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Family level processes associated with outcomes for individuals with autism spectrum disorder: A scoping review

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ABSTRACT

Background: Families of individuals with autism spectrum disorder (ASD) face distinct challenges, and there is a need for research that attends specifically to the family. Despite the recognition of reciprocal influences in the family, research on families of individuals with ASD has tended to focus on child effects within a dyadic subsystem and not necessarily family effects. Thus, this review focuses on whether and how family processes are associated with the behavioral, social, and/or emotional development of individuals with ASD.

Method: A scoping review was conducted to synthesize existing empirical literature regarding links from family functioning to individual outcomes. Family systems approaches are used along with ecological models to provide an inclusive, guiding framework for research design and interpretation of findings in family-based ASD research.

Results: Results suggest that family-wide factors such as adaptability, cohesion, social support, dynamics, and functioning may be important for child development. However, the heterogeneity of the body of literature reviewed makes definitive conclusions difficult.

Conclusions: Recommendations for future research, including the need for theoretically grounded, developmentally appropriate, models that highlight the unique strengths, challenges, and cultural influences of families of an individual with ASD are discussed.

The family is the primary context for behavioral, emotional, and social development and family processes are critical to the healthy adaptation and development of children (Bronfenbrenner, 1986; Cowan & Cowan, 2003). When families function well, they act as a source of social interaction and emotional security, provide structure for routines, social norms, beliefs, and cultural values, and ensure the health and safety of family members (Guralnick, 2006). Policy changes such as the Individuals with Disabilities Education Act (IDEA) and trends in clinical practice toward family-centered care suggest a growing recognition of the family as a key context when considering the developmental outcomes of individuals with neurodevelopmental disabilities, including Autism Spectrum Disorder (ASD; Gabovitch & Curtin, 2009; Hecimovic & Gregory, 2011)

Family processes have been implicated in the mental health and well-being of individuals with chronic illness and neurodevelopmental disabilities ranging from asthma to ADHD, developmental delay, and Down Syndrome (Gerstein & Crnic, 2016; Guralnick, Neville, Connor, & Hammond, 2003; Kaugars, Klinnert, & Bender, 2004; Schroeder & Kelley, 2009; Van Hooste & Maes, 2003). The consistent importance of the family for individual outcomes suggests the potential role of the family for those with ASD as well. From the choice of intervention services to management of daily care strategies, families are a critical component of care for individuals with ASD. Given that the family is an essential context to the lives of individuals with ASD throughout the lifespan, understanding

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how that context influences an individual's well-being is a critical component to the successful development and implementation of intervention services for those with ASD (Rosenbaum, 2011).

A critical component of family-centered practice is the understanding that children develop best when given the opportunity to “live in a family structure and enjoy a rich array of interaction and activity grounded in the family's culture and beliefs” (p. 114; Hecimovic & Gregory, 2011). This suggests that research, policy, and clinical care should include the needs of the entire family system when considering outcomes for all individuals, including those with ASD. Calls for family systems (FS) approaches to ASD research and practice are not new (e.g., Head & Abbeduto, 2007; Morgan, 1988) and continue to be prevalent (e.g., Tint & Weiss, 2016). Family systems theories, which view the family as a complex, integrated whole and hypothesize that the health and well-being of family members are linked (Cox & Paley, 1997; Seligman & Darling, 2017), are likely to offer an organizing – yet dynamic and flexible – approach for ASD researchers. For example, Cridland, Jones, Magee, and Caputi, (2014) specifically describe the many benefits of FS approaches for clinical support services, future research, methodological applications, and statistical recommendations. Indeed, empirical research is increasingly using FS and ecologically-informed approaches and including family variables as important environmental factors (e.g., Derguy, M'Bailara, Michel, Roux, & Bouvard, 2016).

