Congratulations!

The birth of your new baby is a time for celebration and the feeling of joy! Your baby may not be as you have imagined, but rest assured that your baby is more like other babies than different. You may be feeling afraid and uncertain, which is perfectly normal. Most parents experience this when they hear their child has Down syndrome. Take a deep breath and relax. Now is the time for you to get to know your baby and love each other.

Down syndrome is the most common chromosomal anomaly. Your child has had Down syndrome since conception, *nothing you did or didn't do, before or during your pregnancy*, caused this. To help you to make informed decisions regarding your child, we offer an abundance of relevant information about Down syndrome to help you to make informed decisions regarding your child. Please take your time in searching through our website, getting acquainted with our families and becoming more familiar with the links on Down syndrome. It is important to caution our new parents to be sure that the information you access is up to date and relevant to individuals needs today. We are here to answer any questions you may have. If during your research you find any questionable information or are uncertain or unclear about any topic, we will be delighted to help find the answers to your questions.

*Accept no limitations!* The future is bright. The first generation of children with Down syndrome who have benefited from early intervention and inclusive environments are opening new doors. People with Down syndrome are leading meaningful and productive lives. They are now graduating from school, attending college, and having fulfilling careers and relationships.

The Down Syndrome Guild of Dallas has trained parent-to-parent counselors, each of whom has a child with Down syndrome. We would love to talk with you and let you know how we can help. If you are interested in talking to another parent, please call the Down Syndrome Guild of Dallas at 214-267-1374 or click dsged@sbcglobal.net.

The best thing you can do right now is love, nurture and bond with your baby like you would any other baby. Congratulations, you are about to embark on amazing journey!

Warmest Regards,

Down Syndrome Guild of Dallas New Parent Support Group

Down Syndrome Guild of Dallas
1702 N Collins Blvd., #170
Richardson, TX 75080

[www.downsyndromedallas.org](http://www.downsyndromedallas.org)  
dsged@sbcglobal.net
Congratulations on the birth, or expected birth, of your baby! We understand that your baby may have Down syndrome. You probably have a million questions, concerns, and fears right now. That's okay. The most important thing to keep in mind is that this diagnosis is not as "life changing" as the fact that you have a new baby. And in most ways, your baby will be just like other infants. Every baby needs to be fed, held, and most of all, loved.

There will be challenges in raising your child, but there will also be many, many joys. It's normal to be nervous about what lies ahead, but remember that Down syndrome is a condition your baby has, it is not who your baby is. Now is the time to begin learning all you can about Down syndrome and the local services available to you. This New Parent Guide is a great place to start.
creed of babies
with down syndrome

My face may be different
But my feelings the same.
I laugh and I cry
And take pride in my gains.

I was sent here among you
To teach you to love
As God in the heavens
Looks down from above.

To Him, I'm no different
His love knows no bounds;
It's those here among you
In cities and towns

That judge me by standards
That man has imparted,
But this family I've chosen
Will help me get started.

For I'm one of the children
So special and few
That came here to learn
The same lessons as you.

That love is acceptance,
It must come from the heart;
We all have the same purpose,
Though not the same start.

The Lord gave me life
To live and embrace,
And I'll do it as you do...
But at my own pace.
by Erma Bombeck

Most women become mothers by accident, some by choice, a few by social pressures and a couple by habit. This year nearly 100,000 women will become mothers of handicapped children. Did you ever wonder how mothers of handicapped children are chosen? Somehow I visualize God hovering over earth selecting his instruments for propagation with great care and deliberation. As He observes, He instructs His angels to make notes in a giant ledger.

“Armstrong, Beth; son. Patron saint...give her Gerard. He’s used to profanity.”

“Forrest, Marjorie; daughter. Patron saint, Cecelia.”

“Rutledge, Carrie; twins. Patron saint, Matthew.”

Finally He passes a name to an angel and smiles, “Give her a handicapped child.”

The angel is curious. “Why this one God? She’s so happy.”

“Exactly,” smiles God, “Could I give a handicapped child to a mother who does not know laughter? That would be cruel.”

“But has she patience?” asks the angel.

“I don’t want her to have too much patience or she will drown in a sea of self-pity and despair. Once the shock and resentment wears off, she’ll handle it.”

“I watched her today. She has that feeling of self and independence that is so rare and so necessary in a mother. You see, the child I’m going to give her has her own world. She has to make her live in her world and that’s not going to be easy.”

“But, Lord, I don’t think she even believes in you.” God smiles, “No matter, I can fix that. This one is perfect - she has just enough selfishness.” The angel gasps - “Selfishness? Is that a virtue?”

God nods. “If she can’t separate herself from the child occasionally, she’ll never survive. Yes, here is a woman whom I will bless with a child less than perfect. She doesn’t realize it yet, but she is to be envied. She will never take for granted a ‘spoken word’.” She will never consider
a “step” ordinary. When her child says ‘Momma’ for the first time, she will be present at a miracle, and will know it!”

“I will permit her to see clearly the things I see...ignorance, cruelty, prejudice...and allow her to rise above them. She will never be alone. I will be at her side every minute of every day of her life, because she is doing My work as surely as if she is here by My side.”

“And what about her Patron saint?” asks the angel, his pen poised in mid-air.

God smiles, “A mirror will suffice.”

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Jon Will, the eldest of my four children, turns 21 this week and on this birthday, as on every other workday, he will commute by subway to his job delivering mail and being useful in other ways at the National Institutes of Health. Jon is a taxpayer, which serves him right: He voted for Bill Clinton (although he was partial to Pat Buchanan in the primaries).

The fact that Jon is striding into a productive adulthood with a spring in his step and Baltimore's Orioles on his mind is a consummation that could not have been confidently predicted when he was born. Then a doctor told his parents that their first decision must be whether or not to take Jon home. Surely 21 years later fewer doctors suggest to parents of handicapped newborns that the parental instinct of instant love should be tentative or attenuated, or that their commitment to nurturing is merely a matter of choice, even a question of convenience.

Jon has Down syndrome, a chromosomal defect involving varying degrees of mental retardation and physical abnormalities. Jon lost, at the instant he was conceived, one of life's lotteries, but he also was lucky: His physical abnormalities do not impede his vitality and his retardation is not so severe that it interferes with life's essential joys--receiving love, returning it, and reading baseball box scores.

One must mind one's language when speaking of people like Jon. He does not "suffer from" Down syndrome. It is an affliction, but he is happy--as happy as the Orioles' stumbling start this season will permit. You may well say that being happy is easy now that ESPN exists. Jon would agree. But happiness is a species of talent, for which some people have superior aptitudes.

Jon's many aptitudes far exceed those few that were dogmatically ascribed to people like him not long ago. He was born when scientific and social understanding relevant to him was expanding dramatically. We know much more about genetically based problems than we did when, in the early 1950s, James Watson and Francis Crick published their discoveries concerning the structure of DNA, the hereditary molecule, thereby beginning the cracking of the genetic code. Jon was born the year before Roe v. Wade and just as prenatal genetic tests were becoming routine. Because of advancing science and declining morals, there are fewer people like Jon than there should be. And just in Jon's generation much has been learned about unlocking the hitherto unimagined potential of the retarded. This begins with early intervention in the form of infant stimulation. Jon began going off to school when he was three months old.

Because Down syndrome is determined at conception and leaves its imprint in every cell of the person's body, it raises what philosophers call ontological questions. It seems mistaken to say that Jon is less than he would be without Down syndrome. When a child suffers a mentally limiting injury after birth we wonder sadly about what might have been. But a Down person's life never had any other trajectory. Jon was Jon from conception on. He has seen a brother two years younger surpass him in size, get a driver's license and leave for college, and although Jon would be forgiven for shaking his fist at the universe, he has been equable. I believe his serenity is grounded in his sense that he is a complete Jon and that is that.

