

The Silent Sibling: How Current Autism Intervention Neglects Typically-Developing Siblings

JULIA SWEIGERT



WRITER'S COMMENT: My older sister has Down syndrome, so I was introduced to the world of disabilities (Special Olympics, IEPs, speech therapy) from a young age. However, until recently, I knew very few peers who shared this unique world. Last summer, I had the opportunity to sit down with a group of siblings to people with disabilities and hear their stories – the good, the bad, and the hilariously awkward. This particular group of siblings was diverse; their ages ranged from 6 to 26 and they had brothers and sisters with all types of disabilities from Down syndrome to autism to undiagnosed conditions. What I learned during those three hours broadened my perspective and shifted my career goals from support for people with disabilities to support for the whole family. First, I realized that everyone in the group, myself included, shared much in common, despite age gaps and different disabilities. Second, I quickly learned that while any disability can profoundly shape the sibling experience, autism disrupts one's childhood and home experience to a greater extent. After this group discussion, I began thinking more about the sibling experience – both my own and that of siblings everywhere. I took advantage of an informative writing assignment in my UWP 102H course to further explore the topic of siblings of people with autism and, more importantly, what we can do to better support them across their lives.

INSTRUCTOR'S COMMENT: Julia has produced a compelling report that addresses a real gap in understanding when it comes to the treatment of autism. How do siblings of children with autism cope? What do they need and what insights do they bring to autism intervention in the home? With Julia's untiring revisions and focused research in field literature, these questions and their answers took shape, moving from a nebulous cluster of related ideas to a clear and meaningful statement about "The Silent Sibling." At each stage of the writing process for this multi-phase assignment in UWP 102H (Writing in Psychology and Human Development), Julia was diligent: she refined her questions, her paragraphs, her sentences, her choice of words, headings, etc. to craft her coherent, clear, and meaningful insights for readers. I'm glad (but not surprised) that Prized Writing recognizes the merit of Julia's

The Silent Sibling: How Current Autism Intervention Neglects Typically-Developing Siblings

work as worthy of publication.

– Wrye Sententia, University Writing Program

The Centers for Disease Control and Prevention (2014) recently reported that 1 in 68 children is diagnosed with an autism spectrum disorder. Autism spectrum disorders, or ASD, include a variety of developmental disabilities characterized by communication deficits and repetitive interests or behaviors. Because American families average approximately two children per family (U.S. Census Bureau, 2013), the reported autism rate means that about 1 in 68 children is also growing up as the sibling to someone with an autism spectrum disorder. From a young age, these typically-developing siblings experience firsthand the full impact of autism, as they help their parents with the extensive care required of some people with this disability. Yet, siblings rarely receive any external help as they endure the challenges and responsibilities that autism can bring to a family. Despite the growing number of autism research and treatment centers in the United States, very few of these organizations offer programs geared towards siblings. By neglecting the siblings, current autism intervention services leave them isolated and struggling to process their unique experiences, which can be detrimental later in life as siblings prepare to take on the increasing responsibilities of care-giving for their brothers and sisters with autism.

What Makes A Sibling?

In the disabilities community, siblings include any typically developing children in the family of a person with autism or other physical and developmental disabilities. Siblings can be young children living at home or older adults with children of their own. Because autism can affect individuals across many different regions, cultures, and socioeconomic groups, siblings come from various backgrounds as well. Regardless of these differences, siblings share many common experiences and emotional struggles. Research has found that most siblings report some level of frustration, embarrassment, and isolation as a result of their situation (Orsmond & Seltzer, 2007b). These shared experiences result from the stress brought on by disabilities themselves, as well as a failure on the part of disability treatment centers to provide intervention services just for siblings.

While siblings can have brothers or sisters with a number of dif-

ferent disabilities, the recently reported rise in autism rates (Center for Disease Control and Prevention, 2014) coupled with the unique and diverse behavioral profiles seen in individuals with autism makes siblings of children with autism an important group in need of support. In order to be diagnosed with autism spectrum disorder, a child must show two key behavioral traits: a deficit in social communication and interactions, and some form of restricted, repetitive behaviors and interests (American Psychiatric Association, 2013). Commonly, children with autism meet the diagnostic criteria with behaviors including limited to absent verbal communication, increased sensory sensitivity, a strong preference for predictable schedules, and compulsive actions, such as hand-flapping or full-body rocking. Day-to-day experiences that conflict with these behaviors can often trigger a sort of “fight or flight” response from people with autism; they may become aggressive or attempt to escape the situation. Additionally, as a result of these pervasive behavioral deficits, people with autism might have very limited ability to self-care, including both personal hygiene and life skills that allow for independent living. The complexities and magnitudes of these behaviors associated with autism transforms the sibling relationship.

