

For the Cognitively Impaired, Start Planning Early

Identify key people who can help patients make the transition from adolescence to adulthood.

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, medical director of the Down Syndrome Center of Western Pennsylvania at Children’s Hospital of 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.

She advises adolescents with cognitive disabilities to undergo a vocational assessment at their local offices of vocational rehabilitation. That way, the local agencies 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 physicians?’ 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 said. “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 floundering.”

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. ■

Home Visitors May Need More Training to Spot Delays

BY MICHELE G. SULLIVAN
Mid-Atlantic Bureau

A home visit program designed to identify early childhood language delays not only failed to spot most delayed children, but also failed to refer the vast majority of identified children for further evaluation or intervention.

The results suggest that the home visitors didn’t get enough training to properly screen children and that the visitors lacked the skills necessary to communicate concerns about developmental delays to parents, according to Tracy M. King, M.D., and colleagues (J. Dev. Behav. Pediatr. 2005;26:293-303).

“This study argues for prudence in the ongoing proliferation of home visiting programs and for caution in setting expectations regarding child development outcomes,” said Dr. King of Johns Hopkins University School of Medicine, Baltimore, and her coinvestigators.

The researchers compared language delay identification rates for children enrolled in the Hawaii Healthy Start Program (304) with rates in a group of

control children (209). All of the children were at high risk of developmental delay, child abuse, or neglect.

The Hawaii Healthy Start Program (HHSP) provides a regular home visitor, who teaches parents about child development, models good parental behavior, and links parents to a medical provider. The visitor also performs childhood developmental testing—including language testing—when the child is 3 years old. The control group did not receive any home visitation services.

The home visitors identified only 24% of children with severe language delay. Parents and primary care providers in the HHSP group each identified 31% of such children, while parents in the control group identified almost twice as many (56%).

The fact that parents in the control group had an increased identification rate raises the concern that the home visitors actually interfered with identification. This

could be because they lack sufficient training and are giving parents false reassurance of the child’s language development.

Among children with any language delay, home visits identified 17%. Parents and primary care providers also did poorly in this group, identifying 26% and 24%, respectively. Parents in the control

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group identified 20% of children with any language delay and primary care providers, 25%.

Particularly concerning were the low referral rates after children were identified, the investigators said. Among the 72 children identified as having delays, only 2 were referred to their primary care provider, and none were referred to local early intervention programs.

Poor parental identification rates could be related to the high-risk communities in which the families lived, the investigators said. “It may be that language delays have become so prevalent in certain at-risk

communities that it is no longer possible for parents to make accurate assessments of their child’s development based on comparisons with the child’s peers.”

Poor home visitor and medical provider identification rates are probably due to inadequate training in child development.

In an accompanying editorial, Shirley Russ, M.D., and Neal Halfon, M.D., said identification rates could be improved by using trained nurses as home visitors. Similar programs employing nurses have higher family retention rates and much better identification and referral rates (J. Dev. Behav. Pediatr. 2005;26:304-5).

“Professional nurses would be more likely to have knowledge of early childhood systems and resources in the community and would also have had more training in communicating about health and development issues to parents,” said Dr. Russ and Dr. Halfon of the University of California, Los Angeles.

Dr. King and colleagues replied in a second commentary that unfortunately visiting nurse programs are costly and difficult to staff in areas such as Hawaii (J. Dev. Behav. Pediatr. 2005;26:307). ■