

# A Parent's Guide for Supporting Siblings



"The way [children with intellectual disabilities] relate with their siblings is different from me as a mother, the way I relate with my child. For me, I might even be more protective, but [the siblings] let them grow, they let them nurture. They expose them to other youth who are similar to them... We as parents might be limited and we might have our own ideas, so the siblings for us, I would say, are agents of change."

Millicent Palo
Regional Family Coordinator
Special Olympics Kenya

The purpose of this guidebook is to provide parents of children with intellectual disabilities (ID) with strategies for supporting their other children without ID. Siblings of people with ID may face a number of challenges as they grow up. It is important that parents are able to recognize and address these challenges. In this guidebook, we identify strategies to help you support all of your children. Additionally, this guidebook provides an appendix with supplemental information on the benefits of sibling engagement for parents, understanding intellectual disabilities, and an overview of Special Olympics.

Special Olympics can support your entire family, including your children without ID. The <u>Guide for Sibling Youth Engagement</u> provides siblings ages 8-25 with ways to become involved in Special Olympics. Share this resource with your children to begin!

# A Story to Inspire

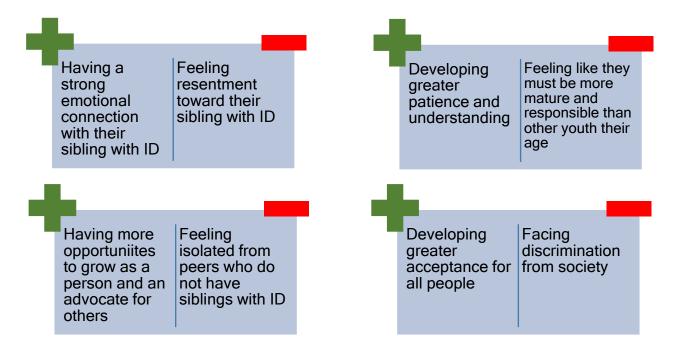
Siblings of people with ID can develop strong bonds with their siblings. They can also become lifelong advocates for people with ID. For example, Rosemary Kennedy, who had ID, inspired her sister Eunice Kennedy Shriver to establish Special Olympics. Despite facing discrimination throughout their childhood, the two sisters were always together. They often played sports together and with their family. Eunice saw that sports could be a common ground to unite people. In 1962, she used this idea to start a camp in her backyard for people with ID, called Camp Shriver. Over time and with her family's support, she expanded Camp Shriver into the international organization that it is today: Special Olympics.



Eunice and Rosemary, right, pose on a boat as they travel through their first tour of Europe together

# Sibling Experiences

Eunice and Rosemary's story shows the power of sibling connections. However, every sibling relationship is different. Age, gender, disability, and other factors can impact sibling dynamics. Most sibling relationships include some positive and challenging experiences. These experiences may include:



Siblings of people with ID need both family and structural support. Greater support can lead a sibling to experience more benefits than challenges. Parents can offer family support through strategies described in this guide. Special Olympics can offer structural support through opportunities for sibling engagement.

# Sibling Engagement

**Sibling engagement** occurs when the sibling of a person with ID is actively involved in their brother or sister's life. They are active participants in their sibling's Special Olympics journey. Together, they play, learn, develop and work. They make their relationship stronger in the process. The siblings are a team who motivate and support each other. They work toward and achieve shared and personal goals. Learn more about how Special Olympics can foster sibling engagement <a href="here">here</a>! Learn more about how sibling engagement can benefit the entire family in Appendix A!



Siblings from around the world with and without intellectual disabilities participate in Special Olympics

Sibling engagement through Special Olympics offers **mutually beneficial** outcomes. Your child with ID will enjoy and appreciate the time his or her sibling invests in them and their ambitions. Sibling engagement can offer your child without ID:

- Pride in themselves and their sibling
- Stronger companionship with their sibling
- Increased self-esteem
- Problem-solving skills
- Leadership skills and opportunities

- Friendships with other siblings
- Greater tolerance and acceptance
- Opportunities for advocacy
- Stronger family unity
- Opportunities for personal and athletic growth

# Supporting Your Child without an Intellectual Disability

In addition to the structural support that Special Olympics can provide, siblings need support from their parents. Family support can help them grow as individuals and leaders. The strategies below offer advice on how to support your child without ID.