Siblings of people with autism grow up experiencing life in a manner distinctly different from members of a neurotypical sibling pair. Children diagnosed with the disability can be very dependent on family members for care and behavioral mediation. While most of this caregiving burden falls on parents, siblings take on a significant portion of the responsibility too. On a daily basis, siblings help feed their affected brother or sister, keep an eye on them in public settings, and help to interpret their limited communication. Because of their close proximity, siblings can also become the target of aggression when the child with autism is upset or over-stimulated (Orsmond & Seltzer, 2007b). Thus, on a daily basis, these siblings become caregivers and emotional buffers, a distinct difference when compared to the playmate relationship of typical sibling pairs.

Why Do Siblings Matter?

Siblings hold a front-row seat to everything that their families go through as a result of the disability and serve as life-long friends and caregivers. In addition to dealing with typical autism behaviors and providing personal care, siblings know their brothers and sisters inside and out, including likes, dislikes, how to annoy them, and how to make them

smile. Thus, the sibling perspective is an invaluable and underappreciated one that can provide a better understanding of disabilities such as autism.

Siblings of autism spend a significant portion of their day interacting directly with their affected brother or sister. Researchers conducting in-home observations found that siblings, age 2-12, spend as much as 40 minutes of every hour in shared activities with the child with autism (Orsmond & Seltzer, 2007b). The frequent and close proximity to each other means that siblings sometimes understand the wants and needs of the child with autism better than the caregiving adults, including parents or teachers. As one 13-year-old sibling said, “I can understand my brother – a lot of other people don’t – even my dad doesn’t always understand him – then he’s asking me: what does he mean? And I always know what my brother means” (Moyson & Roeyers, 2012). While parents pay close attention to all of the care and therapies a child with autism needs, many siblings have a better understanding of what their brother or sister wants and needs. Siblings have a perspective on the disability that differs drastically from their parents, as they do not yet have to face the added stress of being a primary caregiver. Sibling perspectives could supplement parent and therapist perspectives in autism intervention to create a more accurate picture of how autism looks at home.

As parents’ ability to provide care declines, the sibling transitions from companion to caregiver. In addition to normal aging, parents of people with intellectual and developmental disabilities, including autism, experience significantly more health problems by their early sixties (Seltzer, Floyd, Song, Greenberg, & Hong, 2011), which can interfere with their ability to provide care to their dependent child. Consequently during this time, parents must find an alternate living situation for their child. A longitudinal study of parents found that between their mid-fifties and mid-sixties, approximately 20% of parents saw their children with intellectual and developmental disabilities move out of the parents’ home into a different residential living situation (Seltzer, Floyd, Song, Greenberg, & Hong, 2011). As parents experience a reduction in the amount of care provided to their children with autism, the adult siblings begin to take on a greater caregiving and support role.

Siblings may simultaneously have to take on support for their brother or sister with autism and their aging parents, in addition to having careers and families of their own. As siblings enter adulthood, they increasingly take on the responsibilities of their affected brother or sister’s

well-being (Burke, Taylor, Urbano, & Hodapp, 2012). While typical sibling pairs may develop close friendships as they move into adulthood, siblings of people with autism must adjust their future to include the realities of providing care and making decisions regarding their brother or sister. In some instances, the person with autism is moved into a residential facility, but the siblings still provide significant emotional support (Orsmond & Seltzer, 2007a). Thus, siblings play an important and lifelong role in maintaining a stable and enriching environment for their brothers and sisters with autism.

When Are Siblings Absent?