Some of life's pleasures, such as the delights of literature, are not accessible to Jon, but his most poignant problem is that he is just like everyone else, only a bit more so. A shadow of loneliness, an irreducible apartness from others, is inseparable from the fact of individual existence. This entails a sense of incompleteness--we *are* social creatures--that can be assuaged by marriage and other friendships, in the intimacy of which people speak their hearts and minds. Listen to the wisdom whispered by common locutions: We speak of "unburdening ourselves" when we talk with those to whom we talk most freely.
Now, try to imagine being prevented, by mental retardation and by physical impediments to clear articulation, from putting down, through conversations, many burdens attendant on personhood. The shadow of loneliness must often be somewhat darker, the sense of apartness more acute, the sense of incompleteness more aching for people like Jon. Their ability to articulate is, even more than for everyone else, often not commensurate with their abilities to think and feel, to be curious and amused, to yearn.

Because of Jon's problems of articulation, I marvel at his casual everyday courage in coping with a world that often is uncomprehending. He is intensely interested in major league baseball umpires, and is a friend of a few of them. I think he is fascinated by their ability to make themselves understood, by vigorous gestures, all the way to the back row of the bleachers. From his season-ticket seat behind the Orioles dugout, Jon relishes rhubarbs, but I have never seen him really angry. The closest he comes is exasperation leavened by resignation. It is an interesting commentary on the human condition that one aspect of Jon's abnormality—a facet of his disability—is the fact that he is gentleness straight through. But must we ascribe a sweet soul to a defective chromosome? Let us just say that Jon is an adornment to a world increasingly stained by anger acted out.

Like many handicapped people, Jon frequently depends on the kindness of strangers. He almost invariably receives it, partly because Americans are, by and large, nice, and because Jon is, too. He was born on his father's birthday, a gift that keeps on giving.

"WE CANNOT FASHION OUR CHILDREN AFTER OUR DESIRES,
WE MUST HAVE THEM AND LOVE THEM
AS GOD HAS GIVEN THEM TO US."

- JOHANN WOLFGANG VON GOETHE
Getting Started:
Important Things to Know

Women, Infants & Children's Nutrition Program (WIC)

Your child may automatically qualify for WIC if he/she receives Medicaid, Temporary Assistance to Needy Families or Food Stamps. WIC provides free formula and nutritious foods for pregnant women and children from birth to age 5. Gross income must fall at or below 185% of federal poverty income levels to qualify. See contact information under the Resources tab.

Early Childhood Intervention Services (ECI)

ECI is a statewide program for families with children, birth to three, with disabilities and developmental delays. ECI supports families to help their children reach their potential through developmental services. Services are provided by a variety of local agencies and organizations across Texas.

ECI provides evaluations and assessments, at no cost to families, to determine eligibility and need for services. Families and professionals work as a team to plan appropriate services based on the unique needs of the child and family. ECI asks families who can afford to do so, to share in the cost of services. The amount a family pays for ECI services is determined using a sliding fee scale and is based on family size and income after allowable deductions. No child and family will be turned away because of an inability to pay.

ECI goes to families and focuses on working with the child and family in their natural environment, such as at home, grandma's, or a child care center. Essentially, it's where children live, learn and play.

ECI is here to help and can become an important resource for all families. For more information about ECI or to refer a child, call the Department of Assistive and Rehabilitative Service (DARS) Inquiries Line at 1-800-628-5115. Contact numbers and providers can be found behind our Resource tab.

Medicaid Home and Community-Based Waiver Programs

Texas currently has seven different Medicaid waiver programs designed to allow Medicaid funds to be available to provide individuals with disabilities the opportunity to receive supports and services in their community as an alternative to institutional care. These waivers are administered through the Texas Department of Aging and Disability Services (DADS). Medicaid waiver services can be especially helpful to families caring for children with disabilities. Contact numbers for these Waivers are behind the Resource tab.
Oral Motor Skills

Almost all children with Down syndrome will have oral motor issues ranging from very mild to severe. It is recommended by experts that you try to get your baby to suck a pacifier. This may take some trial-and-error to determine the pacifier that works for them, and some babies just won't take a pacifier. Sucking a pacifier will build oral motor control, and helps develop the muscles needed for sucking, drinking, eating, and speech.

Muscle Tone

Children with Down syndrome have low muscle tone and extremely limber joints. This combination delays development in crawling and walking. When your child is lying on his/her back they will probably lie with legs and arms splayed open to each side. It will be more beneficial for them to lie on their side with a wedge to keep them from turning to their back. This will keep legs together and arms at mid-line. When holding your baby, try to keep both arms in front of their body, not falling out beside them.
Questions & Answers about DOWN SYNDROME

What is Down syndrome?
Down syndrome is a chromosomal disorder characterized by the presence of an extra #21 chromosome. Instead of having 46 chromosomes in each of his/her cells, a person with Down syndrome has 47. The extra chromosome may be derived from either the egg or the sperm. It is believed that during cell division of a sperm or egg, the two #21 chromosomes do not separate properly (nondisjunction). Thus, one cell will have an extra #21 chromosome which later, if united with a normal germ cell which has among others one #21 chromosome, may lead to trisomy 21. The first cell at conception then has 47 chromosomes instead of a "normal set" of 46 chromosomes. When this cell with three #21 chromosomes continues to multiply, and the pregnancy is carried to term, a baby with Down syndrome will be born. This form of chromosome error, trisomy 21, is found in about 95% of persons with Down syndrome.

The five percent of babies with Down syndrome who do not have trisomy 21 may have translocation, mosaicism, or partial trisomy. In translocation Down syndrome, there are also three copies of the #21 chromosome. However, one of the #21 chromosomes is attached or translocated on another chromosome, usually a #14, #21, or #22 chromosome. Three to four percent of children with Down syndrome have translocation. About one third to one half of translocations are inherited from one of the parents. When this happens, the carrier parent has the normal amount of genetic material, however one of the #21 chromosomes is attached to another chromosome. As a result, this individual's total chromosome count is 45 instead of 46. The carrier parent is clinically unaffected because there is no loss or excess of genetic material. Doctors refer to a parent like this as a balanced carrier.

Another form of Down syndrome is known as mosaicism, which affects about one percent of all people with Down syndrome. In mosaicism, a faulty cell division most often occurs in one of the earliest cell divisions after conception. This is in contrast to other types of Down syndrome when the error in cell division occurs before fertilization. As in trisomy 21, something causes one of the cells to divide incorrectly. But when this occurs in one of the early cell divisions, only some of the cells of the growing embryo have the extra #21 chromosome and the other cells have the normal number of chromosomes. Depending on the ratio of normal cells to trisomic cells, the child may have fewer Down syndrome features as well as higher cognitive abilities.

Although details of the mechanism of nondisjunction are for the most part unknown, the presence of three copies of the #21 chromosome causes a genetic imbalance that alters the typical course of growth and development of the fetus and child with Down syndrome.
What causes Down syndrome?
Down syndrome occurs in approximately one out of every 800 to 1,000 live births; it is one of the most often observed chromosome anomalies. Scientists have investigated the causes of Down syndrome for the past century. So far, its exact cause has eluded discovery. Although many factors have been considered to be possible causes, the age of the mother is the most often discussed factor related to the likelihood of having a baby with Down syndrome. It has been known for some time that the risk of having a child with Down syndrome increases with the advancing age of the mother, i.e., the older the mother, the greater chance that she may give birth to a child with Down syndrome. The risk at age 20 for instance is about 1 in 1,600, the risk at age 35 is 1 in 365 and the risk at 40 is 1 in 100. However, because there are more younger women having babies, 75-80% of all children with Down syndrome are born to women under 35 years of age.