# 1. Recognize When Your Child Needs Support

Siblings of children with ID may face challenges throughout their lives such as stress management, isolation and stigma. However, siblings may be unable or unwilling to ask for help with these issues. This can make identifying their challenges difficult for parents. To better identify your child's needs, ask them questions. Be aware of the possible challenges they may be facing, such as the ones listed below. Then, use the following strategies to address those challenges.

# Potential challenges faced by youth who have siblings with ID:

- Confusion about their sibling's disability
- Difficulty processing and expressing emotions
- Difficulty managing family stress
- Feeling as though their identity is defined by having a sibling with ID
- Feeling isolated from their peers
- Feeling neglected and overlooked by parents
- Feeling overburdened by caretaking duties
- Feeling resentment, guilt or embarrassment
- Frustration and anger with public stigma
- Uncertainty about how to deal with their sibling's behavioral challenges
- Worrying about the future

**Example**: Lucia asked her daughter, Ana, how she felt about helping take care of her sister, Sophia, who has ID. Lucia was surprised to learn that Ana had been feeling overwhelmed for months. Ana felt like she was not able to spend time with her friends because she was always worrying that Sophia needed her. Together, Lucia and Ana came up with a plan to reduce some of Ana's anxieties and make time for social activities.

<sup>&</sup>lt;sup>1</sup>Caldin, R., & Cinotti, A. (2014). Different mirrors Sibship, disability and life phases. *Italian Journal of Special Education for Inclusion*, 1(1), 95–113.

#### 2. Model Positive Attitudes and Behaviors

Children are greatly influenced by the attitudes and behaviors of their parents. It is important to maintain a positive outlook on your family's situation so that your children may also carry that view. If you handle adversity with confidence and composure, your children will likely feel more at ease and do the same.

**Example:** Hiromi and Isamu welcomed their child with ID, Dai, into this world as a blessing to their family. While they knew there would be challenges, they were excited for the love and joy that their child would bring. Because of this outlook, Hiromi and Isamu's other children embraced their new sibling and his differences. As they grew older, the siblings supported each other in times of hardship.

For more guidance on realizing your child's full potential, check out the <u>Guide for New Parents!</u>

# 3. Promote Acceptance

Children can sometimes feel embarrassed by their siblings with ID when they are out in public or around friends. They may be worried that their sibling's behavior is not "normal" and lead them to be bullied. Help your children understand that there is no "normal" and that everyone is different and special in their own way. By teaching your children to embrace differences and practice acceptance, they will feel greater pride in their sibling with ID. They will also be a positive example to others.

**Example:** Malike noticed that his daughter, Haniah, rarely included her brother with ID, Adric, when she played with her friends. One day, Malike had a conversation with Haniah. He explained that other people's opinions are not as important as supporting your family. Together they agreed that she would not want to play with anyone who does not accept Adric the way he is. Since then, Haniah has joined the Unified swimming team at her school. She is an example of inclusion and acceptance for her friends every day.

Learn more about Unified Sports® here!

# 4. Provide Individualized Opportunities

Some siblings of people with ID may feel like they are defined by their sibling relationship. They may want to be seen as an individual as well. These children may struggle to discover interests outside of their sibling relationship. In this case, it is important to also provide your child without ID chances to explore their own interests and broaden their social circle.

**Example:** Asha noticed that her daughters Imani, who has ID, and Zola, who does not have ID, did everything together. Asha loved watching her daughters bond and play together. However, she worried that they were limiting themselves by only spending time with each other. Imani and Zola have always been Special Olympics Unified Partners. Asha suggested that Zola join a sports team at her school in addition to being a Unified Partner with Imani. Zola made new friends at school and expanded her interests, but maintained her close bond with Imani.