Autism takes center-stage in the life of these siblings and even so, siblings are often left out of the research and services aimed at improving autism outcomes. As parents take their child with autism to a number of behavior therapies and life skills classes each week, siblings are often lost in the shuffle. During the various appointments, neurotypical siblings play in the waiting room or spend the afternoon at a friend or relative's house. This accidental exclusion can leave the siblings uninformed. They might have a basic understanding of what autism looks like because they see it daily at home, but they miss the opportunity to learn fully how autism affects people, and why their brother or sister has such distinct behaviors. Additionally because they do not get to see the interventions in action, young siblings may not understand the benefits of constant therapy and fail to see all the hard work that goes in to little moments of progress seen in the children with autism.

Research into the effects of autism on families relies primarily on assessments of the affected child and reports made by the parents, with minimal to no input from school-age siblings. For example, Gray et al. conducted a longitudinal study of families having a child diagnosed with autism, but only surveyed the parents from each family (Gray, 2002). While he did give some attention to the topic of autism's impact on other children in the family, he based these results entirely on parental reports, without providing the siblings an opportunity to share their perspectives. Thus, his conclusions about the sibling experience came only from parents inferring what their other children might be experiencing, which introduces significant bias to the results. More recently, researchers have begun to consider the sibling's perspective but often rely on retrospective accounts by adult siblings (Arnold, Heller, & Kramer, 2012), rather than

allowing younger siblings to report for themselves. By omitting narratives made directly by school-age siblings, current research encourages the gaping hole in family-based support services, where the typically developing children should be represented.

Because therapy providers base autism interventions on current research findings, the absence of young siblings in research leads to a lack of services geared specifically toward sibling needs. Children with autism receive intervention services to improve behavioral problems and develop life skills, while parents have access to support groups that help them to endure the challenges of raising a child with autism. Siblings have begun expressing a need for help in coping with their unique experiences. In 2012, to more thoroughly assess the needs of siblings, researchers conducted a survey of adult siblings of people with developmental disabilities. Over half of the participants responded with the need for better sibling inclusion, both with services geared directly towards sibling support and also with a definition of "family" that includes the neurotypical siblings, in addition to the parents and child with autism (Arnold, Heller, & Kramer, 2012). Siblings need a safe space to process their experiences and work through challenges, away from their parents and brother or sister.

While they have a general idea of the day-to-day needs of their brother or sister with autism, siblings do not necessarily know the full scope of autism across the lifetime and may not be aware of the services and programs available to support individuals with autism (Arnold, Heller, & Kramer, 2012). As children, siblings might have a general idea of the services their brother or sister is receiving, but they are ignorant as to the process involved in procuring such services. While this ignorance is reasonable in childhood, it can quickly become problematic. As siblings mature and begin to take on an instrumental role in supporting their loved one with autism, they must quickly learn to navigate the complicated system of accessing the necessary autism support programs. The failure to involve siblings earlier in the therapy process can lead to a more stressful transition of care-giving responsibilities as the siblings enter adulthood.

What Do Siblings Need?

The emotional impact of autism on siblings' lives raises the question of how such emotions, particularly the stresses and isolation, can be

better mediated during the earlier years to produce more favorable outcomes. Support groups are being developed that allow siblings a forum to share their stories and connect with people who share those experiences. The efficacy of these programs has not been fully confirmed but preliminary analysis of participant outcomes in one such program showed a positive and persistent effect on the well-being of siblings (Conway & Meyer, 2008).

Unfortunately, such programs are not widespread and need to be made more readily accessible. Sibshop, one such sibling support program that is starting to gain momentum, has only 57 programs within the United States listed in their online database (Sibling Support Project, 2015), meaning that many states have only one such program available to families in need. Incorporating sibling support programs into currently existing autism intervention services could quickly increase availability and access. For example, Easter Seals already provides a variety of services and resources to individuals with autism and their parents (Easter Seals, 2014) and could serve as excellent facilitators for sibling support therapy. These organizations already see the families of autism frequently and could partner with Sibshop to connect siblings and form a support network. By providing these new programs, service providers can engage the siblings more actively in the autism treatments and also allow them to gain a better understanding of their sibling experiences and identity.

Conclusion

School-age siblings hold a unique position in the discussion of autism treatment and intervention. While therapies frequently address the needs of the diagnosed child and of parents, these intervention programs often overlook the siblings. These typically developing children have their own unique set of needs and play a significant role in providing care and company to their brother or sister with autism. Siblings experience frequent frustration and isolation, which can lead to significant stress later in adulthood as they transition into becoming the primary caregivers for their brothers or sisters with autism. By developing programs that meet the emotional and peer needs of siblings, service providers can create a more holistic family-based approach to autism and move towards improved outcomes for people with autism and their entire family.

