



## Sibling Support Project

### How to Let Young Siblings Know You Care

We asked over fifty adult brothers and sisters of people with disabilities:

*“When you were younger, what did your parents, family members, and service providers do to make you feel special and let you know they cared?”*

Here’s what they told us.

- ❖ I grew up in a home where everyone was treated equally. Even though I'm sure my sister got special attention, it felt like we were all held to the same standard.
- ❖ I think it's important for parents to acknowledge typically-developing siblings' accomplishments, big AND small, even if it's just with a verbal "well done" or "I'm proud of you. I hope you're proud of yourself too."
- ❖ My mom would lay in bed with me after putting my brother to bed. We would just talk about anything and everything, and those fifteen to thirty minutes of uninterrupted time with her every day put our relationship on the right track.
- ❖ When a sibling helps with a brother or sister who has special needs, small compliments and appreciation go a long way.
- ❖ My sister’s Speech Therapist let me know that I was super important because I was the only one who could really understand my sib's language!
- ❖ My brother’s tutors make an effort to say hello to me, and ask me how things are going.
- ❖ A doctor made sure I was included in conversations, had space for me, and made sure I wasn’t forgotten.

- ❖ My mom and I had “dates” and do something that I wanted to do. I know planning this was sometimes difficult for her, especially if my brother was having a bad day. But she always made it happen one way or another.
- ❖ I am very close with my brother’s service providers. I can talk freely to them and they let me come into their classes when I want to.
- ❖ My mom always listened to and valued my opinions on things that were going on with my brother and was careful to remember and remind people that I was a part of what was going on, too. She made me feel like a part of his life instead of just a bystander
- ❖ It’s nice to know I have value as an individual, not just as “so-and-so’s brother or sister.”
- ❖ Small moments of acknowledgement help you not feel invisible and give validation to difficult feelings.
- ❖ Those who acknowledge siblings make us feel seen. Too often, we feel invisible.
- ❖ Acknowledging sibs’ efforts makes us feel hopeful.
- ❖ It's never that we don't care, or don't want to help, it's wanting to be acknowledged and taken care of, too.
- ❖ The smallest things, even an "I love you" once a day, made me feel valued and loved
- ❖ Even the smallest reassurance can make someone's day.
- ❖ When someone talked, played, or even smiled at me it reminded me I was human.

- ❖ The most important thing for me growing up was having my parents always shower me with love and affection. It helps to hear you are loved and appreciated. It can make up for all the attention your sib might be getting.
- ❖ Involve young sibs in the care of their brother or sister—but not as a main caregiver. They are important family members who need to be included in what will affect them.
- ❖ Young sibs should be acknowledged for their empathy and ability to be in-tune to other people as well as their sibling with special needs.
- ❖ Many younger siblings of disabled kids feel out of place, having to watch out for their older sibling while craving attention themselves. Any praise you offer them can keep them from harboring resentment into adulthood.
- ❖ Give the kids a hug! That's one of the best things you can do. Hugs feel great.
- ❖ There was never any doubt in my mind that my parents saw me as an individual. They made an effort to get to know my friends and support me in my hobbies.
- ❖ My parents made sure to celebrate my sister's and my achievements separately and equally. I celebrated my sister's milestones and it was expected that my sis would celebrate mine.
- ❖ I felt special when others made an effort to find out what *my* interests were and what was going on in my life and talked to me about them.
- ❖ When family members or close family friends talked to me about my life without making my sib a central part of the conversation, I felt like my life mattered and that my problems were worth addressing -- even if they weren't related to my sib.
- ❖ My mom often complemented me on my accomplishments, skills, and spirit—and still does. That helped a lot!
- ❖ I really appreciated when one of my parents, or even a family friend, took time to really focus on what was going on with me--just me--and my life.

- ❖ My parents made me feel special by letting me know that they were proud of my achievements and attending as many of my soccer games and concerts as they could.
- ❖ My mom especially would make time to take me to places that she and I only enjoyed (like the art museum). That was always very special.
- ❖ My sister and I had a wonderful neighbor. Although she had her own children, she always took time to talk to us about what we were up to. I enjoyed art, and my sister enjoyed writing, and she was the one adult in our lives who knew anything about our passions. It's not that she spent a lot of time asking us about us, but it was powerful to have that five minutes a week to have an adult listen to us with such interest.
- ❖ Every night, my mother would always ask me to tell her one thing about my day.
- ❖ When I was a child, my mother made every effort to attend my school functions. It was a big deal to have my mom in the audience cheering just for me. My siblings (all 9 of them!) were not with her.
- ❖ I liked when they acknowledged that I knew as much about my brother as my parents did.
- ❖ I liked people simply inquiring about MY interests and asking how I was doing.
- ❖ When a service provider did something as simple as remember my name and ask me how my day was, it made me feel acknowledged and appreciated.
- ❖ I liked when adults didn't ask me about my sister every time they talked to me.
- ❖ I liked it when teachers treated me like an individual and not an extension of my sibling.
- ❖ A nun at my sister's program once asked me all kinds of questions about me: what I like to do, what my favorite subject was, who was my best friend. Wow! I was about 5 or so and that 10 minutes remains a shining moment for me.

