
Coming of Age in the 1990s: People with Down Syndrome

by Donna M. Rosenthal

During the decade of the 1980s, our society waked up to the fact that individuals with Down syndrome have the ability to make significant contributions to their community. With this appreciation, we began to understand the importance of integrating people with this genetic disorder into community life.

There are more than 250,000 people in the United States today with Down syndrome. In every 800 to 1,000 births a child with this anomaly is born. Because for many years it was believed that the functional level of a person with Down syndrome was very low, institutionalization often resulted. With the advent of antibiotics and medical advances came improvements in the physical health and life span of people with Down syndrome. The struggle to provide new and appropriate opportunities for education, socialization, employment, independent living, and health care began. During the 1980s this effort expanded dramatically as research indicated that people with Down syndrome have I.Q.'s in the mild to moderately retarded range, and are able to function in the community. It became evident that, like the general population, people with Down syndrome have individual personalities, strengths and weaknesses, talents and abilities. Recognizing this fact, we find that it has become our responsibility to provide new avenues for personal growth and to open doors for participation to people with Down syndrome.

Nowhere is this more visible than in the early intervention programs available to all children with Down syndrome from birth to age five. Because children with Down syndrome develop at a slower pace than do other children, these programs help accelerate motor coordination and socialization, thereby preparing them for entry into school.

Once the children reach first grade, several possibilities are now offered. In most school systems the children are placed in special education programs

and mainstreamed for meals, gym, and assembly. Opportunities are expanding for academically eligible students to participate in regular classes. The availability of choice often depends not only on the child's academic abilities, but also

Like each of us, people with Down syndrome have distinct personalities and talents. We must learn to welcome them into our communities and open up new opportunities for meaningful work and friendship.

on the school administration and resources, plus the parents' involvement.

As we enter the decade of the 1990s, educational choices for children with Down syndrome will widen. Enhanced options will result from (1) research into the learning processes of children with Down syndrome; (2) increased awareness by educators about the abilities of children with Down syndrome; (3) active parent involvement in planning their child's education. The 1990s will focus on the teenage years and early adulthood, a critical stage in every person's development. We are only now just beginning to learn about this stage.

Fortunately, there are several excellent role models who are leading the way. Most prominent of all is Christopher Burke, the young adult with Down syndrome who has become the star of the Warner Brothers/ABC television series, "Life Goes On." Michael Braverman, the show's creator, brought before the public an accurate portrayal of a young person with Down syndrome and, as a result, this program has been instrumental in changing public awareness and opinion about people with Down syndrome. Chris Burke's parents were

pioneers, moving in uncharted directions while raising their son. To provide him with a quality education, they sent him to boarding school in Pennsylvania. Searching for employment opportunities after his graduation, the family found a wonderful job for Chris as an elevator operator in a New York school. However, they recognized their son's interest in being an actor — a somewhat unrealistic goal they thought — and encouraged him. The rest is history. Now Chris portrays a teenager with Down syndrome in a working class family. On the show he meets new challenges weekly, some of which he successfully overcomes and others which overcome him, just like real life.

What can teenagers with Down syndrome look forward to? What problems do they face? What are realistic goals and expectations for the young adult with Down syndrome? What can community people and organizations contribute? These questions all need to be addressed, but for now not all have answers.

Let's look at education. It is important for teenagers with Down syndrome to interact with other teenagers in a variety of school settings, not just during lunch or assembly. This can include participating in regular academic classes and in school activities such as class trips. Integration is important because it enables the person with Down syndrome to strengthen social as well as educational skills, and encourages teenagers in the regular classroom to establish face-to-face relationships with people different from themselves. The more interaction there is, the greater the understanding — not sympathy — understanding. And the more understanding there is, the greater the acceptance.

It is equally important to solidify relationships with peers who have a developmental disability. Ultimately, social relationships such as dating and marriage will probably be strongest among people with related disabilities because of comfort, caring, and understanding, as well as attraction.

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Sexuality for a teenager or young adult with Down syndrome is not unlike sexuality in any person. However, it is important to point out that since people with Down syndrome develop more slowly, they will usually reach this phase at an older age than other teenagers. Regardless of when this happens, the experiences and feelings are the same. The desire to experiment is great, rejection is painful, and love is romanticized. Teenagers with Down syndrome are vulnerable and should be treated with the same understanding and respect as other teenagers. One purpose of sexual education is to empower youngsters to protect themselves from unwelcome advances; this is especially important for a teenager who has a developmental disability.

