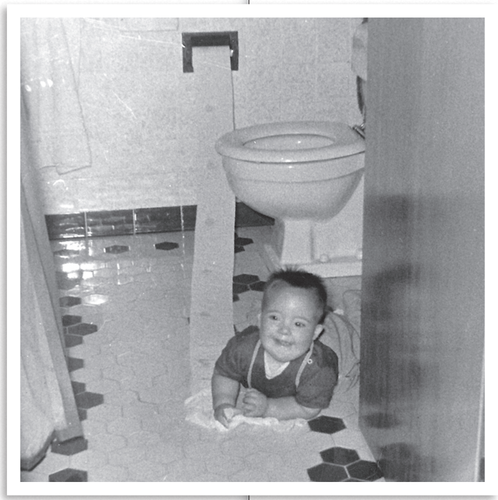
Frequently Asked Questions on Down Syndrome & Changes Over a Lifetime

MY SON BILLY, WHO HAS DOWN SYNDROME, is in his fifties. During our journey together, we have explored unexpected, unknown territory. In navigating that journey, we have encountered more questions than directions.

These questions appear to fall into four time frames: the early, discovery, wondering years; the questions concerning treatment and education; transition questions as our child leaves the protective school environment; and the puzzling questions about the rest of his or her life. Please join us in further exploration of questions and answers on our website, grownmannow.com

Early Years

WHAT IS DOWN SYNDROME?
DID I DO ANYTHING WRONG?



Down syndrome is a chromosome abnormality, usually due to an extra copy of the 21st chromosome. This syndrome usually, although not always, results in mental retardation and other conditions. The exact causes of the chromosomal rearrangement and primary prevention of Down syndrome are currently unknown. Since this occurs at conception, there is nothing the parents have done to cause it.

There are numerous other disabilities, with other causes and characteristics. Some conditions could result from drug use of the parents, overuse of alcohol, and hereditary factors. To research causes and accompanying problems, a good start is to go to *www.nichcy.org* for a complete listing of disabilities and information related to them. This website also offers full explanation of the Individual with Disabilities Education Act (referred to as IDEA).

WILL MY CHILD HAVE MEDICAL PROBLEMS?

With any disability, there can be medical problems. Children with Down syndrome may have heart anomalies, leukemia, and other medical problems. Although Billy has no critical health problems, he does have persistent skin irritation, occasional gout, diabetes, and sleep apnea. When you have a child with a disability, finding a good physician is vastly important. It is a good idea to keep good records of problems that occur and treatment that works.

HOW CAN I EXPLAIN IT TO MY OTHER CHILDREN, FAMILY MEMBERS, AND FRIENDS?

Frequently friends and family members have realized that your child is different in some way, or slow to develop normally. They can be supportive and helpful if you are honest with them, and give the information you have. I have found that explanation usually follows their observations and that friends, as well as family members, are eager to offer assistance.

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WHERE DO I GO FOR HELP? WHAT CAN I DO AT HOME TO STIMULATE MY CHILD'S DEVELOPMENT?

There are many organizations available to make suggestions and to connect you with other parents and groups. The internet is a valuable tool and will provide you with organizations and parent groups in all states. Frequently these groups can offer you understanding and concrete help in raising your child. Sometimes knowing that you are not alone is helpful in itself.

Early intervention programs work with families to suggest strategies designed to meet the needs of infants and toddlers. Stimulating your child's development is a family endeavor, usually resulting in close bonding and understanding with all family members, including extended family and close friends. I think this relates to the question about explaining the condition. In working to help the child with a disability to grow in every way, each family member becomes involved, experiencing the challenges and victories that the parents feel: helping the child to walk, to talk, to acquire good social skills. Every task – eating, toileting, dressing – is a learning opportunity, particularly in the area of language development.

WHY DO PEOPLE STARE AT MY BABY, MY CHILD? HOW CAN I RESPOND TO THAT?