If I already have a child with Down syndrome, is the risk higher that I will have another child with Down syndrome?
If your baby has trisomy 21, the risk for having another child with Down syndrome is approximately 1 in 100 or 1% in addition to the mother's age related risk. For families who have a baby with translocation Down syndrome, the risk of recurrence is also about 1 in 100 unless the condition is inherited from one of the parents. The risk of recurrence depends on the type of translocation and the sex of the carrier parent.

Are any prenatal tests available to detect Down syndrome?
Yes. There are several types of testing available.

Screening Tests: Screening tests are used to look for potential problems and to identify those who are at high risk of having a baby with a genetic disorder.

The triple screen and the alpha-fetoprotein plus, and more recently, the quad test measure the amounts of certain hormones and proteins in the blood including alpha-fetoprotein, human chorionic gonadotropin, unconjugated estriol and inhibin. The results of these tests together with the woman's age, will provide an estimate of her risk of having a child with Down syndrome. These tests are usually performed between the 14th and 16th week of gestation. Approximately 60-80% of fetuses with Down syndrome can be identified prenatally by considering the mother's age and employing these screening tests.

In addition, ultrasound examinations are almost always performed. During an ultrasound examination the physician looks for "markers," such as a thickening of the skin at the back of the neck (nuchal fold), bright spots on the kidneys or heart, short arms or legs, reduced head size, congenital heart disease, and gastrointestinal problems. If any of these "markers" are observed, diagnostic testing is generally recommended.

Diagnostic Testing: Diagnostic testing tells whether or not the baby has the condition. However, there is no diagnostic test that is 100% reliable. Amniocentesis and chorionic villus sampling are the two diagnostic tests most often used to determine whether the fetus has Down syndrome.
**Amniocentesis** is typically performed around the 16th week of pregnancy. Before the procedure, an ultrasound examination is done which shows the location of the placenta, the amniotic cavity, and the fetus. During the procedure, a needle is inserted into the amniotic cavity through the mother's abdomen. A small amount of amniotic fluid is obtained and analyzed. The amniotic fluid contains cells from the fetus, which are cultured and then examined to determine whether or not the fetus has Down syndrome. It generally takes 12 to 20 days to obtain results. Amniocentesis has about a two percent rate of miscarriage as well as other side effects, such as infection, bleeding, cramping, and needle puncture of the fetus.

**Chorionic villus sampling (CVS)** is done in early pregnancy, usually between nine and twelve weeks of gestation. Following an ultrasound examination, a thin tube is inserted through the vagina and a small piece of placental tissue is obtained. Because the cells from the chorionic villi are fetal tissue, they can be cultured and then examined for chromosome abnormalities in one week to ten days. In terms of side effects, CVS is slightly more likely than amniocentesis to be followed by miscarriage or other complications such as infections, bleeding, and leaking of amniotic fluid.

**What are the physical characteristics of Down syndrome?**
The following characteristics are most commonly associated with Down syndrome, but can also be found in the general population. There is some variety of physical features among babies with Down syndrome; not every baby possesses all of the characteristics. Moreover, there is no correlation between the number of characteristic features a baby has and the child's cognitive ability.

Babies with Down syndrome usually have low muscle tone called hypotonia. This means that their muscles appear relaxed and feel "floppy." The baby's face may be broader and his/her nasal bridge may be flatter than usual. Often children with Down syndrome have a small nose. The child's eyelids may appear to slant upward and may also have small folds at the inner corners (epicanthal folds). The baby's mouth may be small and the roof of the mouth may be narrow. The baby's ears are often small and the upper part of the ear may fold over. Babies with Down syndrome usually have small heads. The difference in size, however, is not usually noticeable. The back of the head may be flatter and the neck may appear shorter. In newborns, there may be loose folds of skin on the back of the neck, but these tend to disappear later with advancing age.

The child's hands may be smaller, and his/her fingers may be shorter than other children's. In about 50% of children with Down syndrome only one palmar crease is observed, and the fifth finger may be curved slightly inward. Usually the feet of babies with Down syndrome appear fairly normal, but there may be a wide gap between the first and second toe.
Because children with Down syndrome have an extra #21 chromosome, they may have features that resemble other babies with Down syndrome in some way. However, they will also resemble their parents, brothers, and sisters.

**What are the developmental aspects?**
The baby with Down syndrome will grow and develop like other babies. He/she will do all the things a typical child does, only somewhat later. Compared with typical children, individuals with Down syndrome are usually smaller and their development is somewhat slower. For example, instead of walking at 12 to 14 months, a child with Down syndrome may learn to walk between 18 and 36 months. Most children with Down syndrome will display a delay in their speech and language development. It should be noted that there is a wide variation in the mental, behavioral, and developmental progress in children with Down syndrome. A caring and enriching home environment, early intervention, and improved special education services have a positive influence on the child's development.

**Do all children with Down syndrome have mental retardation?**
No. A few children with Down syndrome are not mentally retarded, they may function in the borderline or low average range. The vast majority of children with Down syndrome function in the mild to moderate range of mental retardation. Children with Down syndrome often attend regular schools in regular education classes with differing levels of support. Most graduate from high school and some are enrolled in post secondary educational programs including colleges and vocational programs.

**What about adults with Down syndrome? Where do they live?**
Today, adults with Down syndrome have choices about where they live and with whom they live. Some live in apartments, condominiums, or houses with roommates and/or with support services, and some adults choose to remain in homes with their parents or siblings.

**Do adults with Down syndrome work?**
Adults with Down syndrome are working at a variety of jobs ranging from regular competitive jobs in the community to supported employment or sheltered employment. People with Down syndrome are clerical workers, computer operators, assistant coaches, photographers, teacher assistants, etc. People with Down syndrome are becoming more and more contributing and tax-paying members of their communities.

**What is the life expectancy of people with Down syndrome?**
Improved medical care has primarily prolonged the life span of people with Down syndrome. It is not unusual for people with Down syndrome to live into their 50's, 60's, and even 70's.
You Are Not Alone: For Parents When They Learn That Their Child Has a Disability

by Patricia McGill Smith

If you have recently learned that your child is developmentally delayed or has a disability (which may or may not be completely defined), this message may be for you. It is written from the personal perspective of a parent who has shared this experience and all that goes with it.

When parents learn about any difficulty or problem in their child’s development, this information comes as a tremendous blow. The day my child was diagnosed as having a disability, I was devastated—and so confused that I recall little else about those first days other than the heartbreak. Another parent described this event as a “black sack” being pulled down over her head, blocking her ability to hear, see, and think in normal ways. Another parent described the trauma as “having a knife stuck” in her heart. Perhaps these descriptions seem a bit dramatic, yet it has been my experience that they may not sufficiently describe the many emotions that flood parents’ minds and hearts when they receive any bad news about their child.

Many things can be done to help yourself through this period of trauma. That is what this paper is all about. In order to talk about some of the good things that can happen to alleviate the anxiety, let us first take a look at some of the reactions that occur.

Common Reactions

On learning that their child may have a disability, most parents react in ways that have been shared by all parents before them who have also been faced with this disappointment and this enormous challenge. One of the first reactions is denial—“This cannot be happening to me, to my child, to our family.” Denial rapidly merges with anger, which may be directed toward the medical personnel who were involved in providing the information about the child’s problem. Anger can also color communication between husband and wife or with grandparents or significant others in the family. Early on, it seems that the anger is so intense that it touches almost anyone, because it is triggered by the feelings of grief and inexplicable loss that one does not know how to explain or deal with.

Fear is another immediate response. People often fear the unknown more than they fear the known. Having the complete diagnosis and some knowledge of the child’s future prospects can be easier than uncertainty. In either case, however, fear of the future is a common emotion: “What is going to happen to this child when he is five years old, when he is twelve, when he is twenty-one? What is going to happen to this child when I am gone?” Then other questions arise: “Will he ever learn? Will he ever go to college? Will
he or she have the capability of loving and living and laughing and doing all the things that we had planned?”

