

Autism:

Why the Whole Family Matters

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Meet Henry. Henry is a playful 8-year-old boy diagnosed with autism. He lives with his parents, grandmother, and 10-year-old sister. He loves dinosaurs and spends hours organizing his coin collection. His functional communication is limited, but he can quote every line from the Disney film *Encanto*. Henry needs encouragement to engage with peers and when he is frustrated, he can become aggressive towards others, especially his sister. At night, he typically wakes up at 2 am and begins pacing throughout the house. Autism is a pervasive spectrum neurodevelopmental disorder characterized by repetitive behaviors, restricted interests, communication deficits, and social skills limitations. Henry's case is just one example of how autism might manifest. The condition impacts each child and family differently. There is no question that rehabilitative services like behavior therapy are essential to help Henry thrive, yet the most crucial services to help this family are not for Henry at all. Accessing services to support parents, siblings, and extended family are critical to ensuring that this child flourishes.

Like many parents raising a child with autism, Henry's parents love their son but express feeling overwhelmed and uncertain if they have the skills to best support Henry. Parent training classes are useful in enabling parents to manage the stress associated with disruptive behaviors and other challenges related to raising a child with autism. Parent training classes are run by experts such as behavioral analysts, financial advisors, educational advocates, etc. When parents have knowledge about autism and their child's needs, they are more likely to make better decisions on behalf of their child.

Disagreements about how to deal with Henry's behaviors and which treatments to pursue has put a strain on his parents' marriage; a common occurrence for couples in their situation. Attending support groups, marriage counseling, or social events just for parents of children with autism is essential for the emotional health of the family. Raising a child with special needs can be an isolating experience. Parents frequently feel that no one can understand the distinct joys and hardships of raising a child with special needs. When parents engage in mental health services, they are better likely to manage stress, strengthen their relationship, and better nurture their children. Additionally, getting involved in support groups and social events allows parents to broaden their support system and feel a part of a community which understands them.

Siblings of children with autism navigate unique family dynamics when compared to siblings of neurotypical children. Henry's sister is often



the target of his aggressive outbursts. When Henry is awake at night, so is his sister because his nightly pacing can be loud and disruptive. The manifestations of autism can create a home environment that is unpredictable and chaotic, which can be traumatic for the siblings. Support groups designed specifically for siblings have been shown to be instrumental in augmenting the benefits of growing up with a sibling with autism while mitigating the potential risk factors. Identified risk factors include having a sense of isolation and reduced sense of belonging. Don Meyer developed a support group model called SibShops that is used worldwide to meet the needs of the siblings (Conway & Meyer, 2008). SibShops give children who have a sibling with autism an avenue to connect with others living in similar circumstances. These age-appropriate, fun-filled events which combine recreation and therapeutic support are led by certified facilitators.

Grandparents play a unique role in the family system as they lend support, guidance, and love to their children and grandchildren. Like numerous grandparents, Henry's grandmother is a source of emotional and economic support for his parents. She also assists with childcare. This multifaceted role obliges grandparents to be a constant source of strength for their families. Yet, who do they turn to when they have concerns and questions about being a grandparent to a child with autism? Support groups for grandparents are key to empowering them to be effective supporters for their families.

The family is a complex, interrelated unit. Thus, the challenges children with autism experience affect every member of the family system. While Henry needs rehabilitative therapies, his parents, sister, and grandmother also need help. It takes a village to raise a child, this is especially true for a child with special needs. For that village to be successful, it is essential that every member has their own support in place because an empowered village has the strength to help children thrive.

Epilogue

JAFCO's Children's Ability Center is committed to serving all children, from birth to age 22, who have been diagnosed or at risk of being diagnosed with a Developmental Disability. The center provides a spectrum of services to families to support them in their journey raising a child with special needs including respite services, social and recreational activities, case management services, life skills, a variety of parent programs, and sibling support services.