If your child has Down syndrome, or another disability that is notably visible, you will find that people stare. This is unsettling and may make you angry. It makes me angry! At first I stared back to make them feel uncomfortable and gained some satisfaction from that. However, I have come to realize that sometimes it is just lack of knowledge or experience and I now counter with a smile and greeting. As our children become more assimilated into the general population, they will be more readily recognized and appreciated.

School Years

AT WHAT AGE SHOULD MY CHILD BEGIN PUBLIC SCHOOL AND PRE-SCHOOL PROGRAMS?

As early as possible! When Billy was born, there were no early intervention or pre-school programs. Now free appropriate public education is provided to all eligible preschool students with disabilities for ages 3 to 5 and early intervention programs for infants and toddlers with disabilities ages birth through age two. I am so glad that parents now have access to professional help and inviting environments. Another advantage to such programs is the opportunity to interact with other children – a valuable learning situation.

HOW DO I SELECT THE APPROPRIATE SCHOOL FOR MY CHILD?

Learn immediately that you must be proactive. Visit the schools; talk with other parents, teachers, administrators. Take your child with you and observe the reactions of your child and of the people you encounter at the school. Is your child comfortable in the environment? Do the personnel react favorably to you and your child? Is the environment inviting and stimulating? Is it safe? Take notes, talk with your family, and don't be in a hurry.

HOW DO I ESTABLISH A WORKING RELATIONSHIP WITH THE TEACHER?

Parents and schools are striving toward a new kind of relationship to help children learn – a partnership acknowledging more fully the need for schools to share educational decision-making with parents. Parents and teachers need to develop attitudes and skills that will promote communication. Successful techniques actively involve parents in the instructional process.

WHAT ABOUT INCLUSION? WILL MY CHILD LEARN AS MUCH AS IN A SPECIAL CLASS?

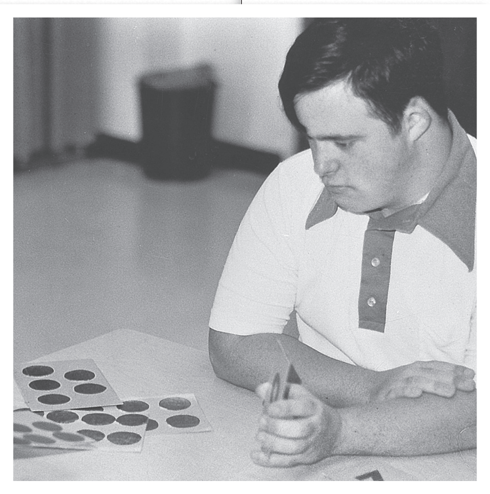
Inclusion in a program of appropriate services requires public school systems to serve all students with disabilities, regardless of the type of disability or the level of its severity. Students with disabilities are entitled to special education and related services designed to meet their individual needs.

Although inclusion is mandated, there are still some special classes and schools in operation. Some parents feel more secure with their child in a segregated environment, but research indicates that children learn more readily in a regular classroom. They learn from their interaction with children who do not have disabilities, and respond to the higher expectation from their teachers. On a personal level, I feel that learning in an integrated school program prepares children with disabilities to live in a normal, integrated environment as adults. This is the ultimate goal for our children.

HOW CAN I BE SURE MY CHILD IS RECEIVING APPROPRIATE/FULL SERVICES?

Again, be proactive. Stay in touch with the teacher and all personnel delivering services to your child. Attend and be active in school activities, participate fully in conferences. If possible, assist the teacher in any way possible without interfering.

Learn about the benefits of IDEA concerning your child and his/her disability and be sure to fill your responsibilities required, such as attending conferences and participating in the individual plan for your child. A positive relationship between the parents and school personnel makes you more secure and labels you as a responsible parent.



WON'T OTHER CHILDREN LAUGH AT HIM OR HER?

Perhaps at first. I remember my first contact with the special class that Billy attended. I was shocked at my initial reaction to my son in a class of different-looking children. However, as I became more involved with the class, I saw them as Cindy, Sonny, and other children who were my son's friends. I have seen this happen in fully-integrated classrooms. Children without disabilities become interested in helping those with disabilities and learning is promoted for everyone. I also see those children without disabilities becoming advocates for their new friends, with no laughing tolerated!