Other unknowns also inspire fear. Parents fear that the child’s condition will be the very worst it possibly could be. Over the years, I have spoken with so many parents who said that their first thoughts were totally bleak. One expects the worst. Memories return of persons with disabilities one has known. Sometimes there is guilt over some slight committed years before toward a person with a disability. There is also fear of society’s rejection, fears about how brothers and sisters will be affected, questions as to whether there will be any more brothers or sisters in this family, and concerns about whether the husband or wife will love this child. These fears can almost immobilize some parents.

Then there is guilt—guilt and concern about whether the parents themselves have caused the problem: “Did I do something to cause this? Am I being punished for something I have done? Did I take care of myself when I was pregnant? Did my wife take good enough care of herself when she was pregnant?” For myself, I remember thinking that surely my daughter had slipped from the bed when she was very young and hit her head, or that perhaps one of her brothers or sisters had inadvertently let her drop and didn’t tell me. Much self-reproach and remorse can stem from questioning the causes of the disability.

Guilt feelings may also be manifested in spiritual and religious interpretations of blame and punishment. When they cry, “Why me?” or “Why my child?”, many parents are also saying, “Why has God done this to me?” How often have we raised our eyes to heaven and asked: “What did I ever do to deserve this?” One young mother said, “I feel so guilty because all my life I had never had a hardship and now God has decided to give me a hardship.”

Confound also marks this traumatic period. As a result of not fully understanding what is happening and what will happen, confusion reveals itself in sleeplessness, inability to make decisions, and mental overload. In the midst of such trauma, information can seem garbled and distorted. You hear new words that you never heard before, terms that describe something that you cannot understand. You want to find out what it is all about, yet it seems that you cannot make sense of all the information you are receiving. Often parents
are just not on the same wavelength as the person who is trying to communicate with them about their child’s disability.

*Powerlessness* to change what is happening is very difficult to accept. You cannot change the fact that your child has a disability, yet parents want to feel competent and capable of handling their own life situations. It is extremely hard to be forced to rely on the judgments, opinions, and recommendations of others. Compounding the problem is that these others are often strangers with whom no bond of trust has yet been established.

*Disappointment* that a child is not perfect poses a threat to many parents’ egos and a challenge to their value system. This jolt to previous expectations can create reluctance to accept one’s child as a valuable, developing person.

*Rejection* is another reaction that parents experience. Rejection can be directed toward the child or toward the medical personnel or toward other family members. One of the more serious forms of rejection, and not that uncommon, is a “death wish” for the child—a feeling that many parents report at their deepest points of depression.

During this period of time when so many different feelings can flood the mind and heart, there is no way to measure how intensely a parent may experience this constellation of emotions. Not all parents go through these stages, but it is important for parents to identify with all of the potentially troublesome feelings that can arise, so that they will know that they are not alone. There are many constructive actions that you can take immediately, and there are many sources of help, communication, and reassurance.

**Seek the Assistance of Another Parent**

There was a parent who helped me. Twenty-two hours after my own child’s diagnosis, he made a statement that I have never forgotten: “You may not realize it today, but there may come a time in your life when you will find that having a daughter with a disability is a blessing.” I can remember being puzzled by these words, which were nonetheless an invaluable gift that lit the first light of hope for me. This parent spoke of hope for the future. He assured me that there would be programs, there would be progress, and there would be help of many kinds and from many sources. And he was the father of a boy with mental retardation.

My first recommendation is to try to find another parent of a child with a disability, preferably one who has chosen to be a parent helper, and seek his or her assistance. All over the United States and over the world, there are Parent to Parent Programs. The National Information Center for Children and Youth with Disabilities (NICHCY) has listings of parent groups that will reach out and help you. If you cannot find your local parent organization, write to NICHCY to get that local information.
Talk with Your Mate, Family, and Significant Others

Over the years, I have discovered that many parents don’t communicate their feelings regarding the problems their children have. One spouse is often concerned about not being a source of strength for the other mate. The more couples can communicate at difficult times like these, the greater their collective strength. Understand that you each approach your roles as parents differently. How you will feel and respond to this new challenge may not be the same. Try to explain to each other how you feel; try to understand when you don’t see things the same way.

If there are other children, talk with them, too. Be aware of their needs. If you are not emotionally capable of talking with your children or seeing to their emotional needs at this time, identify others within your family structure who can establish a special communicative bond with them. Talk with significant others in your life—your best friend, your own parents. For many people, the temptation to close up emotionally is great at this point, but it can be so beneficial to have reliable friends and relatives who can help to carry the emotional burden.

Rely on Positive Sources in Your Life

One positive source of strength and wisdom might be your minister, priest, or rabbi. Another may be a good friend or a counselor. Go to those who have been a strength before in your life. Find the new sources that you need now.

A very fine counselor once gave me a recipe for living through a crisis: “Each morning, when you arise, recognize your powerlessness over the situation at hand, turn this problem over to God, as you understand Him, and begin your day.”

Whenever your feelings are painful, you must reach out and contact someone. Call or write or get into your car and contact a real person who will talk with you and share that pain. Pain divided is not nearly so hard to bear as is pain in isolation. Sometimes professional counseling is warranted; if you feel that this might help you, do not be reluctant to seek this avenue of assistance.

Take One Day at a Time

Fears of the future can immobilize one. Living with the reality of the day which is at hand is made more manageable if we throw out the “what if’s” and “what then’s” of the future. Even though it may not seem possible, good things will continue to happen each day. Worrying about the future will only deplete your limited resources. You have enough to focus on; get through each day, one step at a time.
Learn the Terminology

When you are introduced to new terminology, you should not be hesitant to ask what it means. Whenever someone uses a word that you don’t understand, stop the conversation for a minute and ask the person to explain the word.

Seek Information

Some parents seek virtually “tons” of information; others are not so persistent. The important thing is that you request accurate information. Don’t be afraid to ask questions, because asking questions will be your first step in beginning to understand more about your child.

Learning how to formulate questions is an art that will make life a lot easier for you in the future. A good method is to write down your questions before entering appointments or meetings, and to write down further questions as you think of them during the meeting. Get written copies of all documentation from physicians, teachers, and therapists regarding your child. It is a good idea to buy a three-ring notebook in which to save all information that is given to you. In the future, there will be many uses for information that you have recorded and filed; keep it in a safe place. Again, remember always to ask for copies of evaluations, diagnostic reports, and progress reports. If you are not a naturally organized person, just get a box and throw all the paperwork in it. Then when you really need it, it will be there.
Do Not Be Intimidated

Many parents feel inadequate in the presence of people from the medical or educational professions because of their credentials and, sometimes, because of their professional manner. Do not be intimidated by the educational backgrounds of these and other personnel who may be involved in treating or helping your child. You do not have to apologize for wanting to know what is occurring. Do not be concerned that you are being a bother or are asking too many questions. Remember, this is your child, and the situation has a profound effect on your life and on your child’s future. Therefore, it is important that you learn as much as you can about your situation.

Do Not Be Afraid to Show Emotion

So many parents, especially dads, repress their emotions because they believe it to be a sign of weakness to let people know how they are feeling. The strongest fathers of children with disabilities whom I know are not afraid to show their emotions. They understand that revealing feelings does not diminish one’s strength.

Learn to Deal with Natural Feelings of Bitterness and Anger

Feelings of bitterness and anger are inevitable when you realize that you must revise the hopes and dreams you originally had for your child. It is very valuable to recognize your anger and to learn to let go of it. You may need outside help to do this. It may not feel like it, but life will get better and the day will come when you will feel positive again. By acknowledging and working through your negative feelings, you will be better equipped to meet new challenges, and bitterness and anger will no longer drain your energies and initiative.

