During the past year the Critical Issues Committee of the Developmental Disabilities Division has been working with a group to structure a position paper focused upon the place of Autism Spectrum Disorders within the field of Developmental Disabilities. The following position statement reflects the work of several division members and seeks to clarify the fit of Autism Spectrum Disorders within the Division on Developmental Disabilities. I would like to thank those who worked on this position statement, as well as all those persons who provided input over the past year. If you have questions or would like to comment on the position statement, please address yourself to stodden@hawaii.edu - thanks, Robert A. Stodden, Chairperson, Critical Issues Committee, Division on Development Disabilities, CEC.

CEC-DDD and Autism Spectrum Disorders
A Position Paper of CEC-DDD
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In 2002, the membership of the Council for Exceptional Children’s (CEC) Division on Mental Retardation and Developmental Disabilities (MR/DD), following an extensive consultation process, made a progressive step by voting to change the division’s name to the Division on Developmental Disabilities (DDD). This move reflected the need to recognize and address the plurality that exists among the diverse group of learners served by the division. Concurrent with this action, DDD leadership examined both research and practice to ensure the needs of the entire range of children, youth, and adults identified as having a developmental disability, as well as those of their stakeholders (e.g., family, advocates, teachers and other professionals), were being addressed. This meticulous scrutiny revealed an emerging group of individuals with special needs who had not previously been formally recognized by this or any other division of CEC -- autism spectrum disorders (ASD). After consideration, it was decided by the membership to officially include autism spectrum disorders within DDD. Given the diversity of the individuals with developmental disabilities, this inclusion of persons with ASD was a natural extension of the research and practice examination and the resulting adoption of a new name for the division.

In the history of CEC and ASD and, more particularly, the area of autism, has been an alignment of this population within several different divisions without finding a permanent home. At one point, these individuals were recognized, albeit informally, by The Council for Children with Behavior Disorders (CCBD); at another point they were considered “Other Health Impaired” (OHI), all without officially being adopted by any one group. In the past several years, DDD, while still named MR/DD, served as the ‘clearinghouse’ for matters addressing this population. DDD has, in recent years, recognized individuals with ASD as evidenced by presentations at local, regional, and international conferences, articles in the division’s journal, Education & Training in Developmental Disabilities, and in discussions at board meetings. While such informal inclusion of ASD was a positive movement forward for CEC, it still did not completely meet the needs of serving this group of individuals as members of the organization. The number of sessions traditionally offered at CEC has not met the burgeoning interest of individuals working with this population in the field. In part this reflected the view of ASD as a ‘low-incidence’ disability; however, recent studies have indicated otherwise. Indeed, earlier estimates of autism as 6.5 in 10,000 (Gillberg, 1995) have been amended to as high as 60 per 10,000 (Kadesjo, Gillberg, & Hagberg, 1999). When one includes children, youth, and adults with ASD, the prevalence ranges from those reported in a recent article in the Journal of the American Medical Association as 3.4 per 1000 in 1996 (Yeargin-
Allsop, Rice, Karapurkar, Doemberg, Boyle, & Murphy, 2003) to potentially surpassing 121 per 10,000 (Kadesjo, Gillberg, & Hagberg, 1999). With these increasing prevalence rates and interest in the population, came the need for official recognition within CEC. DDD, in changing the division name and adding the subtitle: Focusing on individuals with cognitive disabilities/mental retardation, autism, and related disabilities, broadened the division focus and filled this void.

The Division on Developmental Disabilities is in a unique position to meet the needs of individuals diagnosed with ASD. The members of the division understand and work with the array of needs of individuals with developmental disabilities. No other division addresses such a broad spectrum of individuals with unique characteristics in the social, adaptive, cognitive, and behavioral realms. Developmental disabilities is a broad and enigmatic term encompassing a range of special needs, including those evidenced in ASD. There are many individuals with developmental disabilities who may demonstrate one or more of the following: (a) difficulty in relating to other people and situations; (b) speech, language and communicative impairments; and (c) stereotypic, repetitive and self-stimulatory responses, all of which are also defining characteristics of ASD. At the same time, however, while demonstrating patterns of normal growth and development, individuals with ASD frequently evidence obsessive insistence on environmental sameness, aberrant responses to sensory stimuli, and isolated unique abilities and other developed splinter skills (American Psychiatric Association, 2000). The fact that individuals with ASD have a wide range of abilities and disabilities, some having near-or above-average cognitive and expressive language abilities, further contributes to the uniqueness of ASD (American Psychiatric Association, 2000; Dunn, Myles, & Orr, 2002; National Research Council, 2001; Simpson & Myles, 1998; Weatherby & Prizant, 2000). The fact that DDD has a history of a multidisciplinary approach focus in terms of the population historically served in the division significantly impacts on the potential success in meeting the complexity of needs of individuals diagnosed with ASD.

To date, professionals involved in serving the needs of individuals with ASD have suffered from a lack of organizational leadership and support within CEC. While ASD has had leadership in terms of other organizations such as the Autism Society of America and there are journals such as the Focus on Autism and Other Developmental Disabilities, CEC has treated this population as a separate entity, rather than as a part of the developmental disabilities field. Without the support and leadership of an internationally recognized, educationally-based organization, problems ensue with regard to recognition of practices that may not best serve the needs of the population. Included in this may be difficulties related to methodology and programming, support and related services, placement decisions, length of services, research-to-practice translation, and advocacy. Perhaps the most salient issues are those related to intervention and treatment. Some intervention programs seem to have little sound theoretical or empirical foundations and many purported interventions for ASD have not been thoroughly evaluated (Freeman, 1997; National Research Council, 2001).

Inclusion in DDD will, it is hoped, change the concerns noted above by giving ASD a voice within the wider CEC community and thus opening up potential opportunities for research and dissemination of findings to a broader audience via DDD communications. By having the organizational leadership and support of a CEC division, an initial and integral first step is being taken in terms of identification and implementation of long-term and scientifically valid solutions to problems that potentially stem from the lack of a centralized information source with a recognized history in the field of special education. We strongly believe that the Division
on Developmental Disabilities of the Council for Exceptional Children will be the most effective voice for individuals with ASD and the stakeholders involved in working with them. Due to its established history, DDD is uniquely qualified to provide leadership and support to professionals seeking to improve their skills and knowledge related to individuals with ASD as well as to researchers and members of the advocacy community.

References


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