

Youth Development: Empowering Siblings With Validation and Support as They Navigate the Complexities of Having a Sibling With Special Needs

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Writing Sample

Mission Statement: [REDACTED]'s ([REDACTED]) mission is to recognize, support, and create a sustainable community for the often overlooked siblings of children with special needs, disabilities, and chronic illnesses (Siblings) through recreationally therapeutic beach-based programs. Since there are limited community-based services to siblings of those with special needs, [REDACTED]'s ultimate aim is to continue developing services any place where water meets the sand.

Program Description: [REDACTED]'s beach camps are carefully tailored to recognize and guide Siblings through their lifelong challenges, providing a safe and supportive environment for Siblings to have some fun, without all the responsibilities they have at home. These proven programs follow the SibShop model designed by our partner, the Sibling Support Project, which guides Siblings to process their emotions and develop coping skills, and introduces them to youth and mentors to build a supportive community alongside a variety of beach-based activities, such as art projects, ocean conservation initiatives and beach clean-ups, yoga, group games and water sports, including surfing and boogie boarding. The intentionally small sessions, with 15 youths, allow Siblings to really connect and develop lasting friendships.

Sustainable Development Goal

Good Health and Well-being: Ensure healthy lives and promote well-being for all at all ages

Problem Statement

Children with special needs garner tremendous attention in families, leaving their Siblings to carry extreme stress and responsibilities. Studies have pointed to a pattern of loneliness, peer problems, and depression in Siblings as young as five years-old. Our Southern California-based programs provide much-needed support for Siblings for the perhaps 20,000 underserved and unrecognized Siblings in our area.

According to Dr. Avidan Milevsky, “there is one member of the overall family system who has been neglected as part of the effort to attend to disability issues: the siblings of those with disabilities.” Most family resource centers focus solely on the child with a disability and their parents, while their Siblings silently suffer with significant emotional and behavioral problems.

Problem Measurement

Metric #1: Of the 2.6 million households in the US that have at least one child in the home with a disability, 66% have mild conditions, 29% have moderate conditions, 5% have severe conditions, and almost all have a sibling.

Metric #2: Currently, the Regional Center of Orange County—a State of California contracted agency that coordinates services for individuals with developmental disabilities and their families—serves over 22,000 Orange County residents. They offer no programs specifically for Siblings.

Metric #3: The prevalence of individuals diagnosed on the Autism spectrum is rising 10-17% every year in North America and 84% of siblings of youth on the Autism spectrum report having difficulties dealing with their brother or sister’s aggressive behaviors. At least 70% of the kids in our programs have siblings with autism.

Contributing Factors

Social:

Limited awareness and understanding of sibling needs. One of the main factors contributing to the neglect of Siblings of children with special needs is the limited awareness and understanding of their needs and experiences. This lack of understanding can lead to a lack of recognition of their needs and a lack of support for their well-being. Siblings are a large and often overlooked population in mental and physical well-being research and assistance because of the focus on their siblings. The 2.6 million households that have a child with a disability represents 7.2% of the 36.7 million households in the US with children, and the majority have at least one Sibling. Despite these overwhelming numbers, the needs of Siblings are grossly unrecognized and frequently neglected.

“Parents are offered services to assist with their special needs child, be it physical or mental health or developmental needs. These services are not routinely offered to siblings. But all the clinical research suggests that siblings have the same issues as parents, plus issues that are uniquely theirs,” said Don Meyer, director of the Sibling Support Project.

Stigma and discrimination. Another factor is the stigma and discrimination that siblings of children with special needs may face in their communities, which can impact the ability of Siblings to receive support and connect with others who understand their experiences. This can lead to feelings of isolation and a lack of connection to their peers, making it even more difficult for them to cope with the challenges of having a sibling with special needs. Although the effects of having a sibling with a disability on peer relationships are mixed, one study found that 70% of youth with a sibling with a disability had been teased or bullied at some point due to this relationship.

Economic:

Inadequate funding for sibling support programs. The lack of funding for sibling support programs is another external factor that contributes to the problem. This can limit the resources available for these programs, making it difficult for organizations like [REDACTED] to reach as many Siblings as possible and provide them with the support they need. This can also limit the ability of organizations to expand their programs and outreach efforts over time, which is critical for ensuring the sustainability of these programs.