Maintain a Positive Outlook

A positive attitude will be one of your genuinely valuable tools for dealing with problems. There is, truly, always a positive side to whatever is occurring. For example, when my child was found to have a disability, one of the other things pointed out to me was that she was a very healthy child. She still is. The fact that she has had no physical impairments has been a great blessing over the years; she has been the healthiest child I have ever raised. Focusing on the positives diminishes the negatives and makes life easier to deal with.
Keep in Touch with Reality

To stay in touch with reality is to accept life the way it is. To stay in touch with reality is also to recognize that there are some things that we can change and other things that we cannot change. The task for all of us is learning which things we can change and then set about doing that.

Remember That Time Is on Your Side

Time heals many wounds. This does not mean that living with and raising a child who has problems will be easy, but it is fair to say that, as time passes, a great deal can be done to alleviate the problem. Therefore, time does help!

Find Programs for Your Child

Even for those living in isolated areas of the country, assistance is available to help you with whatever problems you are having. NICHCY’s State Resource Sheets list contact persons who can help you get started in gaining the information and assistance you need. While finding programs for your child with a disability, keep in mind that programs are also available for the rest of your family.

Take Care of Yourself

In times of stress, each person reacts in his or her own way. A few universal recommendations may help: Get sufficient rest; eat as well as you can; take time for yourself; reach out to others for emotional support.

Avoid Pity

Self-pity, the experience of pity from others, or pity for your child is actually disabling. Pity is not what is needed. Empathy, which is the ability to feel with another person, is the attitude to be encouraged.

Decide How to Deal With Others

During this period, you may feel saddened by or angry about the way people are reacting to you or your child. Many people’s reactions to serious problems are caused by a lack of understanding, simply not knowing what to say, or fear of the unknown. Understand that many people don’t know how to behave when they see a child with differences, and
they may react inappropriately. Think about and decide how you want to deal with stares or questions. Try not to use too much energy being concerned about people who are not able to respond in ways you might prefer.

**Keep Daily Routines as Normal as Possible**

My mother once told me, “When a problem arises and you don’t know what to do, then you do whatever it was that you were going to do anyway.” Practicing this habit seems to produce some normalcy and consistency when life becomes hectic.

**Remember That This is Your Child**

This person is your child, first and foremost. Granted, your child’s development may be different from that of other children, but this does not make your child less valuable, less human, less important, or in less need of your love and parenting. Love and enjoy your child. The child comes first; the disability comes second. If you can relax and take the positive steps just outlined, one at a time, you will do the best you can, your child will benefit, and you can look forward to the future with hope.

**Recognize That You Are Not Alone**

The feeling of isolation at the time of diagnosis is almost universal among parents. In this article, there are many recommendations to help you handle feelings of separateness and isolation. It helps to know that these feelings have been experienced by many, many others, that understanding and constructive help are available to you and your child, and that you are not alone.

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**Article courtesy of National Dissemination Center for Children with Disabilities (NICHCY).**

**About the Author**

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*Ms. Smith has seven adult children, the youngest of whom has multiple disabilities. She also has a seven year old adopted grandson who has Down syndrome.*
The appropriate goal of physical therapy for children with Down syndrome is not to accelerate their rate of gross motor development as is commonly assumed. The goal is to minimize the development of abnormal compensatory movement patterns that children with Down syndrome are prone to develop. Early physical therapy makes a decisive difference in the long-term functional outcome of the child with Down syndrome. Beyond this goal, there is an additional opportunity that physical therapy makes available to parents. Because gross motor development is the first learning task that the child with Down syndrome encounters, it provides parents with the first opportunity to explore how their children learn. There is increasing evidence that children with Down syndrome have a unique learning style. Understanding how children with Down syndrome learn is crucial for parents who wish to facilitate the development of gross motor skills as well as facilitating success in other areas of life including language, education, and the development of social skills.

The mother of an infant with Down syndrome recently asked about beginning physical therapy with her child. She began the meeting by asking: “If we start physical therapy now, what difference will it make when my child is nine or ten years old?” What a great question! It is exactly how she should be thinking about physical therapy, and, in fact, it is exactly how she should be thinking about all the services for her child. She has focused on the long-term functional outcome for her child. That question and that focus have guided my work for many years. This paper will answer her question. What difference, indeed, will it make years from now, when a child is an adolescent or an adult, whether or not he or she had physical therapy as a child? This article will address the goal of physical therapy for children with Down syndrome, and then looking beyond that goal, will discuss an additional opportunity that is available to parents while their child is receiving physical therapy.

THE GOAL OF PHYSICAL THERAPY
Before discussing what the goal of physical therapy for children with Down syndrome is, it is necessary first to understand what the goal is not. The goal of physical therapy is not to accelerate the rate of gross motor development. This statement is more controversial than it may initially seem to be. Many parents, many physical therapists, and many insurance companies assume that the value of physical therapy can be measured by whether or not a child is achieving motor skills more quickly. Some therapeutic techniques promote themselves by saying that children who are treated with that technique develop motor physical therapy skills earlier. If, however, one begins with the premise that the goal of physical therapy is to accelerate the rate of gross motor development, then one needs to answer the question posed by that mother. What
difference will it make in nine or ten years that a child with Down syndrome walked at 21 rather than 24 months of age? How will that three-month difference affect a child’s long-term functional outcome? I do not believe that it will make any difference whatsoever, and, therefore, I do not believe that it is the appropriate goal for physical therapy for children with Down syndrome. The rate of gross motor development in children with Down syndrome is influenced by a number of factors, including:

- Hypotonia
- Ligamentous laxity
- Decreased strength
- Short arms and legs

These factors are determined by genetics, and although some may be influenced by physical therapy, they cannot be fundamentally altered.

So then, what is the goal of physical therapy for children with Down syndrome? Children with Down syndrome attempt to compensate for their hypotonia, ligamentous laxity, decreased strength, and short arms and legs by developing compensatory movement patterns, which, if allowed to persist, often develop into orthopedic and functional problems. The goal of physical therapy is to minimize the development of the compensatory movement patterns that children with Down syndrome are prone to develop.
Gait is a primary example. Ligamentous laxity, hypotonia, and weakness in the legs lead to lower extremity posturing with hip abduction and external rotation, hyperextension of the knees, and pronation and eversion of the feet. (See Figure 1.) Children with Down syndrome typically learn to walk with their feet wide apart, their knees stiff, and their feet turned out. They do so because hypotonia, ligamentous laxity and weakness make their legs less stable. Locking their knees, widening their base, and rotating their feet outward are all strategies designed to increase stability. The problem is, however, that this is an inefficient gait pattern for walking. The weight is being borne on the medial (inside) borders of the feet, and the feet are designed to have the weight borne on the outside borders. If this pattern is allowed to persist, problems will develop with both the knees and the feet. Walking will become painful, and endurance will be decreased. Physical therapy should begin teaching the child with Down syndrome the proper standing posture (i.e., feet positioned under the hips and pointing straight ahead with a slight bend in the knees) when he is still very young. (See Figure 2.) With appropriate physical therapy, gait problems can be minimized or avoided. (See Figure 3.)