WHAT ABOUT EXTRA-CURRICULAR ACTIVITIES? SOCIAL INVOLVEMENT?

According to the law, inclusion in extra-curricular activities is mandated. However, this may not occur without insistence on your part. Students with disabilities who are integrated in the classroom can be involved in some area of all activities. We are seeing this happen frequently, with the national acclaim of a young man with autism who became a basketball star (Greece NY, 2006) and Anthony Robles, a young man with only one leg who became a champion wrestler. We also hear about students with Down syndrome who serve in some capacity with sports teams. There are many non-sports activities in schools that are available to all students. I know a young man with Down syndrome who expressed an interest in theater and who has become a star! Such inclusion may require parents to suggest talents and interests of their child to the teacher.

Social involvement arises from integrated classrooms, where school parties and outings take place. Outside social activities may not occur as naturally and can be instigated by families and friends. If you want your child to go to a party, have a party! Be the one, perhaps with other parents, to set up a bowling party or a closely supervised swimming party. Talk to other students about social activities they enjoy and help your child become involved.

BECAUSE THIS LIST SEEMS SO DAUNTING, we have been told to "take one day at a time." While that may work for a brief time, it is not a good idea in the long run. Being aware of the issues facing us in the future helps us prepare for them. It also helps us see the gaps in services and opportunities available throughout the life span, causes us to observe others as they deal with them, and insists that we work towards filling the missing holes in the system.

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In many cities there are organizations that sponsor social activities specifically for young people with disabilities. In her book *Mama and Margaret* (2005) Embry Burrus describes a number of activities her sister engages in: bowling, bus trips, dances, all sponsored by groups or individuals and planned for young adults who have disabilities.

WHAT ABOUT SEX EDUCATION AND DATING? IS GUIDANCE AVAILABLE FOR THIS?

Talk with your guidance counselor. If there is not a program in your school, look on the internet for sex education programs. There are a number of such programs available for students with or without disabilities. One fact sheet I found was under Better Health and was entitled "Sex education for children with intellectual disabilities." It stresses the importance of sex education for children with disabilities and, in addition to enumerating obstacles and benefits, suggests sources for more information and support groups.

If you attend conferences such as those sponsored by the National Down Syndrome Congress, there are frequently presentations on sex education. This also could be a source to find a person who would lead a program in your school. The fact sheet referred to above, stresses that "It is important that all children are educated about sex and given the opportunity to explore, enjoy and express their sexuality in positive and healthy ways."

Dating depends on opportunities, social skills, maturity, and frequently, degree of disability. I vividly remember Billy's futile attempts to get a date for his senior prom. We finally convinced him that others would be at the dance without a date. This is tough and I don't know the answer, unless you know a parent of someone of the opposite sex who might work with you on this issue. Probably organized activities, such as dance lessons and church events might provide the opportunity and a partner. Dating may also arise out of those programs planned for young people with disabilities.

Transition Years

WILL MY CHILD GRADUATE FROM HIGH SCHOOL?

Your child may graduate with a full diploma or with a certification of completion of a high school program, depending on your state and local laws.

IS VOCATIONAL TRAINING AVAILABLE?

In many school systems vocational programs have been eliminated. However, transition programs may have replaced them. Under IDEA, transition planning from school to adult life begins, at the latest, during high school. Transition planning is required, by law, to start once a student reaches 16 years of age or younger if appropriate. This transition planning becomes formalized as part of the student's Individualized Education Program (IEP).

In a transition program your child would have opportunities to enter work situations, to be involved with community businesses, and acquire the necessary skills and attitudes for work. Inquire about the availability of work related programs before your child reaches high school. You may need to advocate for or assist in acquiring the essential opportunities to prepare him or her for gainful employment.

The acquisition of work skills and attitudes begins in early life for all children, including those with disabilities. Assigning responsibilities in the home – picking up toys, taking out trash, helping with dishes and setting the table – help to build a work ethic.