- ❖ When I was in fifth grade, a service provider who frequently visited our home made a point of asking my mom about me: How I was doing in school, if I had friends and activities, how much did I do around the house to help. The service provider didn't ask me these questions, but just her asking my mom about me felt like I was on center stage!
- ❖ Growing up, I was always treated as an individual—that was never questioned. And my parents had similar expectations for the both of us.
- ❖ Our parents were proud that each of us was unique and had our own skills and abilities.
- ❖ My parents made me feel like I was an important part of my family and that I had a roll to play beyond my siblings needs. When they acknowledged me, it was a gift.
- ❖ Having others acknowledge me and show interest in my life made me realize that my life did not need to be defined by my sibling's disability. Indeed, what person should be defined by an illness or disability? Not the person with a disability, and certainly not their typical sibling(s)!
- ❖ I was generally expected to not take up too much space or attention, and I learned to be okay with that. But small kindnesses always made me feel so important. To a little girl, that's everything.
- ❖ My parents made me feel important and like I mattered. It made me feel like I had a little bit of control, whether I did or not, and that I was indeed separate from my brother and had options in the future.
- ❖ My parents let me know I mattered. They made me feel like I could pursue my dreams without feeling selfish. They taught me about love and family. They made me able to focus on my school work, excel as a student and athlete, attend a top university, and ultimately pursue medicine as a profession. Without these gestures and knowing that I mattered, I'm not sure any of this would have been possible.
- ❖ Being treated as my own person, and not as an extension of my sister, was very important to me.

- ❖ When adults, teachers, doctors and care providers talked to me, I felt like a person, not just my sister's little sister. Not just the "other one." I felt seen for me separate from my sister and her diagnosis.
- ❖ When providers greet siblings and talk to them, they feel acknowledged.
- ❖ It helped to know that my parents cared for me as an individual. They saw my strengths and this made life a bit easier during those times when they couldn't be as accessible due to my sister's disability.
- ❖ My parents acknowledge *me*. It wasn't always "me-and-my-sister" or always "my sister." They acknowledge me as a separate and individual person.
- ❖ Growing up, I needed to feel like a separate individual. I can't emphasize that enough. It was confusing being linked to my brother all the time
- ❖ I had two teachers at school who asked about me, who cared how I was doing, who asked if I was getting out enough, if I needed anything. They also asked about my sib--but their focus was on me. They were a great encouragement to me.
- ❖ Don't let a child's life revolve around the disabled sibling. Siblings have lives, personalities and aspirations that they want to talk about.
- ❖ I'm especially grateful that they were equally as "tough" on both of us. Sometimes my desires would be subsumed by my brother's, but occasionally the inverse would be true.
- ❖ My sister's speech pathologist always gave me a lollipop if my sister got one. When I got older, she always took time to talk to me at the end of the session and asked about my life outside of bringing my sister to her office.
- ❖ My folks raised us in a culture of independence, partially because encouraging my sister to exert her independence is such an important thing for us. They also made sure to teach us solid life lessons -- responsibility, managing money, the value of continual learning.

- ❖ My sister and I share a room. My mom and dad always kissed us goodnight.
- ❖ My sib had chores just like the rest of us - I really appreciate that now.
- ❖ My parents wanted my sister to have as much independence as possible and didn't want her to be my responsibility.
- ❖ They never forced me to take any responsibility for her in terms of babysitting or having her play with my friends when they were over.
- ❖ They treated each of our challenges and milestones as equally important within the context of each of our lives.
- ❖ They held us all a high standard--including my disabled sibling, we all had to do our best, be honest, care for others, and serve somebody.
- ❖ After my brother destroyed some of my toys, my parents made a rule he couldn't go in my room and enforced it.
- ❖ We both had chores to do. This made it seem fair.
- ❖ My parents protected my right to privacy.
- ❖ My parents have done a good job of setting up a special needs trust, etc. but the responsibility will still fall on me when they pass away.
- ❖ My dreams were never downplayed or put second to anything.
- ❖ My sister who has Down syndrome was also encouraged to help with cleaning and cooking.