Trunk posture is another example. Ligamentous laxity, hypotonia, and decreased strength in the trunk encourage the development of kyphosis, which is often first seen when the child is learning to sit. Children with Down syndrome typically learn to sit with a posterior pelvic tilt, trunk rounded and the head resting back on the shoulders. (See Figure 4.) They never learn to actively move their pelvis into a vertical (upright) position, and therefore, cannot hold their head and trunk erect over it. If this posture is allowed to persist, it will ultimately result in impaired breathing and a decreased ability to rotate the trunk. Physical therapy must teach the child the proper sitting posture by providing support at the proper physical therapy level even before the child is able to sit independently. (See Figure 5.) First, the therapist provides upper trunk support, then middle trunk support, then support between the scapula and the waist, then support at the waist and finally pelvic support. The support provided at each level keeps the spine and pelvis in proper alignment until the child develops the strength to hold that segment in alignment himself. Appropriate physical therapy can minimize problems with trunk posture. (See Figure 6.)
Physical therapy services:

- Should be concerned with the child’s long-term functional outcome
- Should seek to minimize the development of compensatory movement patterns
- Should be based on a thorough understanding of the compensatory movement patterns that children with Down syndrome are prone to develop
- Should be strategically designed to proactively build strength in the appropriate muscle groups so that the child with Down syndrome develops optimal movement patterns
- Should focus on gait, posture, and exercise

So the answer to that mother’s question is that physical therapy for the young child with Down syndrome will make an enormous difference not only when the child is nine or ten years of age, but also when he or she is an adolescent and an adult. It can and should result in adults who are healthier and more functional.

THE OPPORTUNITY OF PHYSICAL THERAPY

If physical therapy has achieved the goal of minimizing the development of abnormal movement patterns, it will have influenced the health of the child with Down syndrome throughout the course of his or her life. But there is actually an opportunity beyond the development of motor skills of which parents may wish to take advantage while their child is receiving physical therapy.

There is mounting evidence that children with Down syndrome do not learn in the same manner that typical children do. They have a different style of assimilating information, and, therefore, the usual methods of instruction are less effective. The development of gross motor skills is the first learning task that the child with Down syndrome and his parents will face together. There are many other challenges to come including language, education, and the development of social skills, but learning gross motor skills is the first developmental challenge. The opportunity is for parents to use the arena of gross motor development to begin to understand how their child learns. Knowing how to facilitate their child’s learning will be critical to their success in collaborating with their child throughout his or her lifetime.

Wishart (1991), a psychologist at the University of Edinburgh in Scotland, has done leading edge work in studying how children with Down syndrome learn. She writes: physical therapy despite the absence of an adequate developmental database, theory and practice in this area have nonetheless continued to assume that the process of learning in children with DS is essentially a slowed-down version of normal cognitive development.
An increasing number of recent studies are suggesting that this ‘slow development’ approach may be ill-founded and that learning may differ significantly in structure and organization from that found in ordinary children. (p. 28-29).

Infants with DS consistently showed evidence of underperforming, with avoidance routines being produced on many of the tasks presented, regardless of whether these were above or below the infant’s current developmental level. New skills, even once mastered, proved to be inadequately consolidated, often disappearing from the infant’s repertoire in subsequent months. Follow-up studies using a wider range of tasks provided additional evidence of this tendency to ‘switch out’ of cognitive tasks, with many children failing on items which should have been well within their capabilities and which had been passed in earlier sessions ... (p. 29).

Regardless of whether these irregular performance profiles reflect genuine developmental instability or are the result of fluctuating motivation in assessment-type situations, it remains that if test behavior is typical of behavior in other, everyday situations, development itself must be compromised. (p.29).

Investigation into the learning style of children with Down syndrome is in its early stages. Kumin (2001) and Oelwein (1995) also have made important contributions in this area. In her book Classroom Language Skills for Children with Down Syndrome: A Guide for Parents and Teachers, Kumin discusses how the insights of Howard Gardner can be applied to children with Down syndrome. Gardner’s book, Frames of Mind (1983), presents the theory of multiple intelligences, which postulates that intelligence is multi-faceted. The theory holds that besides linguistic and mathematical intelligences, there are also spatial, interpersonal, and musical intelligences, to mention only a few. Kumin notes that it has been her experience that many children with Down syndrome learn well using music. She has also written about the unique learning style of children with Down syndrome, and how it pertains to learning speech and language in her book, Communication Skills in Children with Down Syndrome: A Guide for Parents (Kumin, 1994).
Oelwein (1995) also has written about the learning style of children with Down syndrome and how it impacts education. She has highlighted the need to consciously assist children with Down syndrome with how information can be effectively filed, stored and retrieved. Her book, Teaching Reading to Children with Down Syndrome: A Guide for Parents and Teachers, provides a comprehensive, step-by-step guide to teaching reading to children with Down syndrome. All of this work points to how important it is for parents to have an understanding of how their child assimilates information so that they can be successful partners in their child’s learning.

It has been my experience in 21 years of providing physical therapy to children with Down syndrome that they do indeed learn differently and that it is necessary to modify my approach if I wish to obtain the best result. I consider it an important opportunity of my work to help parents begin to understand how their child learns. The following “tips” were derived from many years of working with children with Down syndrome. They are offered to provide a starting point for both parents and therapists to begin to explore the unique learning style of the child with Down syndrome.

1. Children with Down syndrome have a decreased ability to generalize. This means that a skill learned in one setting does not necessarily transfer to another setting. For instance, a child may be quite competent climbing the stairs at home, but when confronted with stairs at the clinic, he or she may regress to a much more primitive stair-climbing strategy until he or she has relearned the skill in the new setting.
2. Children with Down syndrome need information to be delivered in small bite sized pieces. It has been my experience that if a child appears to have plateaued, the problem is most likely to be that the next piece of information is too large and needs to be further broken down.

3. The setup is crucial and needs to be as close to perfect as possible. Children with Down syndrome need structure, consistency, and a familiar environment if you hope to get their best performance. Do not try something new or challenging when the child is tired, hungry, or not at his best for some reason. The quality of the work you do together is more important than the quantity. Minimize distractions in the environment.

4. Follow the child’s lead. The child must be motivated to perform a particular skill. Trying to impose your will on a child with Down syndrome is a losing game. I often try to model my style of interaction after the parent’s. It is familiar to the child and most likely to be successful.

5. Be attentive to how the child reacts when learning new gross motor skills. Some children are cautious, and others are risky. A cautious child prefers to stay in one position, while the risky child prefers to be in motion. For example, when learning to walk, the cautious child will want lots of support and will be upset if he or she falls. The risky child will like walking because it involves movement and will not be concerned about support or care how many times he or she falls.

6. Know when to quit. Some children will only give you two repetitions at a particular skill and then insist on moving on. Other children will gladly give you a dozen repetitions. Set up the game so that the child is successful and avoids frustration.

7. Be strategic in planning your session. Practice what the child is ready to learn. Tackle the most difficult skills first before the child becomes tired. Alternate difficult skills with easier ones to give the child time to recover his strength.

8. Be strategic in providing support. Children with Down syndrome tend to become quickly dependent on support. Provide as little support as possible while still allowing the child to succeed and remove the support as soon as possible.

9. Skills will be learned grossly at first and then refined. For instance, children will initially learn to walk with a wide base and their feet externally rotated. This is not the optimal gait pattern, but it needs to be allowed initially and then refined through the post-walking skills.

10. Do not interfere with an established skill in which the child has achieved independence. You will not be successful in introducing change and the child will only experience you as nagging. Changes will need to be made at the next level of motor development. For instance, some children, instead of learning to creep on both knees, learn to creep on one knee and one foot. Once this pattern has physical therapy been established and the child is
proficient in its use, you will not be successful in altering it and will succeed only in angering the child. Teach the child to use both knees in climbing up stairs rather than interfering with this established pattern.

11. Children with Down syndrome learn best through a gradual process.
   
   a. Introduction of the new skill is the first step. The new skill needs to be introduced slowly and carefully with the goal being simply to have the child tolerate the movement.
   
   b. Familiarity is the second step. In this step, the child becomes accustomed to the skill and how it feels physically. This is the “I get it” phase in which the child understands the game and what is being asked of him or her.
   
   c. Collaboration is the third step. The child increases his collaboration and cooperation, and at the same time support is decreased.
   
   d. Independence is the final step where the child has mastered the skill and can perform it independently without support.