One of the benefits of an FS approach is the theoretical and methodological distinction made between family- and dyadic-level processes. Rooted in family therapy, a FS perspective capitalizes on what clinicians have known for some time, that individual outcomes must be contextualized within the family system and that individual change is often directed through changes in the family (e.g., emotional climate of the family, organization, routines, relationships; Minuchin, 1985). A family systems perspective views the family as an interactive, interdependent, and reactive unit in which something that affects one member in the family will affect all members of the system (Goldenberg & Goldenberg, 2012; Seligman & Darling, 2017). FS approaches reject the notion that dyadic relationships represent the broader family system, instead focusing on the interrelations between all members the system, defining the family as a complex, integrated whole (Seligman & Darling, 2017). Thus, the family becomes the unit of measurement and analysis independent of the individual or smaller dyadic subsystems within the family (Cook, 2001). Since all members are embedded within the large family system, the processes of the family unit cannot be inferred from these smaller units of analysis (Parke, 2004). Empirical evidence in typically developing children suggests family level processes such as group chaos, family conflict, and negative family interactions are risk factors for poor psychosocial functioning, coping, and health behaviors (Alderfer et al., 2008; Repetti, Taylor, & Seeman, 2002). While dyadic-level processes or subsystem relationships (parent-child, marital) are important to consider, it is equally as important to recognize family-level processes as distinct proximal influences on individual outcomes.

One hypothesis born of a FS approach is that having a family member with ASD influences family processes. Evidence has consistently supported the notion that caring for an individual with ASD can have negative effects on members of the family and aspects of the family system as a whole. For example, Karst and Van Hecke (2012) reviewed the literature on the impact of ASD on the family and found increased parenting stress, poorer parent mental health, and decreased family quality life in families of an individual with ASD; families also experienced mounting time pressure and significant financial burden related to lifelong care for their loved ones with ASD. The concept of family well-being has also received attention. A recent review of findings suggests that having a child with ASD is linked to outcomes for sub-systems within the family unit, such as increased marital strain, poor parent-child relations, and adverse child-sibling relations (Tint & Weiss, 2016).

Importantly, the literature to date has largely focused on the impact of specific characteristics of the individual with ASD (e.g., age, sex, co-occurring physical and mental health problems, ASD severity, and adaptive functioning) on parent, relational, and family well-being. Challenging or aggressive behaviors have been examined extensively and linked consistently with poor parent mental and physical health, increased caregiver burden and stress, and sibling anxiety (Tint & Weiss, 2016). Finally, family functioning has been investigated as a correlate of ASD-related challenges, and recent research points to a negative relationship between child behavior problems and family functioning that is mediated by parent depressive symptoms (Jellett, Wood, Giallo, & Seymour, 2015). Thus, the pathway from child effects to dyadic and family functioning has been the focus of research and continues to be an important area of investigation.

Less is known, however, about the opposite direction of effects: the influence of family processes on the outcomes of individuals with ASD. The ecological model of ASD posits that the appropriate unit of analysis is the interaction between the individual and his/her environment, which includes the family system (Danforth, 2013). Thus, the focus is on the interconnected and reciprocal influences of the individual and the various environmental systems as they can be leveraged to explain both the proximal and distal impact of subsystem relationships and broader units, like the family, on the behavior and development of the individual with ASD (Danforth, 2013). For instance, challenging behaviors in individuals with ASD may contribute to poor family functioning which then may impact a families' ability to meet the daily care needs of the individual, thus impacting all members of the family system including the individual with ASD. Indeed, studies focused on other developmental disabilities demonstrate the utility of this approach. For example, results from a longitudinal study of children diagnosed with Down syndrome and their families indicated that change over time in children's functioning (communication, daily skills, and socialization) were not predicted by cognitive assessments in infancy but were predicted by measures of family cohesion and mother-child interaction (Hauser-Cram et al., 1999).

Key to fulfilling a true FS approach includes examination of how the family system impacts outcomes for those with ASD. While a large body of literature has examined the path from child effects to family and subsystem outcomes, including several reviews of these literatures (e.g., Cridland et al., 2014; Karst & Van Hecke, 2012; Tint & Weiss, 2016), the evidence surrounding family effects to ASD outcomes has not been explicitly synthesized. The tendency to focus on child effects and on dyadic subsystems has limited our understanding of the dynamic, transactional nature of child and family factors in the development of individuals with ASD (Cridland et al., 2014; Hastings, Petalas, Jones, & Totsika, 2014; Sameroff, 2009); however, reasons for this focus may be historical. Psychoanalytic perspectives popularized by Bruno Bettelheim on the etiology of ASD considered poor parenting the cause (Bettelheim, 1967;

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