

Advice on how to support siblings

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Although little research has been done, recent studies suggest that brothers and sisters of children with Down syndrome are affected more positively than negatively, developing kindness, empathy and a matured respect for diversity. An article in the August 15 issue of the American Journal of Medical Genetics (published online July 5) offers eight recommendations for parents on how best to support these siblings.

The authors -- Brian Skotko, M.D., M.P.P., a physician at Children's Hospital Boston whose sister has Down syndrome, and Susan Levine, a social worker with Family Resource Associates, Inc. (Shrewsbury, NJ) -- draw on 33 years' combined experience running sibling support groups. (Workshops exclusively for brothers and sisters of children with Down syndrome were first established at Children's Hospital Boston in the 1970s.)

Their recommendations are:

- **Be open and honest**, explaining Down syndrome as early as possible. Brothers and sisters often prefer to have not one big conversation, but a continuing dialogue as new questions and concerns emerge. If children shy away from bringing up the topic, parents can help by periodically asking if they have any questions. Providing information may prevent unnecessary confusion and worrying.
- **Allow siblings to express negative feelings**. Like siblings of any child, brothers and sisters of a child with Down syndrome will experience frustrations and negative emotions; parents should know these feelings are generally temporary and allow the space to express them.
- **Recognize difficult moments** that siblings may experience. Parents can help prepare brothers and sisters to handle embarrassing or upsetting situations, such as seeing people stare at or make fun of their sibling. They should honor a child's need to establish distance from their sibling with a disability when out in public, especially during the preteen years when the need to "fit in" peaks.
- **Limit care giving responsibilities**. While these duties make siblings feel helpful and capable, most siblings want them to be limited. Siblings often comment that they don't always want to be available for babysitting. Parents should be encouraged to remember that siblings are children first, and not substitute parents. Limiting responsibilities will help avoid feelings of pressure, resentment and guilt.
- **Recognize the uniqueness of each child in the family**. Brothers and sisters are quick to point out that they, too, need attention and acknowledgement of their accomplishments. Encourage children to reach their full potential, but without feeling the need to "compensate" for their sibling with Down syndrome.
- **Be fair**. Siblings often mention that parents allow the child with Down syndrome to "get away with more," and say that limits for acceptable behavior should be set and applied consistently. Parents should also allow brothers and sisters to have their own friends and interests, separate from their siblings and without guilt.
- **Take advantage of supports for siblings**. Brothers and sisters are often relieved to talk to peers who share their experience, and to voice both positive and negative feelings. There are many books for children and teens about sibling and disability issues; the National Down Syndrome Congress has a list: www.ndsccenter.org/resources/bibliography06.pdf.
- **Parents need support, too**. In workshops, many siblings comment that their parents should talk with other parents of children with Down syndrome, and learn to "relax more and worry less." When parents are coping effectively, their children benefit, too.

Skotko and Levine provide lists of "frequently asked questions" that siblings may pose -- ranging from medical questions ("How long is their life expectancy?") to philosophical questions ("Why does my brother have Down syndrome?") to questions about dealing with difficult moments ("How do you deal with people who use the word 'retard'?"). "The brothers and sisters we've met experience both positive and negative feelings in their sibling relationships, but positive emotions usually outweigh the negative ones," says Skotko. "Many find camaraderie and helpful information in sibling support groups."

Source: Children's Hospital of Boston