These tips are offered tentatively, knowing that they are far from definitive answers. Much more research is needed to truly begin to understand the learning style of children with Down syndrome. It is crucial, however, that parents gain skill in facilitating the learning of their child. Otherwise, as Wishart (1995) says, we “could run the risk of changing slow but willing learners into reluctant, avoidant learners.” (p. 62).

Parents who are newly assuming the responsibility of caring for a child with Down syndrome are confronted with a confusing array of treatment options and opportunities. It can be difficult to know where to focus limited time and resources. It is hoped this article will provide parents and caregivers with a starting point and a framework for making decisions about what is important. They should think about proposed therapies just like the mother described in the first paragraph, from the perspective of the child’s long-term functional outcome. Physical therapy is a crucial service, not because it will accelerate a child’s rate of development, but because it will improve a child’s long-term functional outcome by preventing the development of abnormal movement patterns that are likely to become even more serious problems in adolescence and adulthood. Secondly, because gross motor development is the first learning task a child faces, it provides parents and other caregivers with the physical therapy opportunity to learn how a given child learns. Let the long-term functional outcome guide decisions about what to work on, and let understanding of the child’s learning style guide decisions about how to work on them.
REFERENCES


Helping Babies with Down Syndrome Develop Speech & Language

By Libby Kumin, Ph.D., CCC-SLP

Welcome to the great adventure of helping your baby learn to speak. It is exciting to get to know your baby and to watch them learn about their world. While your newborn cannot talk to you, they can communicate with you through cries, smiles, gestures, sound, and body language. Your baby wants to communicate with you and they begin communicating right from birth. When your baby cries, he is often sending a message that he wants attention. When your baby smiles and looks at you, he is sending you a message that he is happy and content, and maybe that he wants to play with you or be held. The way that you react to these messages can foster further communication. If you respond by coming to the baby and taking care of their needs, the baby will gradually become aware that making noises and sounds affects the environment. You are the most important person in your child’s life, and you will be instrumental in helping your baby learn language.

There are many things that we can do to help children move along the road to speech. Speech involves coordinating breathing, voice, and rapid and precise movements of the lips, tongue, palate, and jaw. We use the same structures and muscles for speech that we also use for breathing, eating, drinking, blowing bubbles, and making clicking, popping, and “throwing a kiss” sounds. Through feeding and play, we can begin to work early on some of the same skills and movements that your child will need to speak. Here is what you can do to help your infant develop language and speech:

LOOK

Infants look all around, taking in the many sights of their new world. To learn language, infants need to learn three visual skills:

- To look at you
- To look at an object together with you
- To focus on an object and explore it

You can help your baby learn these skills through play. Encourage your baby to look at your face by making funny faces and smiling. Hold objects up to your face so that your baby looks right at you, but also hold objects in your hand and look at the object together with your infant. When you look at an object together, take time to explore it. Use sound effects and look interested in the toy. Touch the toy, smell it, look at it, and comment on what you see and feel. That will increase your baby’s interest in exploring.
LISTEN
In order to listen, your baby needs to have adequate and reliable hearing. Children with Down syndrome often have fluid in the middle ear and fluctuating hearing loss. Hearing needs to be checked frequently. The Healthcare Guidelines for Individuals with Down Syndrome recommend hearing testing by three months of age, with follow-up testing every six months to three years of age and annually throughout childhood. The pediatrician or otolaryngologist (ear, nose and throat medical specialist) working with the audiologist (specialist in hearing testing and treatment) can develop a treatment program to ensure that your baby’s hearing will be the best hearing possible.

You can teach your child to pay attention to sound, and to listen longer to sounds. Musical tapes, CDs, and musical toys (such as bells and xylophones) are terrific! Comment on sounds and look for the source of the sound, e.g., “Do you hear an airplane? Look, there it is!” or “I hear a meow. Let’s look for the cat.” When you come into your child’s room, call his name and wait for him to turn to you. Sing songs and play with musical toys. Sway back and forth, dance with your child, and respond to the rhythm. Many of the speech rhythm concepts can be learned through music.

INTERACT
You want to help your infant develop the awareness that making noises or using gestures will get results from the environment. This is known as communicative intent. How can you help your child develop this skill? Interpret anything that your child does as communicative and respond to it in that way. So, if your baby kicks her feet, play a game with her toes or put a balloon or even a tambourine near her feet that she can kick. If she looks over at the front door, ask if she wants to go outside. If she makes a “mmm” sound, react to it as if she said “mama” and respond. Say the word “mama” and point to mama. If she makes a “bbb” sound, react to it as if she said “ball.” Point to the ball and play with it. Engage your baby in the play. Show by your actions how delighted you are at your child’s attempt to communicate.

TOUCH
Infants respond to touch. They may find it comforting or they may find it uncomfortable. Some infants with Down syndrome are hypersensitive to touch, i.e., they don’t like being touched especially around the mouth. Current thought is that children who are hypersensitive need lots of sensory experience with touch through massage and play. Use a washcloth and lotion to massage your child’s skin. Rub cotton, velvet, wool, and burlap on your child’s skin during play. You might use different types of
teething toys, which have different surface designs and shapes. Put together samples of all kinds of textures for your child to explore. For example, you might hide small toys in a shoebox filled with pasta or rice and help your child find the toys. You might have pieces of sandpaper, cotton balls, aluminum foil, Velcro, sponge, and velvet in a bag for your child to feel and learn about different textures (be sure to supervise; safety first). Provide interesting toys for your child to bite, mouth, and explore. Infant massage specialists and occupational therapists can provide assistance when needed.

FEEDING/STRENGTHEN MUSCLES

Feeding uses many of the same muscles and structures that are used for speaking. Sometimes, infants with Down syndrome have difficulty with feeding because of low muscle tone (floppy muscles) or tongue or lip strength and control. If your child is experiencing any difficulty with feeding, ask for help. Many hospitals and/or early intervention programs have feeding specialists, and a feeding evaluation can be done within the first week after birth, if needed.

PLAY WITH SOUNDS

Your baby makes sounds during the course of the day. When your baby makes a sound, such as papapa, imitate that sound and smack your lips together making the p sound. Follow your child’s lead, and repeat the sounds or movements (lip puckers and throwing a kiss) that your child makes. Repeat the same sound that your child made, but then vary it a bit. For example, sing the p-p-p up and down the scale. Or say it in a very high voice, then a very low voice; shout the sound, then whisper the sound. Make it fun! Make a variety of sounds – use lip-popping sounds, click the tongue on the roof of your mouth, say chachacha to exercise your jaw.

Oral massage, oral exercises, and sound play can help your child learn skills that will be needed for speech. A speech-language pathologist who specializes in working with muscles of the facial area is known as an oral motor specialist. A complete oral motor evaluation is recommended before one year of age. The specialist can develop a home treatment exercise program that will help your child prepare for speech.

STIMULATE LANGUAGE

Create a language-rich environment for your infant. In the course of the day, label any objects or people in whom your child shows interest. Make this a part of your daily activities, and follow your child’s lead. Certain activities lend themselves to stimulating specific vocabulary. For example, eating lends itself to talking about food and drink, utensils, kitchen items, and verbs (drink, eat, open). Bath time lends itself to talking about body parts, water, soap, shampoo, and hot and cold. When you go outside, there are trees and flowers, vehicles, stores, community workers, and neighbors. Use short phrases, so your child will learn the important words in his environment. Wait and see if your child will try to say words and sounds; take time to give him a chance to participate. A language evaluation is recommended by or before one year of age.
We learn language by watching and listening to people around us. Babies learn to make connections between words they hear and the objects and people they see. Most children with Down syndrome make that connection and are ready to use language on or before one year of age. At that age, they can usually understand words, but they are not ready to speak. But it is important that they continue to learn new language concepts, and that they have a more complex way of letting you know their needs than just crying, smiling, or looking. Babies and toddlers with Down syndrome have a lot to tell us and they become frustrated if they cannot make their needs known. Therefore, babies and toddlers need to use a system other than speech as a transitional system to communicate their needs until their muscles, nerves, and coordination skills are ready for speech.

