

Contents lists available at SciVerse ScienceDirect

Research in Autism Spectrum Disorders

Journal homepage: http://ees.elsevier.com/RASD/default.asp



Parental perspectives on the importance and likelihood of adult outcomes for children with Autism Spectrum Disorders, Intellectual Disabilities or Multiple Disabilities

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ARTICLE INFO

Article history:
Received 2 July 2012
Received in revised form 23 October 2012
Accepted 24 October 2012

Keywords:
Autism Spectrum Disorders
Intellectual Disability
Multiple Disability
Parental expectations
Importance
Likelihood
Adult outcomes

ABSTRACT

Aims: This study examined parental perspectives on the importance and likelihood of future adult outcomes for children with Autism Spectrum Disorders (ASD), Intellectual Disabilities (ID), or Multiple Disabilities (MD) and some of the factors that may affect parental aspirations.

Methods: Parents of 105 children with ASD, ID, or MD were presented with 21 possible future outcomes and were asked to indicate how important and how likely they considered these outcomes for their children with disabilities when they become adults. Results: Parents rated the overall likelihood of their child attaining various future outcomes significantly lower than the importance they placed on these same outcomes. They mostly valued future outcomes relating to their children's personal satisfaction, safety and security over and above those relating to social participation. Parental ratings of the importance or likelihood of outcomes did not differ across the diagnostic groups. Ratings of importance were independent of the child's age, gender, diagnosis, or severity of functioning, but likelihood ratings were significantly predicted by the children's symptom severity.

Conclusions: The implications of this study's findings for service development, intervention and transitioning planning, and treatment outcome research are discussed in relation to existing literature and the study's strengths and limitations.

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1. Introduction

Autism Spectrum Disorders (ASD), Intellectual Disability (ID), and Multiple Disabilities (MD), are all complex developmental conditions that affect the lives of individuals with these conditions and those around them across the lifespan. As larger numbers of children with these conditions are being identified through increasingly more informed diagnostic procedures (i.e., Ho, 2007; Matson & Kozlowski, 2011), educational, health and social care initiatives in research and practice have emphasized the importance of monitoring and supporting the development, functioning and well being of children and youth with developmental disabilities as they grow older (i.e., World Health Organization, 2011).

In earlier years, outcomes were traditionally measured in terms of individuals' gains in adaptive behaviour skills, increases in scores on cognitive or language tests or reductions in symptom severity or challenging behaviours. However, in

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recent decades, a number of changes have resulted in the assessment and conceptualization of a broader range of 'outcomes' encompassing individual, family and community functioning, quality of life and general well being (see also Schalock et al., 2002). These changes include the deinstitutionalization movement, the development of community-based health and social care partnership services (i.e., Miller, Whoriskey, & Cook, 2008), the rise of service users' empowerment emphasizing family-and person-centred planning (i.e., Kim & Turnbull, 2004), and the increased focus on the importance of developing and working towards collaborative and mutually agreed goals between the individual, their family and services in the transition to adulthood (i.e., Young et al., 2011).

1.1. Parental hopes, values and expectations of outcomes in adulthood

One common finding in the existing adult outcome research literature of individuals with developmental disabilities is that many such individuals continue to live with their families and that many family members (particularly parents) continue to play an important role in their adult children's lives considerably beyond the length of time that is typically observed among the general population (e.g., Krauss, Seltzer, & Jacobson, 2005). Transitioning from school to post-school life, for example, is typically a complex process that often involves co-ordination, collaboration and joint decision making among school, families, the adults with disability themselves and various community agencies (Flexer, Simmons, Luft, & Baer, 2005). Despite family involvement being considered important for successful transition, few studies have examined parental perspectives and experiences during and following transition to adulthood. When such studies have been carried out, they often have involved qualitative methodologies and/or very small sample sizes (i.e., McIntyre, Kraemer, Blacher, & Simmerman, 2004); these studies have nevertheless pointed towards low levels of family involvement in goal setting, high levels of dissatisfaction and many concerns about the limited options available for their adult child with developmental disabilities (i.e., Davies & Beamish, 2009; Smart, 2004).

Caregivers are a central source of financial, social, psychological and practical support for individuals with developmental disabilities in adulthood and they have been found to contribute to exploring resources, services and opportunities, to encourage setting goals and reinforcing independent living skills (Sitlington, Clark, & Kolstoe, 2000). The role of parents throughout the process of transition to adulthood has been found to enhance the outcomes of youth with ID (Kraemer & Blacher, 2001; Kraemer, McIntyre, & Blacher, 2003; Young et al., 2011). A number of professionals recommend beginning transition preparation and planning by age 14 or even earlier (e.g., Beirne-Smith, Patton, & Kim, 2006), but very few studies have systematically examined caregivers' values and expectations in relation to future adult outcomes for their children with disabilities before transition actually takes place. Understanding parental perspectives, priorities and expectations at an early stage can enhance transition planning, increase parental participation in the transition process and identify service and community 'gaps' earlier. One study by Ivey (2004) examined the hopes and expectations of 25 parents of children with ASD aged 4-20 years, using a 20-item list of various social outcomes. In this study, parents were asked to rate how important and how likely they thought these outcomes were for their children when they reached adulthood. They highly rated the importance of outcomes such as attending school or other learning institution, being safe from physical harm, having a support network of friends, being financially secure, being accepted in the community, being able to hold a job, and living independently. There was a marked discrepancy between how much they valued these outcomes and how likely they thought their children were actually able to achieve these outcomes (Ivey, 2004). Although this study highlighted parental ratings on the importance and likelihood of outcomes, there was considerable variability in the age of the children with ASD as well as their functional levels given the small sample size.

A small number of recent qualitative studies have also provided additional insight into what is valued by caregivers. Employing focus groups and individual interviews, Miller, Cooper, Cooper, Cook, and Petch (2008) coded data from 87 adult service users with ID. Analyses of individual interview transcripts indicated that three main types of outcomes were valued as most important for caregivers: quality of life outcomes (being safe, being engaged in meaningful activities, having social contacts, staying well, living where they want and as they want); process outcomes (being listened to, being valued, treated with respect, given choices) and outcomes relating to change (reducing symptoms, improving mobility, restoring skills and confidence). McIntyre and colleagues (2004) asked 30 mothers of 18–24 year old adults' with severe ID to describe and evaluate their child's quality of life. Among the themes that emerged from the analyses of interview transcripts were that maternal visions related to their child's life stage and that the child's quality of life was considered within the broader context of the child's current living situation and environmental supports. In addition, most mothers mentioned recreation, activities and hobbies as important components of quality of life as well as having their child's basic needs met and belonging to a social network.

Studies investigating the factors that may possibly influence the types of outcomes mostly valued by users themselves or their caregivers have been scarce. In their study of parental expectations of transitions to adult living and working environments, Blacher, Kraemer, and Howell (2010) reported that parents of young adults with ASD had significantly more worries and more restrictive expectations for their children than parents of young adults with Down's syndrome. Hamre-Nietupski, Nietupskim, and Strathe (1992) reported that parents of children with severe or profound disabilities valued social relationship outcomes more highly, while parents of children with moderate disabilities attributed greater importance to functional life skills. These studies highlight the possible role of diagnosis/condition and the severity of associated challenges as factors that might influence parental expectations. In addition, a recent study reporting semi-structured interviews with parents of 20 Singaporean adolescents with ASD showed that these parents had low expectations of social

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