In addition to the little funding available to assist Siblings, families who care for a child with a disability also lack funds themselves to provide support for their neurotypical child and are more likely to have non-reimbursed expenses for disability-related support. The literature reports troubling findings that uncover an association between low income and children with special needs that go both ways; children with a disability are often born into low income families *and* families who care for a child with a disability often find themselves sliding towards poverty.

A recent national U.S. study reported that 40% of families of children with special health care needs experience a financial burden due to their child's condition. In order to meet their child's needs, families who care for a child with a disability are more likely to be single income families with lower quality jobs yielding lower incomes, to live in poor quality housing, and to live in poverty. With less access to resources, the Siblings are often left with less opportunity to participate in the activities that most children get to experience.

Political:

Siblings not seen as a priority group for funding and support. The political landscape also plays a role in the limited funding and support for Sibling support programs. Government policies and funding priorities often prioritize the needs of children with special needs and disabilities, which while essential, also results in the overlooked needs of their Siblings. This can leave Sibling support programs without the necessary resources and support to effectively serve this population.

The limited recognition and prioritization of the needs of Siblings has resulted in a lack of funding and resources, resulting in a gap in support for this population. This neglect can have long-lasting consequences on the well-being and success of Siblings, as programs designed to support them are left without the resources they need to reach and serve as many Siblings as possible, and Siblings without the recognition and support they need to cope with the challenges of having a sibling with special needs.

Strategic Vision

We aim to create a supportive and empowering community for Siblings of children with special needs, so that they can lead happy and fulfilling lives. Our ultimate goal is to have every family resource center offer a Sibling support program of some sort, so that communities can better recognize and provide Siblings with the support they need. By reaching as many Siblings as possible, ■■■ hopes to create a network of support that will help them navigate their lives more effectively.

To achieve this vision, ■■■ will continue to develop its programs and outreach efforts, so that it can reach even more Siblings and provide them with the support they need. In addition, ■■■ will also work to establish partnerships with other organizations and institutions that share its mission, so that it can pool resources and knowledge to achieve its goals more effectively.

Innovation

Many organizations do excellent work to help children with special needs, but their Siblings, who undergo related anxiety and trauma, have little to no support available. Of the 500 organizations presenting Sibshops, ■■■ is the only one offering beach-based programs. We have also adapted therapeutic games to work in the water (especially helpful during COVID-19) which has proven expressly powerful for de-stressing, relaxing, and having fun!

Activities

Providing Recreational Therapy: Engaging in beach-based activities such as guided journaling, therapeutic group discussions, expressive art projects, ocean conservation initiatives and beach clean-ups, group games, and recreational water sports.

Encouraging Social-Emotional Learning: Providing a safe and supportive environment for siblings to process their emotions, communicate with their parents and peers, and develop positive emotions towards their siblings. A majority of participants improve their ability to communicate, have heightened mental and emotional health, and foster stronger relationships among family members.

Engaging in Mentorship and Network Building: Encouraging the formation of lifelong friendships and mentorships among participants, fostering a sense of community and support for Siblings.

Outputs Summary

The number of Siblings who participate in the program and receive support and services; The degree to which participants experience improved emotional well-being and coping skills after participating in the program; The degree to which participants develop empathy and positive emotions toward their brother/sister, and better understand their needs.

Output Metrics

- 1) Number of Participants: 150 Siblings served annually
- 2) Improved Emotional Well-being and Increased Coping Skills: 83% of parent feedback reported improved well-being of their children and less concern about their emotional health.

- 3) Increased Empathy and Positive Emotions Toward Sibling: 100% of parent feedback reported satisfaction on the impact the program has had on their child's feelings toward his/her brother or sister with special needs.

Outcomes Summary

The degree to which participants continue to experience improved emotional well-being over time as well as increased resilience and improved ability to handle stress related to having a sibling with special needs; The degree to which the community becomes more aware of the needs of siblings of children with special needs; The number of new support services offered to siblings, as well as the number of partnerships formed with other organizations to expand the reach of these services.

