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An overview of developments in research on persons with intellectual disabilities

Johnny L. Matson *, Jessica A. Boisjoli

Department of Psychology, Louisiana State University, Baton Rouge, LA 70803, United States

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ABSTRACT

Intellectual disabilities (ID) are one of the largest, most complex, and frequently studied of the mental health and medical specialty areas. Thousands of papers have been published dating back to the early work on IQ testing more than a century ago. Many reviews have been published on specific topics with the field of ID, but to date no papers have appeared providing an overview of trends in this vast literature. In this paper we looked at studies published in referred journals from 1979 to 2008. Fifty-six thousand, three hundred and twenty studies were identified using the terms mental retardation and ID. The number of papers published per year ranged from 1038 to 2075 with the fewest papers published in 1980 and the greatest number of studies appearing in 2005. Genetics was by far the most frequently studied topic. The implication of these and related trends in the literature are discussed.

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The field of intellectual disabilities (ID) has been one of robust and varied research for some time. A variety of topics ranging from the evaluation of genetic phenotypes (Chiurazzi, Schwartz, Gecz, & Neri, 2008), aggression (Matson & Nebel-Schwalm, 2007; Valdovinos, 2007) self-injurious behavior (Hill, Powlitch, & Furniss, 2008; Matson & Minshawi, 2007), social skills (Agaliotis & Kalyva, 2008; Chung et al., 2007; Lancioni et al., 2008), adaptive behavior (Krakovsky, Huth, Lin, & Levin, 2007) and perceptions of college students (Ahlborn, Panek, & Jungers, 2008) have been studied. This massive and rapidly growing literature has led to a splintering in the field which has become more and more specialized with subspecialties such as dual diagnosis emerging. Given the nature of these

* Corresponding author at: Department of Psychology, Louisiana State University, 236 Audubon Hall, Baton Rouge, LA 70803, United States. Tel.: +1 225 578 4104; fax: +1 225 578 4125.
E-mail address: johnmatson@aol.com (J.L. Matson).

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developments, topical overviews seem to be a prudent course to help organize this large information base, and have occurred to some degree.

The range of topics covered has been considerable as would be expected. Review papers have been published which described current status with respect to specific aspects of treatment such as drug interventions for challenging behaviors (Matson & Dempsey, 2008; Valdovinos, 2007), self-injury interventions using applied behavior analysis (Matson & LoVullo, 2008), or epilepsy in ID (Grasso et al., 2008), assessment reviews such as those on challenging behaviors (Matson & Minshawi, 2007), as well as publications on etiology, genetics, and legal rights. Despite these developments however, no general overview of research trends in the field of ID has emerged to date. Such a paper would appear to be of value since a broad overview of the field has not occurred, and because the research on the topic is so massive. The purpose of the present manuscript then was to present a general overview, discussing publication trends. Data on rates of articles from 1979 to 2007 are presented, along with data on the most frequently studied topics and the journals where these papers have been published.

1. Method

For the purposes of the present study, the terms mental retardation (MR) and ID were entered into the search engine Scopus. This search vehicle has data on 15,000 peer-reviewed journals from over 4000 international publishers. Topics covered in the 33 million available records include technical, medical, scientific, and social science topics. From the 1979 to 2007 period plus the first quarter of 2008, 56,320 articles were identified. This information served as the foundation for our analysis. To determine the most current topics in the literature, the most recent 500 publications for each of these two topics (MR and ID) were assessed for content. Also, the number of articles by journal and number of articles by year were evaluated.

2. Results and discussion

One of the first items we looked at was the primary journals which included ID research as defined by the number of articles published on the topic. Using a cutoff of 500 articles published on the topic, or more, for a given journal as the criterion, we identified 9 journals. The publications with 500 or more articles on MR and ID included the *American Journal of Medical Genetics*, *Mental Retardation* (*MR*), the *American Journal on Mental Deficiency* (*AJMD*) (*MR* and *AJMD* have been renamed to put their titles more in line with current terminology), *Research in Developmental Disabilities*, the *Journal of Medical Genetics*, *Clinical Genetics*, *Nursing Times*, *Journal of Intellectual Disability Research*, and *Human Genetics*. Four of these journals were specialty journals in developmental disabilities and the remaining 5 journals primarily had medical content. Of the 5, 4 were journals dedicated to the study of genetics.

Regarding publication rates over time, they have been very consistent. For the 28-year span represented in our graph (see Fig. 1), the most striking issue is the consistent, high number of articles that have been published on the topic. While 1996 saw a further escalation in the number of published papers, which has not abated, even prior to this time the number of studies published was impressive. These data would suggest that ID/MR will likely continue to be an area of considerable research interest for some time to come, based on these past trends.

Table 1 covers topics in the ID literature, which are quite varied. In order of magnitude, genetics was the most frequently studied ($N = 227$), followed by nosology ($N = 106$), generic treatments ($N = 105$), reviews ($N = 97$), perception and cognition ($N = 84$), psychopathology ($N = 59$), diagnosis ($N = 46$), developmental course ($N = 35$), prevalence and incidence ($N = 34$), etiology ($N = 33$), scale development ($N = 31$), challenging behavior ($N = 24$), epilepsy ($N = 21$), and communication ($N = 19$). Next, there was a three way tie with social skills, physiology, and pharmacology ($N = 17$), followed by neuropsychology ($N = 13$). Table 1 lists sample issues for each topic just described. As illustrated in Table 1, genetics had more than twice as many publications as any other topic. The primary focus of research was on further illuminating the causes of specific forms of the disorder and identifying new types of genetic forms of ID. Nosology, the second most occurring reported topic in the literature we sampled, covered a wide range of dimensions of ID including dementia, obesity, and co-occurring autism. The other primary topics covered, as the reader will note, include a range of topics and issues.

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