# 5. Provide Fair Opportunities to Both Siblings

Siblings of children with ID may find it challenging to relate to their brother or sister. This may occur if their sibling is treated differently. Perhaps their sibling with ID is given fewer chances to engage and play with others. It is important to provide all of your children with similar opportunities and activities that are appropriate for both siblings to do together. That way, they will be more likely to see each other as equals and treat each other with respect, acceptance and love.

**Example:** Rebecca noticed that her son, Sam, frequently talked about how much fun his friends had with their siblings. However, Sam rarely interacted with his own sister, Eileen, who has ID. Rebecca wondered if Sam felt like he was missing out on the "typical" sibling experience. Perhaps they were not able to bond as easily because Eileen was not participating in the same types of activities as Sam. She signed Eileen up for music lessons and Special Olympics bocce practices. She started to see Sam reconnect with his sister as they discovered common interests.

Learn more about Special Olympics sports <a href="here!">here!</a>

# 6. Include All of Your Children in Family Conversations

Siblings of children with ID can feel left out when they are not included in conversations about their sibling's disability. Parents may not want to worry or burden siblings with these matters. However, children often want to learn about their sibling's disability. Although, they may not know what or how to ask. Depending on the age of your children, consider inviting all of them into conversations about your child's disability. You may also consider including them in doctor's visits. These small changes may help your child to better understand their sibling and feel closer to the family as a whole.

**Example:** Mariana's brother, Rafael, was diagnosed with ID over 5 years ago. As time passed, she still did not fully understand his disability. She did not know why he was in different classes at school. One day, she asked her parents for some answers. They did not realize that Mariana was so curious about her brother and felt excluded from important family matters. From then on, Mariana's parents made an effort to teach her about ID and answer all of her questions.

For more information about ID, check out the information in Appendices B and C!

# 7. Spend Quality Time with your Child without ID

Sometimes, siblings of children with ID can feel like their parents are not able to provide them with as much attention as they would like. In this case, try to set aside some time in your week to have alone time with your child without a disability. This quality time together will help your child to feel important and valued.

**Example:** One day, Liz went to her mom, Elise, and expressed that it felt unfair for her mom to focus all of her time and attention on her sister, Erin, who has ID. Elise did not realize that her attention to Erin was making Liz feel unhappy. Elise reached out to a close friend that she trusted to spend time with Erin one night per week so that she could dedicate some quality time to Liz. Liz enjoys catching up with her mom and feels like a valued member of her family.

# 8. Foster Inclusive Play at Home

Depending on the nature of your child's disability, it may seem challenging for your children with and without ID to play together at home. You may be concerned about the safety of your children or the different ways in which they play. However, there are many ways to foster inclusive play at home to allow children of all abilities to have fun and learn together. Starting with structured play can be helpful. Select two or three activities to do with your children for 20-30 minutes, at least three times per week.

**Example:** Camila worried that her son, Andres, might accidentally hurt her daughter, Amada, who has ID, when they played. Andres is bigger and plays rougher than she does. Camila's friend, who also has children with and without ID, showed her the Special Olympics <a href="Young Athletes Activity Guide">Young Athletes Activity Guide</a>. Camila used it to pick an activity that would allow her children to play in a safe and controlled way. Camila decided to try a bowling activity with her kids in which they stack paper cups and roll a ball to knock them over.

For examples of inclusive activities that can be played in the home, check out the Young Athletes Activity Guide!

# 9. Do Activities as a Whole Family

It is also important to do fun activities as a family. By doing so, siblings with and without ID are able to interact more and share fun experiences. These activities will help your children bond and learn from each other. Work together as a family to determine an activity that is practical and exciting for all family members! Some examples include having a game night at home, taking a walk around the neighborhood, seeing a movie or performance, or going to a nearby festival.

**Example:** Cam and her dad, Hai, used to watch live bands perform together to bond. Cam enjoyed spending time with her dad, but always wished her brother with ID, Minh, could join them. Minh would be bothered by the loud music if he went. Cam told her dad that she wanted to do something the three of them could enjoy together. Cam, Hai and Minh discussed their options. They all decided to sign up for Fit Families, a 6-week fitness challenge for Special Olympics athletes and their families.

Learn more about Fit Families here!