- ❖ I remember my mom telling me that she loved us equally but in different ways. She always said that even though sometimes it appeared that he got more attention than I did, or that he never got in trouble, I was also special.
- ❖ When my parents were preoccupied with my brother, they were always quick to let me know they still loved me.
- ❖ Even though I didn't get as much of my parents' time, it was enough to know that their love was shared equally between my brother and me.
- ❖ I asked my dad a lot of questions about my sister and her future, which he always answered honestly. I appreciated his honesty and willingness to talk about hard things with me.
- ❖ I appreciated my family for creating a plan for my sibling's future that would give me responsibility when I was ready, but not before, and carefully explaining it to me.
- ❖ From the start, my parents set everything up so that in the event of a death my sister was taken care of. I think they did this for their own peace of mind and for my well-being.
- ❖ My parents never made me feel like caring for my brother was my responsibility. I was able to go away to college and "do my own thing" without guilt. Naturally as an adult I am very close to home still and take on some responsibilities, but because of my parents' approach while we were growing up I'm very close with my sib and at times involved in his care with no resentment.
- ❖ My parents have also done an amazing job of planning for my sib's future. They have always included me in the process, asked for my advice and let me know that they value my opinion with it comes to my sib.
- ❖ My mother always said, "Do not bring them into your home when I die. That's too much responsibility and too hard on a marriage. But," she'd say in a stern tone, "listen to me: I DO EXPECT you to make sure they are taken care of. I appreciate both her removing the guilt of not taking direct care of them and yet the firm lesson in the importance of seeing after them.

- ❖ My parents have been very careful to plan out my sister's future financially and practically. They have also said in words that they never wanted my sister to feel like a burden.
- ❖ My parents tried to make sure that when they died my two brothers would be already "taken care of" with a placement of their own. They felt it was important that we have our own lives and my brothers would also.
- ❖ It's important for parents and providers to recognize that children understand more than is thought. You can't always protect them, so please inform them!
- ❖ Talk to the "well" sibling and keep them apprised of the situation, on whatever level they can understand. I hated being left out of the family.
- ❖ My parents gave me creative tools and access to books and let me do my own exploring and learning.
- ❖ My parents never put any pressure on me to follow a particular academic path. They only asked that I try my best and reach my full potential. This helped any pressure I had on "making up" for my sibling, which many siblings may have thought about at times.
- ❖ My parents made it a habit to encourage each of their children - disability or not - to pursue their own interests. We were each allowed to be an individual, without our individuality being sacrificed because of a disability.
- ❖ My parents always made sure I had a good education and had the opportunity to do extracurricular activities. They wanted me to pursue my passions, and they celebrated my accomplishments.
- ❖ My parents wanted me to have a life of my own.
- ❖ My parents definitely supported all of us going to college, having our own careers and lives. My parents did focus on each of us individually as they could.

- ❖ They really pushed me to have a separate life whether it be through sports or other extracurricular events.
- ❖ They wanted me to have time away from my brother to figure out who I am, and what I want.
- ❖ They always told me he wasn't my responsibility and tried to keep me very focused on my own success.
- ❖ My mom spent an enormous amount of time and energy planning for my sibling's future. While she was planning, she would always talk about how important this was for my brother - which it absolutely was. But I realize now the impact this has on me.
- ❖ Overall, my parents worked extremely hard to show they cared. I knew my parents cared about me as an individual, and that made a big difference. Even just investing in my education, caring about my future, and caring about the extracurriculars I was involved in made a huge difference.
- ❖ My dad let me go away to university even though my mother wanted me to stay home. Amazing.
- ❖ They always made an effort to let me know that I had permission to live my own life and supported me no matter what.
- ❖ Mom wanted me to live my own life for myself, for as long as possible. It was an empowering moment. I was far less nervous about moving away and going to college because of that.
- ❖ My dad said that I should live life as long as I possibly can and when the time comes to plan for Lindsey's future, we will cross that bridge together. Knowing that Dad is willing to have inevitable conversations in the future is heartwarming.
- ❖ It was so important that my parents believed in my success and encouraged me to pursue my passions. It helped me believe that I could do great things and that my life was more than my role in the family.