IS COLLEGE A POSSIBILITY FOR MY TEEN-AGER? IF SO, WHERE?

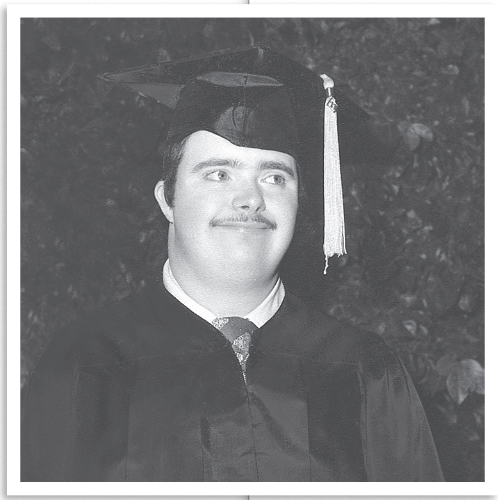
Students with mild disabilities have been attending college for some time. If your child falls in this category, consult your guidance counselor for a list of colleges that offer assistance to students who need help or who may be entitled to a helper. In my career as a college professor, I have worked with students who have physical disabilities, learning disabilities and visual and hearing impairments. Any modifications for testing and note-taking are required by law to be provided.

A new practice on the horizon is the opportunity for students with more severe disabilities to attend college. There are a number of colleges and programs available on the internet. I have never understood why our children with disabilities have not had adequate opportunities for post-secondary education. It seems to me that they would need it even more than those without disabilities.

IF COLLEGE IS NOT AN OPTION, WHAT IS AVAILABLE AFTER SECONDARY PROGRAMS?

A number of young people with disabilities begin work after leaving the school system. This is what Billy did, for there were no opportunities at that time for someone at his level of aptitude for post secondary education. Through our local mental health organization he was placed in a job at the local lumber yard. The job did not work out, mainly because of his lack of readiness, and he went to work in a sheltered workshop. That move ultimately made it possible for him to work in an inclusive situation, with personnel from the workshop as trainers. Later on, in a different job, the workshop again provided him with on-the-job training. In some cases, training will be provided by the employer.

For young people who are not capable of working in competitive employment situations, the workshop may be a terminal position.



HOW CAN WE PLAN FOR LIFE AFTER HIGH SCHOOL? IS HELP AVAILABLE FOR THAT?

If you have a transition program in your high school, school personnel will help your child plan for work and living situations. It will begin with visiting some possible solutions and linking him or her to community resources and counselors.

If you do not have a transition program, look into such programs in other areas. If you cannot create one in your school, talk with the people who have the programs, take your child to visit them, get ideas from them.

This question and its answer should begin way before your child enters high school. Enlist the help of other parents and talk with school and community personnel. Remember to involve your child in all decisions.

WHAT KIND OF WORK IS AVAILABLE? WHAT KIND OF TRAINING?

In the past, fast- food restaurants seemed to be the answer. That did not work for Billy. Let a tour bus arrive, with a large group to be fed, and the pressure weighed him down! Obviously it works for others. He now works in a grocery store, bagging groceries. I have seen two other baggers who have Down syndrome working there. He was trained by a job coach from Goodwill Industries.

If you had a transition program in your school, your child was introduced to a number of job opportunities, depending on the availability of suitable work in your community. I supervised a transition program where the largest local industry was preparing chickens for distribution. Naturally jobs there were a primary consideration.

Our expanding opportunities for communication put us in touch with programs, people, and plans that will assist us at each level. Conferences give us chances to know professionals who have answers, parents who have "been there," and those who are, along with their children, seeking answers.

Together we must continue to advocate for our children and our adults who have Down syndrome. We can make good things happen!

—Jane B. Schulz, EdD

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If you are on your own, see the local Vocational Rehabilitation center. They will evaluate your child, make recommendations, and refer you to the proper agency. With job placement, training would be available. In our town, many young people with rather severe disabilities are working in restaurants, rolling silverware in napkins and other simple tasks.

HOW DO WE LEARN ABOUT AND APPLY FOR GOVERNMENT BENEFITS?