References

- American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders*. 5th ed. Arlington, VA: American Psychiatric Association.
- Arnold, C., Heller, T., & Kramer, J. (2012). Support needs of siblings of people with developmental disabilities. *Intellectual and Developmental Disabilities* 50(5), 373-382.
- Burke, M., Taylor, J., Urbano, R., & Hodapp, R. (2012). Predictors of future caregiving by adult siblings of individuals with intellectual and developmental disabilities. *Journal on Intellectual and Developmental Disabilities*, 117(1), 33-47.
- Centers for Disease Control and Prevention. (2014). Prevalence of autism spectrum disorder among children aged 8 years. *MMWR Surveillance Summaries Publication*, 63(2), 1-21.
- Conway, S. & Meyer, D. (2008). Developing support for siblings of young people with disabilities. *Support for Learning*, 23(3), 113-117.
- Easter Seals Inc. (2014). *Autism Spectrum Disorder Services*. Retrieved December 7, 2014 from <http://www.easterseals.com/our-programs/autism-services/>.
- Gray, D. E. (2002). Ten years on: A longitudinal study of families of children with autism. *Journal of Intellectual & Developmental Disability*, 27(3), 215-222.
- Moyson, T. & Roeyers, H. (2012). 'The overall quality of my life as a sibling is all right, but of course it could always be better.' Quality of life of siblings of children with intellectual disability: the siblings' perspective. *Journal of Intellectual Disability Research*, 56(1), 87-101.
- Orsmond, G. & Seltzer, M. (2007a). Siblings of individuals with autism or Down syndrome: effects on adult lives. *Journal of Intellectual Disability Research*, 51(9), 682-696.
- Orsmond, G. & Seltzer, M. (2007b). Siblings of individuals with autism spectrum disorder across the lifetime. *Mental Retardation & Developmental Disabilities Research Review*, 13, 313-320.
- Seltzer, M., Floyd, F., Song, J., Greenberg, J., & Hong, J. (2011). Midlife and aging parents of adults with intellectual and developmental disabili-

ties: Impacts of lifelong parenting. *American Journal on Intellectual and Developmental Disabilities* 116(6), 479-499.

Sibling Support Project (2015). Sibshops. Retrieved July 22, 2015 from <https://www.siblingsupport.org/about-sibshops>.

U.S. Census Bureau (2013). FM-3: Average number of own children under 18, for families with children under 18. Current Population Survey. Retrieved December 6, 2014 from <https://www.census.gov/hhes/families/data/families.html>.

Hsp90 Inhibitors: What's Taking So Long?

CLAIRE JARAMISHIAN



WRITER'S COMMENT: When I received the literature review assignment in my UWP 104F class, I was excited to write about a project that I worked on with Dr. Ken Kaplan in the Molecular and Cellular Biology Department at UC Davis. This review synthesizes the conclusions we made based on the literature published about a class of chemotherapeutic drugs called Hsp90 inhibitors. These drugs have been in the clinical testing phase for decades, yet none of them have been approved as a standard treatment for cancer. I hope you enjoy reading this piece as much as I loved writing it. Thank you Dr. Amy Clarke and Dr. Ken Kaplan for all of your guidance and expertise throughout this process.

INSTRUCTOR'S COMMENT: In Writing in the Health Professions, students spend the quarter focused on a narrow topic of their own choosing. They research new findings in the peer-reviewed literature and write a series of pieces, culminating in that most difficult of undergraduate assignments: the literature review. When she came in to discuss topic selection, Claire described a project she had worked on previously – tracing the path of drug development of several cancer therapies. She had already read and collated some 25 experimental reports on the topic, but she felt that there was something missing, some room to more definitively answer the research question. But she was hesitant to revisit a topic on which she had already spent so much time. I often tell students to build on their strengths and to follow their instincts. I also tell them that they will get more from less – a narrower approach will allow for deeper analysis. Whether she took my advice or just knew what to do, Claire chose to revisit the topic but to narrow the focus. The genius of the resulting literature review, a model of economy and precision which focuses on a single, long-delayed but potentially groundbreaking drug, is all Claire's doing.

– Amy Clarke, University Writing Program