- ❖ It's important for sibs to know that that their families will be okay even if they leave to pursue their own lives. Sibs can feel lots of guilt when their personal desires for school or career or love take them far from home.
- ❖ My parents are very proud of me and have never tried to force me to stay near home, but they often tell me how much they wish I was closer to home. It makes me feel like I am directly responsible for hurting them emotionally with my life decisions. Pursuing higher education or living abroad to gain language skills aren't decisions that should create guilt and regret.
- ❖ Siblings need a place of their own, a space of their own. It's so invasive. It takes all of you. Things that should be private are public. Sibs need safe spaces.
- ❖ My parents were always very clear with me on my sister's condition when I was younger. I liked that because I felt trusted and important.
- ❖ My parents let me help make decisions when I reached a developmental stage where it was appropriate for me to do so.
- ❖ My parents treated me with a great deal of respect and listened to my opinions seriously.
- ❖ Sometimes we'd have a "family conference" when we needed to talk something through to make a good decision. We'd all sit down together, and everyone had a voice.
- ❖ My father laid it all out for me and kept me informed about my brother's illness. He treated me as an intellectual being with the capacity to understand.
- ❖ My parents withheld some information about the severity of my brother's situation. As a result, I didn't treat it, or them, with the sensitivity it deserved. I realize now that they were just trying to protect me. However, I think it is important to give siblings as much information as is developmentally appropriate, so they feel included.

- ❖ My mother used to put little notes in my lunch box. But both my parents always devoted time to me especially when I got to my teenage years. We spent a lot of time talking. They always tell me they love me and always give me meaningful advice.
- ❖ My parents would always make time for me to go out with just them when I was younger.
- ❖ I also really appreciated when my parents gave me time alone with my friends, without my brother around.
- ❖ My dad would read a chapter of a book with me every night before bed. It was never a rule that my sister wasn't allowed in the room--but he made sure she wasn't.
- ❖ My mom and my aunt would sometimes take me out shopping—just the three of us. They'd give me lots of choices because when my sister was around, we had much less flexibility.
- ❖ My mom would take me out for "coffee" from time to time--just the two of us. That meant a lot.
- ❖ It's really important to get some alone time with parents.
- ❖ Any time I got alone with my parents was awesome--going grocery shopping with my mom and fishing with my dad, whatever!
- ❖ I appreciated when family members or people from church asked me about my life, how I was, how school was going before they asked me about my brother.
- ❖ My parents also made an effort to spend some time just with me. My dad coached my soccer team - and I knew that was just for me, not for my sibling with a disability.

- ❖ I had special one-on-one activities with each parent. My parents also did not let my brother mess with my stuff and had strict rules about whether he could go in my room or touch my things.
- ❖ My mom made sure that once a month we had one day for just the two of us. We would go out to breakfast, then sometimes just run errands all day. I just enjoyed spending time with her one-on-one.
- ❖ The other thing we did was at night when she cooked dinner. I would sit in the kitchen and talk with her about everything, anything and nothing.
- ❖ Our grandmother spent equal time and money on each grandkid. We each spent one week with her every summer. She you feel like you were the only important person in the world.
- ❖ During the longest period that my sister was hospitalized, I was living with just my dad while my mom and my sister stayed at the hospital, and my dad and I visited every weekend. But during the week of my birthday, my mom and dad switched places and I got to spend a special week with her.
- ❖ My parents would arrange sleepovers and outings for me with those other relatives and I remember loving them.
- ❖ Also growing up with my sib, it was hard for us to go on some of the vacations that other families would go on (Disney World, far road trips, etc.) so I would take those trips with my grandparents.
- ❖ My dad would take me to sports events. It was our together time away from the family.
- ❖ Mom would leave me notes, sometimes hand-made cards, expressing how dear I am to her. They always made me feel special.
- ❖ Both of my parents made time for me. My mom was my Girl Scout leader and my dad shared his love of gardening with me. They also made sure to celebrate any of my accomplishments and made sure my birthday was a big deal. In a house with lots of kids, I'm sure that was not easy!

- ❖ Getting respite was a lifesaver. It meant that we could have mother-daughter time.
- ❖ One of my parents would always read me a bedtime story. It was a very sacred ritual for us. If for any reason my sibling or something else interfered with story time, I always got two stories the next evening.
- ❖ My brother had a tutor who would come to work with him once a week. She would always bring her laptop with a couple of different computer games I could play during the hour she spent working with him.
- ❖ One of my grade six teachers sensed my struggle. I am grateful to her and am still in touch with her.
- ❖ Mrs. Betty was a resource teacher at my elementary school. When my mom came to school to talk to her about my sister, Mrs. Betty would always walk over and hand me a book. A simple gesture but a big impact.
- ❖ My sister's longest-ever hospital stay included the week of my birthday. The Child Life workers at the hospital surprised me with a big basket of really cool presents. I'm pretty sure I cried with joy. Without a doubt, it was one of the moments in my life when I felt most appreciated.
- ❖ The OT and PT department of the therapy center where my brother received services would always let me play with the toys at the end of the session while they talked to my mom.
- ❖ My parents always listened to my dreams and took time to support them. My dad always was able to find time, even if we had to schedule a meeting, to talk to me about my plans for college, finances, moving, etc.
- ❖ My mother made sure to let me know that I didn't have to make up for my sister's disability. She used respite and even took me to a sibling group.
- ❖ Time by myself with my parents is invaluable just to get us together out of the house.

