Plan Early to Transition Down Syndrome Teens

BY DOUG BRUNK
San Diego Bureau

San Diego — When it comes to helping adolescents with Down syndrome and other cognitive disabilities transition to adult services, the earlier the better, William I. Cohen, M.D., advised at the annual meeting of the Society for Developmental and Behavioral Pediatrics.

Such an approach "makes perfect sense at one level, and at another level it's very hard to do, because some families don't start looking ahead early enough," said Dr. Cohen, director of the Down Syndrome Center of Western Pennsylvania, Pittsburgh.

"When you receive a diagnosis of a disorder that is associated with cognitive disabilities, the crushing blow is knowing that forever and ever your child is going to be different. And [parents] begin to think about all of these things in the future. That is what I think terrifies them."

He pointed out that needs of the adolescent and the family may exist on different levels. For example, the adolescent may want to live independently or in a group home when he or she turns 18, while the family may feel obligated to care for the child at home for the foreseeable future.

"Identify key individuals who can assist in this process and start with the end in mind," he recommended. "Decide where you want to end up so you can begin early on" heading toward that goal as opposed to it all of a sudden springing up on you: All of a sudden the child is 13-18 years of age with all of these needs.

Dr. Cohen called the transition to adult services "a journey, not a destination. It is a continuous and dynamic process and is variable depending on the individual, family, community, and state in which they live, and the financial and emotional resources [of the family] as well."

He and his associate, Sheila A. Cannon, offered the following tips on making transition planning run as smoothly as possible:

► **Identify the educational needs.** By the time the child turns 14 years of age, families should identify a course of study that matches the teen's interests and goals, and consider the need for supplemental services such as occupational therapy, speech/language therapy, and physical therapy. Then they should identify community resources and interagency responsibilities.

By law, all people with cognitive disabilities qualify for school services through age 21. Some remain in high school past age 18 to receive such services, but others choose to graduate with their peers and move on to other educational programs in the community that prepare them for employment, money management, and independent living skills.

Ms. Cannon's daughter, who has Down syndrome, was adamant about not going back to high school after graduating. "She took a certificate and opted for a program that is sponsored by another organization and provides vocational training on a college campus," said Ms. Cannon, coordinator at the Down Syndrome Center of Western Pennsylvania. "So she is with her same-age peers" and the school district provides transportation.

The transition plan should encourage students to take courses in nutrition or fitness. Courses that address sexuality and self-esteem also are important.

She advises adolescents with cognitive disabilities to undergo a vocational assessment at their local offices of vocational rehabilitation. That way, the local agencies have them on their radar and may be able to match an employment need based on their interests and skill levels.

"The transition plan should encourage students to take courses or have some type of planning in nutrition or fitness," Ms. Cannon said, adding that her daughter attends a behavioral health class at a local college once a week.

Courses that address sexuality and self-esteem also are important. "It's important to have those options available for kids to learn about appropriate social distance and appropriate social interaction," she said.

► **Help the family identify an appropriate primary care physician.** In the shift from pediatrician/family physician to internist or another physician, the real dilemma for patients and their families is the loss of their medical home, Dr. Cohen said.

"Families will ask, 'Who can be my child's primary care physician?' We ask the parents, 'Could it be your own physician, or someone you have a relationship with and would be willing to take on that role?' "

A key quality for the new physician is a willingness to partner with the family and other clinicians on behalf of the adolescent. "Even if they don't know much about the particular condition, their willingness to partner with the family and use available resources is most important," Dr. Cohen said.

The new physician must be able to address chronic health problems, understand specific medical vulnerabilities, manage acute illness, and identify adult specialists.

If all else fails in the search for a new physician, have the family call its health insurer or managed care organization, Ms. Cannon said. "Often they have a special needs case manager that the family can connect with. They can give them a list of physicians who take that insurance."

Dr. Cohen noted that young adults with Down syndrome who show signs of depression are often misinterpreted as having early Alzheimer's disease.

"We've known for quite some time that individuals with cognitive disabilities get depressed the same as other individuals for the same kinds of things, such as siblings moving on, loss of a caregiver or a roommate, or death of a parent," he explained.