Opportunities to participate in social events, dances or parties are important. Teenagers with Down syndrome want to be invited and their peers should be encouraged to include them.

Just as independence is a key goal for all teenagers, it is vital that teens with Down syndrome learn to function independently. And although this requires attentive support and guidance, families, friends, and professionals should not over-protect teens with Down syndrome. Too much "helpfulness" is often counter-productive. Riding the bus, traveling on errands, shopping for personal and household items, grooming, going to dances, movies, and sporting events, spending the weekend away from home — all need to be learned and can be learned especially well when each family member does his or her share toward fostering independence.

Employment is necessary for self-

Young adults with Down syndrome share the same experiences and feelings about sexuality as do all teenagers, so it is important to respect their dignity and understand their vulnerability.

esteem as well as for purchasing power. People with Down syndrome can perform very well, but (like everyone) need support and training. Preparation for employment should begin in the early teenage years. Many opportunities exist in the hotel industry, manufacturing plants, fast food restaurants, and local stores. People with Down syndrome are

being hired for a variety of jobs, including food preparation, assembly line work, sales, etc. Persons with Down syndrome bring many wonderful contributions to the job - a pleasing personality and gregariousness, willingness to do a repetitive job and do it well, reliability and responsibility in carrying out a job. Like everyone else, people with Down syndrome want to be rewarded, promoted, supported, and challenged. They want to feel good about the job they are doing and proud of their affiliation. That is certainly not different from any other employee's feelings. Employers need to learn more about people with Down syndrome so that they can offer appropriate employment opportunities. Young adults with Down syndrome can fill many unmet needs in the working world, but employers must be receptive to this concept before it can be successful. Not every job is the right job. Not every job works out. But many jobs are the right jobs.

If socialization, education, and employment are encouraged, so too must independent living. Too often neighborhood residents have fought the establishment of group homes and other living arrangements. Their fears are usually tied to old myths and stereotypes. But we're not talking about dangerous criminals, we're talking about people who contribute to our society. People with Down syndrome have every right to live among people with whom they interact. Some supervision and support are needed in choosing and maintaining a living arrangement, but this assistance may change over time. Creative housing environments are being explored. A cluster of apartments with a supervisor is one model gaining popularity. A house with six or seven young adults and a support person is another variation. And of course there is the popular group home residence. Like everything else, there need to be options. No one arrangement is the answer.

As some of those with Down syndrome begin to marry, new questions arise. For example, will there be children? Most parents are very uncomfortable about this question. Until recently it was believed that males with Down syndrome could not father a child. This has been proved wrong. It is currently believed that a woman with Down syndrome will have a 50 percent chance of having a child with Down syndrome. Will these young adults be able to care for and bring up a child? What supports will be needed? These questions will certainly be addressed during this decade.

Is there adequate health care for teen-

agers and adults with Down syndrome? Today we know that people with Down syndrome may live into their fifties and sixties, and with this longer life span comes an increased need to learn about their medical care in adulthood. Few doctors are specifically knowledgeable about the complexities and recent ad-

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vances in treating teenagers and adults with Down syndrome. But this is changing quickly as young people living in the community grow into adulthood.

Acquiring health insurance for individuals with Down syndrome remains difficult. Insurance companies tend to reject applications for a person with Down syndrome, and families struggle to pay medical bills for ailments routinely covered for other people. Solutions to this problem need to be found in the 1990s.

With the publicity about the link between Alzheimer's disease and Down syndrome, many people have jumped to the conclusion that every person with Down syndrome will suffer the dementia associated with Alzheimer's. This is not true. It is estimated that approximately 25 percent of adults over age 35 with Down syndrome will suffer from this illness. However, for that group, which is affected at an earlier age than others with Alzheimer's disease, resources need to be made available for treatment and care. At the same time it is imperative to continue research that will find the cause for this debilitating illness.