- ❖ It is good to know that you are as much a part of the family as your sibling--that your parents acknowledge you and care for you, and to let you know that if you have any problems you can talk to them. It's not all about the disabled person.
- ❖ Having alone time with one of my parents allowed me to have their undivided attention. Even though it didn't happen very often, it made me feel very special.
- ❖ It is important to know that the lack of attention is not because you aren't loved as much. Although saying it is helpful, actions always speak louder than words. We just want parents to make time for us and feel included in the family.
- ❖ Getting one-on-one time with one of my parents allowed me to get some needed attention. In the end, it helped foster and maintain my relationships with my parents.
- ❖ My mom always gives me that uninterrupted attention and she never judges, she just listens and understands.
- ❖ I think the act of asking how my day was is helpful because it shows that I am noticed and gives me attention.
- ❖ Even something as simple as an hour and a half at an ice cream parlor can make a huge difference to a typical sib. Years later, I can still remember that delicious bowl of peppermint ice cream!
- ❖ Speak the truth to children don't ignore one's needs for another
- ❖ Have one or two close family member or friends demonstrate greater interest in the sibling than the disabled child. This person would make the sibling feel like they are the "special one" to at least one person.
- ❖ My mom discovered the SibTeen Facebook page for me and it's been so great.
- ❖ My mom found a Sibshop just for me when I was really young.

- ❖ Probably the most special thing that my parents did was sign me up for Sibshops. This gave me a safe place to talk about my sib, positive or not.
- ❖ My parents sent me to Sibshops and made a point of asking me how my day was and conversing with me.
- ❖ When I was younger my mom took me to a sibling panel where I spoke to younger kids about what it was like to be a sibling of a person with a disability. It really showed me that I wasn't alone.
- ❖ Our pediatrician spent as much time on my concerns as she did on my sister's concerns. I always felt heard by her.
- ❖ My parents let us know they loved us equally, valued each of our interests equally, were aware of the strain that dealing with disability caused, and tried to address it. Their efforts also let me know that they were open to hearing my views, questions, and problems.
- ❖ My parents allowed my sister's and my relationship to develop organically, without force or facilitation, and they enabled us to interact as sisters, not as caregiver/care recipient.
- ❖ Meeting other sibs helps so much! It means the world to us to make new friends who won't judge our siblings—or us!
- ❖ It was good to meet others who have a sibling with a disability. They provided insight into what my life is like on a daily basis.
- ❖ No one asked me what it was like to have a sibling with a disability until I was 17. Being asked to share my story gave me the chance to process that narrative in a way that helped me better understand who I was in relation to my sister.
- ❖ Young siblings need to know that it is okay not to be perfect and that they are just as important as their disabled sibling. Often, we feel alone because we have no one else to talk to about our feelings. The people who we want to talk to -- our parents -- are occupied with our disabled sibling.

- ❖ Having open conversations about the challenges of having a sibling with a disability is a gift that a lot of siblings are never given.
- ❖ It's important to offer support to siblings - through Sibshops or other groups where sibs can meet other sibs. It's a place for acknowledging the difficulties, providing an atmosphere where it is safe for all to voice their opinions and feelings, even when they are difficult.
- ❖ Protecting siblings from physical or verbal aggressions (if the affected sibling has these) is really important too.
- ❖ Schools can connect students who are sibs with other sibs and make counselling a more available.
- ❖ Teach young sibs how to tell their friends about their sib.
- ❖ Teach sibs self-defense if their sib tends to be violent.
- ❖ Have respite services so that the sib and family can have a break every couple of months.
- ❖ Let sibs be more involved in the choices affecting them.
- ❖ I want young sibs to have a "safe place" to express positive and negative feelings about their family. I want them to have people in their life who can give them regular, quality attention for themselves.
- ❖ Young sibs can overcome obstacles when they know they are valued, they are acknowledged, and they are cared for.