When we recently moved from North Carolina to Tennessee, our first order of business was to contact the State of Tennessee Division of Mental Retardation Services. Following an interview and necessary documentation, we were assigned a case manager.

The case manager meets with us when needed and gave us a copy of The Family Handbook, A Roadmap to State Services for Adults and Children Who Have Mental Retardation. A further resource given is a link to a central clearinghouse for statewide information, resources, and links to organizations and groups.Such resources are available in all states.

WHERE DO WE GO FOR HELP AFTER HIGH SCHOOL?

The high school guidance counselor, transition coordinator, or local advocacy groups such as the ARC should be able to lead you in the right direction. However, if you do not get answers from these sources, seek your local mental health agency or other parents.

Adult Years

HOW DO I EXPLAIN TO MY ADULT CHILD WHO HAS DOWN SYNDROME: WHY IS HE/SHE NOT GOING TO COLLEGE LIKE SIBLINGS OR FRIENDS? WHY DOES MARRIAGE NOT APPEAR TO BE AN OPTION? AGAIN: WHY DO PEOPLE STARE?

These are the really tough questions and they begin long before adulthood. They begin with the concept of difference and may have been asked in some form from early childhood.

Billy asked me, on the occasion of his sister's marriage engagement, "Mary is younger than I am; why am I not getting married?" I was tempted to say, "Because you can't afford it." Then I remembered that his dad and I couldn't afford it, but we still got married and at an age younger than his. The only truthful answer I could come up with was "Because you have Down syndrome." It's not fair, but it is truthful. I also told him that marriage is very difficult and now he has a friend who recently married. The friend must work two jobs because, as Billy says, "He's married." That helps.

To counteract this cruelty, you might suggest that when he/she is ready, there is the possibility of a home and a life separate from the original family. This is probably a good time to investigate the possibilities of a new adult life.

WHERE DO WE GO FOR VOCATIONAL EVALUATION AND TRAINING?

The local Vocational Rehabilitation office will refer you for a psychological evaluation and may administer job related tests. After an extensive interview, medical history and other information, they will probably refer you to a program such as Good Will Industries, where vocational aptitude tests will be administered. Based on these findings, job placement will be recommended and a job coach assigned. Based on criteria of the employer, the person with a disability will be trained until competency is acquired. The job coach should also be available if problems arise on the job.

WHAT WORK IS AVAILABLE AND APPROPRIATE? DOES THE INDIVIDUAL HAVE A CHOICE?

The training agency, such as Good Will, has a list of employers willing to accept adults with disabilities as employees. Based on their tests and observations of the client, the training agency will make recommendations. The individual can certainly express a choice, but the availability and appropriateness are determining factors.

HOW DO WE FIND A JOB?

Sometimes jobs are available through family or friends and the process mentioned above is not necessary. Sometimes the jobs presented do not work and there are not others available. The task of finding a job may then fall on the parents or other interested and involved persons. And this requires observation and sometimes brass.

At one point when Billy needed a second job because his hours had been cut drastically, I was involved with a nursing home. I looked around and saw a number of jobs, such as filling water jugs and calling Bingo, that I felt he could do. I approached the administrators; they offered him a job if we could supply training. The nearby sheltered workshop trained him until he obtained proficiency and he had a good job. As always, parents must be proactive.

WHAT LIVING ACCOMMODATIONS ARE AVAILABLE?

Billy has lived in a group home, a supervised apartment, a trailer near our home and at the present time an apartment in my home. In considering options, the adult with disabilities and the family should explore expectations and possibilities.

Factors to be considered are responsibilities, interests, week-end activities, current life style, as well as what is available in the community. We are initiating a conversation about various housing possibilities on this website and welcome your input.

WHAT SUPERVISION FOR LIVING IS AVAILABLE?

Group homes and assisted living situations are supervised by a person or persons appointed by the appropriate agency. Other supervision may be provided by the family or by persons appointed by the family. The amount of supervision required is determined by the needs of the adult with disabilities.

IS THERE HELP FOR ASSISTANCE WITH MEDICAL ISSUES?

