusted information within high-impact general medical journals is an important sign that there is a weaker evidence base for the care of persons with IDD than there is for other conditions causing high morbidity and mortality^[31] and is likely a primary reason why clinicians feel that they do not have the information and skill necessary to provide an equitable level of evidence-based care for this population. Although Canadian family physicians have released guidelines for the primary care of persons with IDD,^[32] most recommendations are consensus rather than evidence-based and do not address diagnosis or evidence-based management of the acute and chronic problems that frequently cause increased morbidity and mortality in the IDD population.

The impact of this “evidence void” is profound. Although efforts are currently underway to create medical school curricula for the care of persons with IDD, the absence of a high-quality, technical evidence base is a clear impediment to creating an effective clinical curriculum or any training module for active clinicians because the source of evidence-based guidelines and training for clinical care comes from work published in high-impact general and specialty literature. Therefore, it is highly unlikely that, given the present state of the high-impact

clinical literature, students would have the knowledge base necessary to make effective, evidence-based care decisions after taking such a course. This lack of trusted literature not only creates an information void for practicing clinicians but also without a trusted, evidence-based standard of care available to all clinicians, the IDD population can be vulnerable to exploitation by those who purport to be experts based on their self-reported clinical experience, or to suffer the consequences of commercially-driven care recommendations. For example, industry-driven recommendations for off-label use of atypical antipsychotic agents in the 1990s to manage “challenging behaviors” in persons with IDD,^[33] a practice associated with life-altering adverse health effects,^[34] have had a lasting impact on prescribing patterns in the IDD population despite evidence that these medications may not be more effective than placebo.^[35,36]

Research published in high-impact clinical journals will likely improve confidence in caring for persons with IDD, thereby improving access and quality of care. Although there have been efforts to include persons with disabilities such as IDD in clinical trials likely to be published in high-impact journals, there are very few large studies organized to evaluate and treat health issues that cause frequent and unnecessary morbidity and mortality in the IDD community. However, one recent NIH effort, the INCLUDE (INvestigation of Co-occurring Conditions across the Lifespan to Understand Down syndromE) Project was launched in June 2018. This project is a trans-NIH research initiative on “critical health and quality-of-life needs for individuals with Down syndrome” and its goals include assembling a large population of Down Syndrome (DS) study volunteers and will include volunteers with DS in clinical research trials.^[37] Projects such as these, as well as those designed to enhance the participation of persons with IDD in health research,^[38] have the potential to yield information worthy of publication in the highest impact journals and therefore may improve the quality of healthcare of those with IDD. Other recent initiatives, such as a toolkit for researchers to respectfully engage persons with IDD in clinical research studies,^[39] may also be useful for effective recruitment to study novel diagnostics and treatments.

Limitations and Strengths

Bibliometric analyses do not examine the full content of each article counted. Therefore, we do not have information regarding the proportion of IDD articles devoted specifically to diagnostics or treatments compared to the other conditions affecting similar proportions of the population. However, the low frequency of publications within high-impact clinical journals and the decline in publications that in any way reference IDD within the past two decades, is clear evidence that, despite persistent health disparities, clinicians are not receiving a robust quantity of cutting-edge information about the diagnosis and management of persons with IDD from trusted sources as they would for other clinical populations.

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Conflicts of interest

There are no conflicts of interest.

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