#### 10. Discuss Future Plans

Who will take care of your child with ID when you no longer can? This is a difficult but necessary scenario to consider. Most young siblings do not think this far into the future but can worry about it as they get older. Siblings often make suitable caretakers for people with ID due to their long relationships and strong bonds with their brother or sister. However, they may feel like the responsibility is required of them. Talk to your children about your family's options for future caretaking. Ask for their opinions and make a plan so that they can feel prepared for whichever role they take.

**Example:** Durah has one daughter with ID and two sons without ID. She was not worried about her ability to care for her daughter, Elinah, at the moment. However, she knew it was better to prepare her children earlier than later for the possibility that one day she might not be there to take care of Elinah. She sat down with her three children and started the conversation about future caretaking. She told her sons that they could have as small or big of a role as they were comfortable with. She asked Elinah what her preferences were, too. Together they made a plan that met each person's wants and needs and then made a list of helpful resources to use when they need them. Although the conversation was difficult to begin, each family member left feeling comfortable with the plan they created.

### 11. Take Care of Yourself

Being a parent is challenging, especially when one of your children has ID. You might find yourself feeling stressed or exhausted from managing all of your daily responsibilities. Often times, when children see their parents feeling overwhelmed, they also feel distressed. To improve you and your family's emotional health, take some time in your day to relax and ask others for help. By taking care of yourself, you will be better able to take care of others.

**Example:** Isaac, a father of four, often felt tired from working all day, managing his children's activities, and taking care of his daughter with ID, Samantha. Meanwhile, his son, Zach, was secretly struggling in school. Zach did not tell his dad about this problem because he did not want to overburden his dad with another issue. Isaac finally discovered Zach's poor grades. At this point, Isaac decided that he could only take care of his family if he also took care of himself. Now he makes an effort to sleep 8 hours every night so that he will have the energy to help his family each day.

# 12. Involve All of Your Children in Special Olympics

In addition to using the strategies listed above, you can provide extra support to your children by involving them in Special Olympics. Special Olympics can offer your children without ID opportunities to connect with other siblings, learn about ID, develop leadership skills, and become advocates for inclusion. Special Olympics is not only an organization for people with ID, but one for your entire family!

**Example:** Last year, Wen signed up both of her children for the Special Olympics Unified Sports® program at their school. Since then, she has noticed her children, Meili and Li, become closer as siblings and Unified partners. Meili, who does not have ID, has become more outgoing and interested in leadership roles in her community. She has a new group of friends who share her interests and support her ambitions. Many of her friends are also siblings of people with ID. Wen was surprised that Special Olympics could be so instrumental in the development of both of her children with and without ID.

For more information on Special Olympics, check out Appendix D! To learn more about how siblings can become involved in Special Olympics, check out our <u>Sibling</u> <u>Engagement Guidebook!</u>

# Appendix A: Special Olympics Sibling Engagement is for the Entire Family



A family poses in front of the hospital where their daughter with an intellectual disability received treatment through the Special Olympics Healthy Communities program in Mexico

The Special Olympics Sibling Engagement Program does not only benefit your children. It also has positive implications for the entire family.

When your child is actively engaged in their sibling with ID's life, they can be helpful to you. They may lessen some of your responsibilities and reduce your stress. For example, an engaged sibling may accompany their sibling with ID to a Special Olympics practice if you are unable to attend. They may also become more familiar with their sibling's behavioral and communicative challenges. For instance, they may be able to assist you when these challenges arise.

Siblings can also connect with each other in a unique way. Their connection can allow them to learn new details about each other that they can share with you. For example, your child may discover new strengths and talents in their sibling with ID while they play and learn together. Then, you can learn more about your child with ID through their growing sibling relationship.

Sibling engagement can also create more unity among your family. The emotional closeness that your children develop can influence other family members. Your child's mission for inclusion may spread throughout your family. Your family may find more common interests, values and experiences.

# Appendix B: What is an Intellectual Disability?

The following information is designed to provide parents with an overview of intellectual disabilities. It is important to understand your child's disability for many reasons. This information will help you educate your child without a disability's about their sibling. To learn more, check out the <u>Guide for New Parents</u> or visit our <u>website</u>.

