Assisting Parents in the Struggle to Access Science-Based Information and Treatments for their Children with ASD

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Families of children who receive a diagnosis of an autism spectrum disorder (ASD) are faced with profound challenges, and many feel a tremendous burden (Mulligan, Steel, Macculloch & Nicholas, 2010). The time of diagnosis may represent a pivotal point for both the child and the individuals closely connected to the identified child, and may have been preceded by months or even years of unanswered questions, long-standing concerns, and previous observations, including comparisons with siblings or other peers.

Once a child has been diagnosed, parents enter a phase which includes information seeking and the desire to access services, possibly accompanied by questions regarding the validity of the diagnosis and questions related to the uncertainty associated with the course of this developmental disability.

Given that the primary and secondary characteristics of autism present themselves in a pervasive manner across all aspects of a child's life, such as adaptive skills as well as access play, social and educational domains, this new diagnosis may present significant emotional challenges for the family (Mulligan, Steel, Macculloch & Nicholas, 2010). It is, therefore, unfortunate that families frequently report dissatisfaction with the quality of information they receive following a diagnosis of autism (Howlin & Moore, 1997). Parents also report that having to locate information on their own leads to increased feelings of worry and hopelessness, due in large part to the lack of credibility and negative tone of the information they find (Osborne, 2008). It is not surprising, then, that parents frequently are using other parents of children with ASDs as a means of both information and support (Mackintosh, Myers, & Goine-Koebel, 2006). In addition to accessing other parents, mother and fathers are more often turning to books and websites for facts than to physicians and other professionals. Since physicians and other professionals generally have the greatest access to science-based resources, it is concerning that parents do not seem to be utilizing these individuals more.

The amount of trust parents place in different sources of information is another area of concern. A recent study of a large national sample of parents of children with ASD (n = 1,525) examined the amount of credibility parents placed in different sources regarding the topic of vaccine safety (Freed, Clark, Butchart, Singer, & Davis, 2011). Although parents trusted the information from their doctor most often (76%), parents placed “some trust” in the information provided by relatives (24%) and by parents who believe their child was harmed by vaccines (65%). Since parents are gaining access to information from multiple sources and putting their trust, at times, in individuals based on their visibility in the media and/or their emotional appeals, it is even more important for the scientific community to assist parents in accessing accurate information.

As many families experience the two-fold challenge of: 1) the profound personal and family life changes associated with an autism diagnosis, and 2) the existence of a large array of low quality information and many non-credible and non-validated treatment methods and strategies for which there is little in the way of scientific support and efficacy (Simpson & Myles, 1998), there are several factors which provoke an even larger dilemma for some families. Certain child and parent characteristics, as well as resource-related characteristics, pose additional barriers to accessing high quality autism-related information, including science-based treatments which have met rigorous peer review and have shown positive results over an extended period of time (Simpson, La Cava, & Gruner, 2004). These child-parent characteristics and resource-related factors determine access to quality information and care are multi-fold. Children of minority race and ethnicity are less likely to receive services, and if they do receive services, it is at a lower level.

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later age. Also, children of minority race and ethnicity receive a different mix of services compared to Caucasian children. Lower parental income decreases the likelihood of accessing a developmental pediatrician or speech-language therapy (Levy et al., 2005; Mandell, Levens, Levy, & Pinto-Martin, 2002). Moreover, lower income families tend to use fewer information sources and are less likely to attend autism group meetings (Mackintosh et al., 2006). Factors posing a challenge to accessing services include: a child not being covered by public or private insurance; older children (Green et al., 2015; Kraus et al., 2003); and families living in rural areas (Thomas, Ellis, Melchior, Daniels & Morsesey, 2007). In addition, increased levels of parental stress (Tobin & Geller, 2002) not subscribing to a major treatment approach, and lower levels of parental education make access to quality services less likely (TEACCH: Mur- cies, Gurkle, & Woltry, 2001).

So how can the research community and autism experts assist parents in overcoming challenges in obtaining accurate information about autism and in accessing evidence-based treatments? The logical place to begin is following diagnosis. Providing parents with assistance in sitting through the information they are accessing and also in forming support networks with other parents can be extremely valuable, as are developing programs to bridge the gap between the doctor’s office and the autism community. The University at Albany’s Center for Autism and Related Disabilities (CARD) has recently received a grant through the Office of People with Developmental Disabilities to implement a parent education program to meet this need. The program is offered at no cost to families of young children recently diagnosed with ASD in the Capital Region. The goal of the program is to offer accurate evidence-based information to parents in a timely manner (within 6 months to one year following diagnosis) on a variety of important topics such as how to choose treatment, medical developmental issues, accessing resources and living with ASD. The program is delivered in a group format and sessions are led by both a clinical psychologist from CARD and a nurse clinician from CapitalCare Developmental-Behavioral Pediatrics. Program format was selected to assist parents in deciphering information they are accessing from various sources (i.e., pediatrician, autism community, internet, etc.). Preliminary data on parents who have completed this program are positive; parents appear to be gaining knowledge about ASD and at the same time raising their stress levels and improving their family’s quality of life.

Assembling parents with obtaining accurate information following diagnosis is only one part of the battle. Autism professionals and researchers need to work with parents to overcome common barriers to accessing science-based treatment, particularly in families with lower socioeconomic status and families of minority race and ethnicity. Providers of evidence-based treatments need to reach out to these families by offering programs at no- and low-cost, and by providing stipends for access to transportation and/or childcare. In addition, use of distance learning and telemedicine has promise as a solution to reach families that may not otherwise be able to access services. More and more families are using the internet as a quick and readily available means to find information and complete activities in their busy lives. A recent study suggests that the majority of all households own a personal computer (68.9%). In addition, it is encouraging that internet access is available in the homes of most families (81.4%), including 60% of families with an annual household income of $10,000-$25,000, and 71% of families with only a high school diploma (Carroll, Rivara, Ebel, Zimmerman & Christakis, 2005). Although the rapid increase in accessibility and use of technology can make it more difficult for parents to sort through information, it also opens the door for the scientific community to bring cutting-edge science-based treatments that were previously available mostly to families in city centers or university towns, to a more diverse group of children with autism spectrum disorders.

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