Online Resources, Support, and E-Health for Families of Children with Disabilities:
A Review of Empirical Evidence Regarding Attitudes, Use, and Efficacy

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INTRODUCTION

In the last 10 years, web-based support and information for parents of children with disabilities has grown exponentially (Jones et al., 2013; Pagliari et al., 2005). Researchers, practitioners, and educators who serve these children and their families have increasingly turned to technology to find innovative ways to increase parent engagement, expand the reach of empirically-based interventions, and collect data on usability, acceptability, and efficacy. Although access to the internet, web-based applications, social media, mobile devices, real-time video calls, and other technology have great potential to increase support and access for families, important questions remain about their actual impact.

The quintessential questions around the use of internet-based tools involve four key issues. First, there is the question of the *digital divide* (Graham, Hale, & Stephens, 2012). While access to the internet has increased across socioeconomic boundaries (U.S. Census Bureau, 2010), there are still reservations regarding whether or not those that could most benefit from internet-based services (such as those living in remote or underserved areas) actually have the requisite access to a reliable network and associated technical support, hardware, and software to utilize the tools. Second, even if families can consistently access a network, there are issues related to the *acceptability divide* or the degree to which parents find these services helpful, credible, or engaging compared to other modalities. Third, ethical considerations based on maintaining privacy and confidentiality, ensuring parents are informed consumers, and verifying the quality of online information and resources continue to plague the emergence and widespread adoption of remote delivery models for professionals and researchers alike (Self-Brown & Whitaker, 2008). Finally, rigorous study of the actual impact of online information, support, and interventions is still in its infancy and thus, many questions remain regarding when, how, and for whom these tools are most beneficial.

Although a critical review of all four of these areas is beyond the scope of this chapter, the present review seeks to specifically address how the current literature base elucidates feasibility, acceptability, and empirical support for impact of internet technology for parents of children with developmental,

learning, and social-emotional disabilities. Specifically, this chapter examines the current literature on internet-based support, online learning, and information-seeking for parents, and family-centered interventions for families of children with developmental and related disabilities.

BACKGROUND

The term "disability" can encompass a number of conditions including cognitive, physical, psychological, acquired or congenital conditions. The Individuals with Disabilities Education Improvement Act (IDEA, 2004) recognizes 13 distinct disability categories for eligibility for special education services. For the purposes of this chapter we focus on those disabilities that include significant behavioral, psychological, and cognitive impact, specifically, neurodevelopmental disorders. Although focusing on a specific diagnostic category (e.g., traumatic brain injury [TBI] or intellectual disability) may make for clearer diagnosis-to-treatment conclusions, many of the disorders for which parents seek assistance include overlapping symptom profiles and comorbid diagnoses. Neurodevelopmental disorders (ND) characterize a number of developmental disabilities including Intellectual Disabilities (ID), communication disorders, Autism Spectrum Disorders (ASD), attention deficit hyperactivity disorder (ADHD), neurodevelopmental motor disorders, and Specific Learning Disorders (SLD) (American Psychiatric Association [APA], 2013a). Symptoms range widely, but generally involve one or more impairments related to personal, social, academic, or occupational functioning that generally manifest before a child enters grade school (American Psychiatric Association [APA], 2013a). Although not categorized as such in the Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM-5; APA, 2013b), Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure, otherwise known as Fetal Alcohol Spectrum Disorder (FASD), is considered an extension of ND given the neurological basis and the similarities in functional impairments (Di Pietro, Whiteley, Mizgalewicz, & Illes, 2013).

Millions of children nationwide are diagnosed with ND, FASD, and TBI. It is estimated that 5% of children by first grade have a speech or language impairment (National Institute on Deafness and Other Communication Disorders, 2014); ASD and ID effect about 1% of children; SLD estimates range between 5-15% of all children; and ADHD affects around 5% of children (APA, 2013a). Despite improved diagnostic and treatment options, schools and professionals struggle to provide adequate services due to lack of funding, resources, and trained professionals to deliver evidence-based interventions consistently and with fidelity. Without professional services or guidance, parents and caregivers must search for, and determine the credibility of, information on their own. Advances in technology can connect parents to professionals and other caregivers for information, support, and treatment, but the research in this area is relatively young. Identification of factors associated with reliable and valid sources of online information and the utility and efficacy of remote service delivery is needed.

PRESENT REVIEW METHODOLOGY

The present review includes a comprehensive and systematic review of the literature related to how internet technology (including information seeking, support, e-Learning, and *e-Health*) may assist families of children with neurodevelopmental, learning, or behavioral/ mental health disorders. The study was guided by two primary aims. First, the study aimed to understand the breadth of research available on information and services for parents available online. Specifically, only one diagnostic category was not

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