Research to understand aging in people with Down syndrome is in its infancy. As the care giver grows older and the person with Down syndrome ages, new problems will arise. Because most parents assume they will outlive their child, little preparation is made for their child's finances, living arrangements, activities, and care once the parents have died. Professionals in the aging and disability fields are beginning to explore how to make aging a positive experience

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for the person with Down syndrome and his or her family. What resources, programs, and services do they need to continue functioning actively in the community? Who should do the planning and provide the services? What is the role of siblings and other concerned individuals? All these questions need to be addressed.

Individuals with Down syndrome have every right to live in neighborhoods among people with whom they work and interact.

Relevant to all these issues is basic research into key questions about Down syndrome. Medical research into treatments for leukemia, respiratory problems, heart defects, and other illnesses that particularly affect people with Down syndrome must be continued. Behavioral research which looks at speech, language, memory, and motor coordination should expand. Social science research which focuses on employment, education, socialization, and living arrangements is essential. Advancing knowledge about these important issues will open up significant new possibilities for people with Down syndrome.

The 1990s will offer many exciting opportunities for people with Down syndrome. Pioneering parents will encounter new challenges as they strive to provide the widest possible choices for their children. As people with Down syndrome make strides toward achievement, professionals must continue to explore new options in delivery of services, education and training, and health care.

In the year 2000 we will look back at the 1990s as the time when people with Down syndrome moved forward to take on meaningful roles as teenagers and adults in our society.

Now is the time to do research and planning so that people with Down syndrome can branch out toward new directions in our society.

Aunt Jewell and Sammie

by Julie Heide

Good afternoon Principal Tompkins, ladies and gentlemen of the PTA, boys and girls. As the principal told you, I am Samantha Eckhardt. I am very pleased to return to Price Elementary School to receive this citizenship award and to tell you about my citizenship project. I attend Valley Middle School as a seventh grader. Middle school is pretty cool when you're in the seventh grade but sixth grade stinks. Well, anyway, back to my project. . .

It all started when I went to visit my Aunt Jewell last summer. Now here's a picture of her sitting next to where she gets her mail. Her box is number F-110. It's a shame she doesn't have number F-109 or 108 or something, because she can't reach number F-110 very well. She can get the key in but sometimes she can't reach all the mail if it's sitting at the back of the box.

She's not really my aunt. Technically she's my great aunt, because she was married to my father's uncle. She has my same last name, and she likes it when I call her Aunt Jewell. Aunt Jewell calls me Sam or Sammie, but not when my mom's around. My mom tells me I should like the name Samantha because of that girl who wrote to the president of the Soviet Union and got to fly over to Russia to meet some Russian kids. She says if I try really hard I'll have a chance to do something really important like that. Samantha is a beautiful, important name she says. I think they named me that because my dad had this thing for Elizabeth Montgomery. It's okay Mr. Tompkins, I'm getting to my project. I just wanted to point out that right from the beginning my Aunt Jewell and I got along because we knew what name to use to make the other one feel comfortable.

The first time I met Aunt Jewell I had rode my bike over to this retirement village where she'd just moved to. If you'd like to know it's called Happy

Valley, and all these old people live there. Aunt Jewell has a little apartment there. My mom sent me over there with a loaf of banana nut bread. I found Aunt Jewell's apartment okay and I pushed the buzzer. Nobody answered the door and I pushed it a few more times and I was getting ready to leave when the lady in the next apartment came out and asked me what I was doing. When I told her I was a relative she told me to go on in, that Jewell didn't hear well and was probably in the bathroom.

It seemed kinda strange to just walk in somebody's house but I did what that other lady said. Once I was inside I said, "Mrs. Eckhardt. I'm here to visit you. I'm Harry's girl, Samantha. I brought you

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some bread that my mom made." Well, Aunt Jewell heard me calling to her I guess and she came walking out of the bedroom pushing a wheelchair in front of her, leaning on the chair as she pushed it along. Her feet were all covered by these padded soft shoes, sort of like slippers only different. She walks really slow and careful. She picks her foot up pretty high and then she looks at where she should put it down again, and then she sets it down. She really concentrates, like she was walking on the moon or something. My dad says it's because she can't feel her feet anymore and if she doesn't put them down really careful that maybe she'll fall. Like when your foot or your whole leg falls asleep when you're watching TV and you get up to go to the bathroom and it feels like pins and needles. Aunt Jewell's hair is sort of light orange and gray, and it sticks out from

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