In closely supervised living situations, determined by the needs of the client, medical needs are monitored by the involved agency. In less restrictive living situations, medical issues will be monitored by the supervisor and any problems referred to the client's physician. Where families are the supervisors, this procedure is followed.

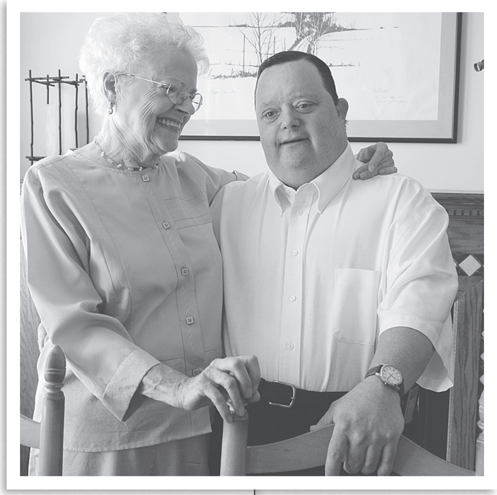
WHAT BENEFITS ARE AVAILABLE FOR ADULTS WHO HAVE DOWN SYNDROME?

Adults with disabilities will probably be eligible for Medicare or Medicaid (see The Family Handbook). Other benefits are SSI (Supplemental Security Income), SSDI (Social Security Disability Insurance), food stamps, housing vouchers, and grants. Eligibility requirements can be found from the Beach Center on Disability. This center, associated with the University of Kansas and directed by Ann Turnbull, is setting up a website dealing with the concept of Whole L.I.V.E.S. This concept focuses on the elements necessary for creating an inclusive and meaningful life in the community, including housing, employment, relation-

ships, community inclusion, financial control, and independent decision-making. I think it will be a valuable, interactive resource for all of us.

WHAT SOCIAL OPPORTUNITIES ARE AVAILABLE FOR ADULTS WHO HAVE DOWN SYNDROME? HOW ABOUT DATING?

Some of the supervised housing situations may provide social and dating opportunities. If you are close to a college, sororities and/or fraternities could be interested in organizing appropriate events. Church functions, community celebrations and cultural events also offer a number of possibilities.



WHAT HAPPENS WHEN THEIR SIBLINGS GROW UP AND MARRY PEOPLE WHO HAVE NOT GROWN UP WITH THEM AND DON'T UNDERSTAND THEM? WHEN THERE IS ANOTHER GENERATION OF CHILDREN WHO ASK QUESTIONS AND NEED ANSWERS?

It is a lot to ask of in-laws to understand the needs and idiosyncrasies of adults with disabilities when they haven't known them for a lifetime. Developing positive relationships takes time! Hopefully as they get acquainted they will become friends, but sometimes this places a strain on the new family member, the old family members, and the person with disabilities. It takes time and patience but the result can be a blessing. I clearly remember when my oldest grandson asked me in surprise, "Why can't Billy read? He's 18 years old!" It was a time for explanation and honesty.

There are so many questions, and although the answers to many remain fairly constant, there is constant movement in addressing many of the others. We hope you will join our "loose affiliation of characters" on our website blog, where we hope to facilitate communication, learn from and inspire each other.

—Jane B. Schulz, PhD

REFERENCES

Better Health, (2008), "Sex education for children with intellectual disabilities." www.betterhealth.vic.gov.au

Blue-Banning and Turnbull, A. (2008). "Creating Whole Lives and Accessing Resources in Ways that Promote Inclusive, Self-determined Lives." National Down Syndrome Conference, 2008.

Schulz, J.B. and Carpenter, C.D., (1995). *Mainstreaming Exceptional Students: A Guide for Classroom Teachers* (4th Ed.) Boston: Allyn & Bacon.

Schulz, J.B. (1986). *Parents and Professionals in Special Education.* Boston: Allyn & Bacon

Tennessee Division of Mental Retardation Services (2005). *The Family Handbook, A Roadmap to State Services For Adults and Children Who Have Mental Retardation.*

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