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Siblings of Disabled Have Their Own Troubles

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When he was growing up in Oregon, Graham Seaton found it virtually impossible to bring children home from school to play.

"I knew there was something wrong with my place," he recalled. "But I didn't know how to explain what that was."

He knew that he would have to tell his friends why they could play only in his bedroom — and only with the door locked. And that, ultimately, he would have to explain what was "wrong" with his older brother Burleigh, who is profoundly autistic.

"I just didn't have the words," he said.

Now 30, Mr. Seaton said he realized that as a child, he felt he could not ask his parents for those words.

"I was so aware I couldn't make a big deal with my family," he said. "My parents already had enough on their hands."

An estimated seven million "typically developing" American children have siblings with disabilities, according to the Arc of the United States, a leading advocacy group for the mentally retarded. Those children face many of the same challenges — and joys — as their parents, but they also face other problems. Some resent the extra demands placed on them at an early age by their disabled siblings, and many feel neglected by their often overburdened parents.

Some children say they fear "catching" their siblings' disabilities. Others may wish that they, too, were disabled, so that they could get all the attention their siblings do. And many suffer embarrassment about their siblings' inappropriate behavior or abnormal appearance, and then feel guilty about it.

These are difficult emotions for children to struggle with, and Don Meyer, director of the Arc's sibling support project, says the needs of siblings like Mr. Seaton are often overlooked. Most assistance organizations and support groups are intended for disabled children themselves or for their parents.

"These brothers and sisters will likely have the longest-lasting relationships of anyone, relationships easily in excess of 65 years," Mr. Meyer said. "They should be remembered at every turn."

Still, many siblings welcome the early maturity and responsibility that come with having a disabled brother or sister. They are often well versed in the details of their siblings' disabilities, and they take pride in being able to explain them in sophisticated ways. For example, Hannah, 16, of Dearborn, Mich., who did not want her last name used out of concerns for her privacy, said she related better to adults than to children her age because of having to cope with her brother Ian's autism.

But that maturity does not inoculate her from embarrassment about Ian's outbursts, particularly during church services.

"Sometimes he'll kind of start making noises, and then sometimes he'll kick and flail his arms, or he'll start rocking and crying," Hannah said. "My mother will take him outside, but it's still, like, okayyyyy. ..."

Suzanne Ripley, who has two sons with cerebral palsy, says that a child's disability can embarrass parents, too, but that embarrassment can be more acute for siblings, especially those in the throes of adolescent conformity. Young siblings are also prone to teasing from other children, who do not have the social inhibitions of adults.

But Ms. Ripley, the director of the National Dissemination Center for Children With Disabilities, based in Washington, notes that adults can often be just as rude.

"People tend to be uncomfortable with anyone who's different, so they look for a second and then look away," Ms. Ripley said. "Imagine how that would make you feel" as a child.

Parents like Ms. Ripley are likely to seek comfort through talking with others about their conflicting emotions. But children may not have the sophistication to do so or they may feel guilty about acknowledging any negative feelings they have.

Hannah, for example, says she loves her 13-year-old brother and feels terrible about her reactions to his outbursts.

"I know it's not his fault and that's the way he is, and so I shouldn't really be embarrassed, but sometimes I am," she said.

But she said she did not discuss those feelings with her parents.

"They'd get that, 'Oh well, you can deal with it' kind of attitude," she said. "I know they would listen, but they would get defensive."

Ally Cirelli, a 9-year-old in Towson, Md., whose sister is developmentally disabled, says the biggest complaint she hears from her peers is that the disabled siblings get all the attention.

Some are so jealous of their siblings that they wish they had their own disability, and the special treatment that comes with it, she said. But Ally, too, avoids talking to her parents about her feelings. And she is quick to backpedal when she does talk about it, insisting that her sister, Katie, 8, does not embarrass her "all that often," and that she is "really fun" to play with.

Mr. Meyer, of the Arc, says children need a place where they can openly discuss these concerns and emotions. To fill this gap, he started the sibling support project, which is based in Seattle and provides information and holds discussion groups for children around the country. In 2005, Mr. Meyer also published "The Sibling Slam Book: What It's Really Like to Have a Brother or Sister With Special Needs," a collection of candid remarks by 80 children.

Mr. Meyer said that when asked about the most embarrassing moment of their lives, few of the children cited anything having to do with their disabled siblings. Instead, most recounted the usual teenage humiliations: problems in romantic relationships or dealing with parents.

And that, Mr. Meyer says, underscores an important point: "When I talk to parents about embarrassment (about disabled siblings), I ask them to keep in mind that it's an age-related condition," he said. "That's the good news, that a lot of that seems to be resolved by even their late teens."

The work of disability advocates and the mainstreaming of children with special needs in schools and in the wider society has fostered more awareness of — and less discomfort with — disabilities.

Ms. Ripley, for her part, says she has noticed a change in public attitudes, especially when she is struggling to maneuver with her sons in public places.

"I'm finding that people are more and more helpful," she said. "That didn't used to happen."