

Open Communication and Special Needs Siblings

Every couple and all family members want a healthy baby when they learn about their pregnancy. Having a child with disabilities puts stress and anxiety on parents and other family members as this would mean a change in the family structure and roles of the family members (Kaytez, 2015). In 2019, around 13.2% of the U.S. population had some type of disability and in 2020, the number of disabled persons enrolled in Medicaid reached 11 million (Statista, 2021). When there is a disabled child in the family, the typical siblings usually take up a special role in the family structure. However, according to Aksoy (2008), the family's attitude towards a disabled child impacts the coping abilities of the healthy siblings, as well as their responsibility towards the special-needs siblings. They are affected as much as the parents and experience very similar emotions (Aytekin, 2016). Beyond the natural acceptability process, there are many other factors involved in the coping strategies of the healthy siblings with the disabled siblings. One of the most important factors is the way in which wants, and needs are expressed.

According to Myers (2018), a communication expert, open communication in a family helps the members to show love and respect among each other. Open communication is a key in the resolution of conflicts whenever they arise in addition to helping family members to increase their confidence level, self-esteem, collaboration, and forming healthy relationships. Parent–child communication is recognized to have a significant impact on children's well-being, particularly during stressful situations (Ackard et al., 2006). According to Hirsch (2015), children with special needs are questioned about why they cannot do things done by their siblings, as they seek understanding of themselves and their bodies. Therefore, parents and siblings are encouraged to share open and honest answers which will help in maintaining their worries and clearing up any confusion. In essence, open communication helps people with disabilities to feel understood and loved by their families.

On the other hand, special needs siblings also grow up in a situation that is likely to cause a lot of stress. Research indicates that these siblings have a higher risk of psychological problems and a lower level of resilience (Venmaes et al., 2011). Their social functioning is impacted (Alderfer et al., 2010) as well as their school functioning (Gan et al., 2017). When confronted with situations they don't understand, those healthy siblings also seek information and emotional support from their parents. They do not only try to understand the medical conditions of their special needs siblings, but they also try to make sense of their own functioning within the family and all areas of their life (Jaaniste et al., 2020). In general,

when healthy siblings cannot "understand" the true meaning of the information, the error is usually attributed to the parents, who do not understand and choose the appropriate way to convey the information to the children (Mattey et al., 2018).

The relationship between siblings has been regarded as one of the longest relationships among people and the emotional bonding is usually very strong (Senner & Fish, 2012). It is noted that children can learn very first through equal relations as they rebel and align with one another, they also learn compromise and solidarity (Kolarikova, 2018). Sibling interactions are also an opportunity to learn about each other's feelings and to share secrets (Lam et al., 2012). Most people in the United States grow up together with at least one sibling. The National data shows that 84.6% of children live with at least one sibling, which is much more than previously thought (US Census Bureau, 2020). The sibling relationship is universal and unique, generally impacting both the family system and individual development (McHale et al., 2012). Unlike any other relationship, it provides physical and emotional connection at key life stages of a person (Gallagher et al., 2006). Siblings are important socializing agents for each other and according to Anderson et al., (1994), this process is the basis of compassion development, caregiving, social understanding, and conflict management between siblings. As Gallagher et al., (2006) states, brothers and sisters also support each other acting as confidantes, good listeners, and advisors during difficult times.

However, the study of sibling relationships does not have its own guiding theory. Considered as "theory-free", Stoneman (2005) agrees that it has been largely developed under the umbrella of family systems theory. Mattey et al. (2018) explains that family systems theory and social ecology theory highlight the importance of not considering people in isolation; everyone is influenced by family members and society. The main idea behind these theories of family is that the family consists of several interconnected subsystems and one of those subsystems is 'sibling'.

Both theories about family systems and social ecology are suitable for people with disabilities. Kovshoff et al., (2017) argue that when a family member has a disability, typical challenges that each family faces, such as schooling or family composition, become even more difficult. Thus, it becomes necessary to understand the development of siblings within this complex relationship system, as the characteristics of the sibling with special needs affects the family in some way, which in turn affects the relationship between the siblings (Stoneman, 2013). King (2007) claims that relationship between siblings in such a family

system is one of the most important as the presence of a special-needs sibling provides a different kind of experience to a healthy sibling.