# **Intellectual Disability**

Intellectual disability (ID) is a term used when a person has certain challenges. These challenges make it harder to carry out daily activities. They may struggle with communication, social and/or self-care skills. A child with ID may learn and develop differently than other children.

Intellectual disability used to be called "mental retardation." However, the R-word (retarded) became exclusive and offensive. "Intellectual disability" is now the official term.

#### Causes of ID

For many children, the cause of their ID is unknown. Injury, disease, or a problem in the brain can cause ID. Some causes can happen before, during or soon after birth. These might include genetic conditions, infections during pregnancy, or lack of oxygen. Other causes of ID may not occur until a child is older. These might include severe head injury, infections or stroke.

# Societal Impact on People with ID

People with ID are not at fault for having different challenges. Some communities do not do a good job of supporting people with ID. This may make it hard for people with ID to function in that community. For example, a student with Down syndrome is not disabled by her diagnosis. Her school's curriculum assumes that all students learn at a similar pace and have similar abilities. If her school offered the appropriate support and adaptations, she would be successful in her schoolwork. Therefore, her school's curriculum is disabling. <sup>2</sup>

When your child with ID is struggling with a task, try to identify his or her obstacles. Then, ask yourself: Is there something I, or my community, could be doing to make this task more accommodating for my child and other people with ID?

<sup>&</sup>lt;sup>2</sup> Social Model of Disability
Oliver, Michael. "The social model in context." *Understanding Disability*. Palgrave, London, 1996. 30-42.



# Appendix C: Myth Busting!



Below are common myths associated with people with ID. Knowing the difference between these myths and facts will help you to answer your children's questions and share accurate information with them. Learning about the capabilities of your child with ID will help your whole family become advocates for people with disabilities.

People with intellectual disabilities cannot play sports.

If given the opportunity and appropriate adaptations, people with intellectual disabilities can overcome barriers and play sports.







People with intellectual disabilities cannot learn.

People with intellectual disabilities may learn differently, but they can still learn. Everyone learns at their own pace.







I, or one of my family members, caused my child to have an intellectual disability. Intellectual disabilities are not contagious or caused by other people. They are caused by genetics, injury, or exposure to disease.



FACT

# Appendix D: What is Special Olympics?

Special Olympics' mission is to offer year-round sports training and competition for people with ID. This gives them ongoing chances to become healthy, show courage and feel joy. They can share gifts, skills and friendship with their families, other Special Olympics athletes and the community.

There are 200 million people with ID in the world. Our goal is to reach out to every one of them – and their families, too. Special Olympics reaches out through trainings, competitions, health exams and fundraising events. We also create chances for families, community members and others to meet and participate. Everyone can change attitudes and support athletes together!

Special Olympics relies on volunteers. We have many events for siblings, parents, other family members and friends to become involved. Families are its most powerful and valuable natural resource!

To learn more about the Special Olympics movement and the important role of families in it, visit our website.



Siblings and other family members who participated in the Special Olympics Africa Sibling and Family Workshop in Johannesburg, South Africa pose for a group photo

# Appendix E: More Resources

Do you need support from Special Olympics in other areas? Check out these helpful resources below:

# What is Intellectual Disability?

Information on the definition of ID, its causes and global presence. You can also access information about specific types of ID through this page.

# **A Guide for New Parents**

Provides information about diagnosis, coping with feelings, understanding ID, and finding resources for support.

# Family Toolkit- Welcoming Families

Provides an overview of Special Olympics, opportunities for people with ID, and opportunities for family involvement.

# **Special Olympics Sports and Games Information**

Access information about Special Olympics opportunities such as sports, Unified Sports and Young Athletes.

# **Special Olympics Program Finder**

Reach out to your local Program to volunteer, register an athlete, join a Unified Sports team, work as a coach and learn about upcoming events.

# **Helpful Websites for Families**

Links to external websites for more information on specific types of ID, health initiatives, family support and research.

# Keep up with Special Olympics news and stories with our blog at https://medium.com/specialolympics