"We have seen a number of young adults who have developed some significant reactions to the loss of support, in terms of depression. They find themselves foundering."

Obsessive-compulsive disorder also may emerge as a coping mechanism.

► **Talk about living arrangements.** Ms. Cannon pointed out that most opportunities for independent living or community living arrangements for young adults with cognitive disabilities are handled through state offices of mental retardation.

In Pennsylvania, for example, candidates for housing must prove they have a cognitive disability before the age of 21. Then they're put on a waiting list.

"If families don't do a reassessment of need every year, they can be dropped from the system," Ms. Cannon cautioned.

She called the transition to adult services "as stressful and as unknown as when parents got the initial diagnosis for the child. It's really important to do educational planning and health care planning, to do as much as we can to help these families know what's really out there."

For resources on transition planning, visit the "tools and solutions" section of the Healthy and Ready to Work National Center, a federally funded clearinghouse of information, at www.hrtw.org. ■

How to Protect Development in Down Syndrome Patients

BY MICHELE G. SULLIVAN
Mid-Atlantic Bureau

Washington — Recognizing and acting on areas of medical vulnerability can prevent secondary developmental disability in children with Down syndrome.

"For most parents, Down syndrome already implies that the child will not develop as they had expected," William I. Cohen, M.D., said at the annual meeting of the American Academy of Pediatrics. "But it's possible to optimize their learning by early detection of issues that have developmental consequences."

Problems with hearing, vision, sleep, and hypothyroidism are most likely to affect learning, said Dr. Cohen, director of the Down Syndrome Center of Western Pennsylvania, Pittsburgh.

The midfacial hypoplasia typically seen in Down syndrome is the root of many ear, nose, and throat problems, he said. "All the midfacial anatomy is smaller, and this contributes to the numerous ENT infections we see in these kids."

Purulent nasopharyngitis and sinusitis are common, as are repeated otitis media infections. These problems can result in hearing loss if not aggressively managed, he said. "Hearing loss can be due to fluid in the middle ear getting trapped because of the really small eustachian tubes, which may also have an abnormal orientation."

Sometimes the ear canal is so small that it's not possible to visualize the tympanic membrane. This warrants an immediate referral to an otolaryngologist.

"These children need aggressive medical management. If this fails, they may need ventilating tubes. It is common for children with DS to need tubes, and some require multiple sets. The risk of hearing loss is really increased because of the anatomy," he said.

All Down syndrome children should have a behavioral hearing screen every 6 months until they are 3 years old, and annually thereafter.

A smaller oropharynx, with normal-sized adenoidal and tonsillar tissues, makes snoring and sleep apnea a problem as well; a tonsillectomy and adenoidectomy might be indicated. Sleep disturbances probably also arise from a decrease in REM sleep, which is common in children with Down syndrome.

The trachea and upper airway also are narrower in these children, predisposing them to croup. "Much of this is misdiagnosed, though, and is actually laryngeal inflammation caused by gastroesophageal reflux disease," he said.

Down syndrome–related ocular problems also can impair learning, Dr. Cohen said. "All of these children could be referred for an ophthalmologic evaluation by the time they are 6 months old."

The dense congenital cataracts sometimes seen in Down syndrome infants are obvious at birth, but other problems can be present as well. Strabismus is frequent, and refractive errors occur in up to 50% of these children.

Congenital hypothyroidism is about 27 times more common among Down syndrome children, though it is still rare. In general, 20% of children with DS may develop hypothyroidism. The etiology is usually autoimmune, most often Hashimoto's disease. Newborn screening will pick up congenital hypothyroidism, but children should have repeat measures of thyroid-stimulating hormone and free T_4 at their 6-month and 1-year checkups. The measures should be performed annually thereafter, he said.

Dr. Cohen also recommends using both normal and Down syndrome–specific growth charts for these children. "The Down syndrome charts will pick up growth problems, but since they're adjusted for weight and height, they might not pick up weight problems like a regular growth chart will." ■