Nonetheless, as evidenced by Dyke et al., (2009) there is not much attention paid to fraternal relationships in families with special-needs children, as most research focuses on parents, especially mothers. Senner & Fish (2012) also confirm that siblings are neglected in pediatric family-centered services, where all communication about the special needs sibling is generally addressed to the parents. According to Lee and Burke (2018), research is very focused on parents and their own relationship with the special-needs child or their emotional zones and financial situations, and the subsystem of the family unit 'sibling', is simply forgotten.

Siblings of disabled children often experience a different range of emotions compared to their peers. Often their feelings are conflicting and change frequently. The highs are usually higher, the lows are often lower, and it becomes difficult to predict their reaction to their sibling's condition at any time (Eames, 2013). Healthy siblings sometimes try to strengthen the family dynamics while trying to go through ups and downs of development (Roberts, 2016), they often take on a lot of different roles in the family. Often referred as the 'glass children' (Martin, 2021), not because they are weak but rather because parents put their siblings' needs ahead of their own, the typically developing siblings are tasked, most of the time unknowingly, with becoming an additional caretaker to their disabled sibling. They run the danger of being entangled with their self-worth and may struggle to separate their own identity from that of a secondary caregiver. Also, taking such roles at a young age can put a lot of pressure and be very stressful. As Wetchel (2008) explains, children taking more responsibility than is developmentally appropriate at a too early age, of wanting to help special-needs siblings and parents might be hectic to manage.

A lot of times typically developing siblings exhibit a connection between them and their special-needs siblings and eventually, they develop feelings of loyalty and protection. Barr et al., (2008) found that siblings act as protectors of their disabled sibling from strangers, for example, defending the disabled child from bullying or unwanted friends. However, as the researchers also point out, there is a risk of identity loss when the healthy siblings take on a parenting role and sacrifice their own needs.

Typically developing siblings often feel that their disabled sibling takes away their parents' attention, resulting them in feeling isolated and lonely. Barr et al., (2008) confirm that they feel so as their parents are more concentrated on the needs of the disabled sibling. McCarty (2001) agrees that in such circumstances the healthy siblings become resentful as

they do not feel gaining the same full attention from their parents. On the other hand, they experience conflicting emotions as while they compete for the attention of their parents, they still are concerned about their sibling's well-being. Connors & Stalker (2003) also mentions this mixed feeling of resentment they might feel for their disabled sibling while at the same time, feeling love and desire to protect them.

A typically developing child might feel guilty for being healthy and end up envying the sibling with special needs, as unlike the latter, their problems go overlooked by parents many times (Siller, 2002). The healthy children also often go through extreme assessment made by the parents on how they treat their special-needs sibling and on this, Fisher (1992) pointed out the risk of psychological threat to the healthy siblings, such as depression, educational problems, or disrupted relationship with the disabled sibling. They also feel guilty if for instance, they have fought with their disabled sibling. They blame themselves instantly because they are always told that they should be affectionate towards their disabled sibling (O'Kearny, 2004). Guilt over caretaking is another important concern, as sometimes healthy children do not want to take care of their special-needs sibling. But finally feel guilty about feeling this way.

According to Rutter (2000), siblings are much more comfortable when they know what is happening with their disabled sibling. They like to be informed so that they can at least speak about it when they are asked by their friends and other relatives. Being excluded in the conversations at service centers or at home creates frustration, loneliness, and isolation. Kutner (2007) states that parents and professionals should provide age-appropriate information about the sibling disabilities to the healthy siblings. Many previous studies believed the above-mentioned emotional experiences as being the negative ones leading a healthy child towards low self-concept, depression, and aggression issues but it all depends on the child and how he faces those challenges (Cicirelli, 1994). Every disability comes with different challenges, such as children with autism do not always have special needs instead, they want to engage more with their siblings and develop a healthy bond. Increased number of negative interactions from parents could lead towards more conflicts between siblings whereas on the other hand a fair and soft direction from them could lead towards positive behavior towards each other (Dyches, 2004). Zaidman-Zait (2020) confirms that the relationship between typically developing and disabled siblings is even more favorable than the relationship between healthy siblings. Open communication is essential for healthy children in building and connecting with their special-needs sibling, as well as with their parents and general environment.

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