Outcome Metrics

- 1) Long-Term Emotional Well-being and Resilience: as measured by follow-up assessments. A study evaluating the lasting impact of Sibshops found that 75% of respondents (who participated as children) reported that Sibshops affected their adult lives and 94% said they would recommend Sibshops to others.
- 2) Increased Community Awareness: as measured by the number of community events, partnerships and media coverage. Example: "25% increase in the number of community events focused on Sibling support and recognition and 10 new partnerships formed with local organizations to increase awareness and support for sibling needs."
- 3) Expansion of Sibling Support Services: Example, "50% increase in the number of support services offered to Siblings in San Diego and Orange County."

Progress

Over the past 5 years, since its inception, ■■■ has made substantial progress in achieving its goals. Beginning with only a few programs at San Clemente Beach, ■■■ has expanded to serve more communities and families, including adding San Diego Beach in the fall of 2020 and Huntington Beach in the summer of 2021. The organization has seen continuous growth in the number of programs, community support, scholarships provided to low-income families, and events hosted. These efforts have already produced tangible results in the mental and emotional well-being of participants, family dynamics, and community awareness, and ■■■ is poised to continue growing and making a difference in the lives of families for years to come.

The expansion of ■■■'s programs has also led to a marked improvement in the relationships between Siblings and a deeper understanding of their needs. Participants report experiencing an increase in positive emotions towards their siblings, and a sense of purpose derived from caring for them. Furthermore, the friendships formed through our programs provide a supportive network for the siblings, reducing feelings of isolation and empowering them to handle difficult situations. These friendships have also opened up avenues for socialization, connection, engagement, and fun beyond the confines of our program.

Following are testimonials from parents that speak to ■■■'s transformative abilities:

“I am so grateful for [REDACTED] and their counselors. [REDACTED] has helped my oldest daughter with our family crisis. We are a family with a chronically ill child. Our youngest has gone through many health challenges and this program came to our rescue. My daughter looks forward to each week's gatherings. She always comes home with a smile and is looking forward to the next week.”

“I was so afraid for my daughter; she wouldn't talk to anyone. Her younger sister has autism and cerebral palsy, and I feared losing her! [REDACTED] has helped her and my whole family stay close and communicate better.”

“[From attending Sibshops, my child has] learned about himself and how he can grow with a sibling with needs, his feelings, and how to manage with all of what he deals with in a healthy way, and is finding friends that are in the same scenario.”

“I am impressed with the entire program, their dedication to the kiddos, and their consistency. They are helping my daughter and letting her know that she is not alone having a sibling with chronic health issues.”

[REDACTED] measures program success by recording Sibling and parent reflections, like testimonials above. In addition, we gather data through parent surveys where parents give feedback on administration logistics, as well as rank the impact of the program on their child's feelings toward their brother/sister, the impact on parents' levels of concern for the Sibling, and other qualitative data on friendships made during the program, activities that made strong impressions and other benefits they noticed. Success is also measured by returning Siblings; of the 300 children [REDACTED] has served since 2017, over 70% still participate.

We will continue to expand our services and serve as many Siblings as we possibly can; the more Siblings we can reach, the more communities will recognize their understated needs, celebrate their successes, and support them through more programs and outreach.

Sources

Anderson, D., Dumont, S., Jacobs, P., & Azzaria, L. (2007). *The personal costs of caring for a child with a disability: a review of the literature*. Public health reports (Washington, D.C. : 1974), 122(1), 3–16. <https://doi.org/10.1177/003335490712200102>

University of Victoria. (n.d.). *Inclusion & Engagement Report*. University of Victoria: Centre for Youth and Society. <https://www.uvic.ca/research/centres/youthsociety/resources/summaries-reports/inclusion-engagement/index.php>

University of Victoria. (n.d.). *Siblings of Youth with Disabilities*. University of Victoria, Centre for Youth and Society. <https://www.uvic.ca/research/centres/youthsociety/assets/docs/briefs/siblings-youth-disabilities-research-brief.pdf>

Young, N. A. E. (2022, August 22). *Childhood disability in the United States: 2019*. Census.gov. <https://www.census.gov/library/publications/2021/acs/acsbr-006.html>