The research has shown that children with Down syndrome begin to use speech anywhere from nine months to eight years of age. This is a very wide range, but we don’t need to passively wait for speech to happen. We can provide a pre-speech communication system, and we can help the child learn the skills that they need to be able to speak. The speech-language pathologist can help by providing information, and teaching you the skills that you need to help your child. Books and newsletters can provide helpful information to you. Some suggested readings are included at the end of this article.

The systems that are generally used by children with Down syndrome to communicate until they are ready to use speech are sign language, communication boards, picture exchange communication, and electronic communication systems. Sign language systems are symbolic hand gestures. Gestures that resemble actual real life situations, e.g., pointing to the mouth for eating or pretending to drink from a cup for drinking, may be used. Formal sign language systems such as American Sign Language (ASL) and Signed Exact English (SEE) may be taught. They may be used as a short-term transitional communication system until the child develops speech. Communication Boards are individually designed communication systems made up of pictures, photographs, line drawings, or words (for older children). Your child points to the pictures that represent what he is requesting. Communication boards may be made of tag board, or may be plastic sheets with pictures tucked into pockets, photo albums with communication pictures, or magnets on the
refrigerator with pictures of apples, juice, milk, water, and soda. There are many varieties of communication speech therapy boards and they are inexpensive and individualized. Picture exchange systems may also be used where parent and child physically exchange photographs or line drawings as the basis for communication, much like a speaker and listener. Electronic communication systems can also be used. They are more costly, but provide an early “voice” for your child.

In all of these systems, you will be using speech along with the sign or picture, so your child will continue to hear and learn speech. Although your child will be communicating through the sign or picture, you will always accompany that sign or picture with speech. This combination is known as Total Communication.

The speech-language pathologist can work with you and your child to help you learn the signs, and to choose materials for the communication board or exchange system that will be useful for you and your child. Why is it important to use a transitional communication system until your child is ready to use speech? Through the signs and pictures:

- Your child will be able to communicate his messages to you
- You will be able to understand the communication, lessening frustration for you and your baby
- Your child will be able to continue progressing in language, learning new words and concepts, and using them
- You will be able to get to know your child’s personality, and sense of humor through his communication

FINDING A SPEECH-LANGUAGE PATHOLOGIST

Speech and language information and help is available. A speech-language pathologist has professional training in communication development and disorders. The American-Speech-Language-Hearing Association awards professional credentials when the speech language pathologist has successfully completed undergraduate and master’s degree accredited programs, completed extensive clinical practicum and a clinical fellowship year, and passed a national certification examination. Speech-language pathologists who have been awarded professional credentials will use CCC-SLP after their name.

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REFERENCES AND RESOURCES


Occupational Therapy and the Child with Down Syndrome

by Maryanne Bruni, BSc OT(C)

If you are a parent reading this, you likely have a child with Down syndrome, as I do. My intent with this article is to provide you with some information about how an occupational therapist (OT) may be able to help you and your child. Occupational therapists who work with children have education and training in child development, neurology, medical conditions, psychosocial development, and therapeutic techniques. Occupational therapists focus on the child’s ability to master skills for independence. This can include:

- Self-care skills (feeding, dressing, grooming, etc.)
- Fine and gross motor skills
- Skills related to school performance (e.g., printing, cutting, etc.)
- Play and leisure skills

When your child is an infant, your immediate concerns relate to his health and growth, development of the basic motor milestones, social interaction with you and others, interest in things going on around him, and early speech sounds and responses. At this stage an OT may become involved to:

- Assist with oral-motor feeding problems (this can also be addressed by speech pathologists). Due to hypotonia and weakness of the muscles of the cheeks, tongue and lips, feeding is difficult for some infants with Down syndrome. OTs suggest seating positions and feeding techniques, and can be involved in doing feeding studies, if necessary
- Help facilitate motor milestones, particularly for fine motor skills. Occupational therapists and physical therapists work closely together to help the young child develop gross motor milestones (e.g., sitting, crawling, standing, walking). OTs work with the child at this stage to promote arm and hand movements that lay the foundation for later developing fine motor skills. The low muscle tone and loose ligaments at the joints associated with Down syndrome are real challenges to early motor development and occupational therapy can help your child meet those challenges.

When your child is a toddler and preschooler, she will likely have some independent mobility and will be busy exploring her environment. To assist her development, you will want to provide her with many opportunities for learning, you will want to encourage the beginning steps in learning to feed and dress herself, you will want her to learn how to play appropriately with toys and interact with other children, you will be encouraging speech and language skills, and you will continue to provide opportunities for refinement of gross motor skills. At this stage an OT may become involved to:
Facilitate the development of fine motor skills. This is an important stage in the development of fine motor skills for children with Down syndrome. Now they will be developing the movements in their hands that will allow them to do many things as they get older, but many children need some therapy input to ensure that these movements do develop. Children do this through play; they open and close things, pick up and release toys of varying sizes and shapes, stack and build, manipulate knobs and buttons, experiment with crayons, etc. Your child may face more challenges learning fine motor skills because of low muscle tone, decreased strength, and joint ligament laxity.

Help you promote the beginning steps of self-help skills. An OT can help parents break down the skills so expectations are appropriate, and can suggest positioning or adaptations that might help the child be more independent. For example, a child may have more success feeding herself with a particular type of spoon and dish.

Then your child enters the school system and the focus of your energies changes somewhat again! You help your child adjust to new routines, you attend school meetings to plan your child’s educational program, you focus on speech and communication, you help your child practice fine motor skills for school (such as learning to print), you expect your child to develop more independence in self-help activities, and you search out extracurricular activities that will expose your child to a variety of social, physical, and learning experiences. At this stage an OT may become involved to:

- Facilitate fine motor skill development in the classroom. Many OTs work in the school system and provide programs to help children with Down syndrome learn printing, handwriting, keyboarding, cutting, etc. They will also look at physical positioning for optimal performance (e.g., desk size, etc.) and assist with program adaptations based on the child’s physical abilities.

- Facilitate self-help skills at home and at school. As with all children, our kids with Down syndrome vary in personality, temperament, and motivation to be independent. Some children with Down syndrome have a desire to do things themselves, such as dress and feed themselves. These children may learn these skills by watching others and participating from a young age. Other children may be happy to let others do things for them, and may resist attempts to help them learn these skills. In these cases, an OT may be able to help a parent work out these challenges while helping the child develop better motor skills to be successful in self-help skills.

- Address any sensory needs your child may have. Sometimes a parent has a concern about things their child does that may relate to the child’s sensory development. For example, a child may excessively put toys in her mouth, she may have poor awareness of her body in space, she may squeeze everything too hard or drop things a lot, or she may not tolerate very well some routines like washing and brushing hair. An OT can offer suggestions to help the child and parents deal with these issues.
As parents we must be concerned with the well-being of our child in all respects. We have so many things to think about and keep track of: medical and dental needs, motor and communication needs, educational needs, advocacy, social and behavioral needs; the list seems to go on and on! We need the help of trained professionals to guide us and to work with our children to help them achieve their potential in life. An occupational therapist is one member of the team that we can rely on to provide professional assistance throughout the growth and development of our children. In Canada, occupational therapy services for children with Down syndrome can be accessed through hospitals, home care programs, infant development programs, specialty nursery schools, public schools, and through private therapy services.

(Editor’s note: In the US, OT services can be obtained through Early Childhood Intervention programs, public and private schools, and from private therapists.)


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Feeding

Babies born with Down syndrome can be bottle or breast-fed, but they may require a little additional assistance. Many factors can affect feeding, but the most common ones are due to a small mouth size, low muscle tone, or heart problems, which can make sucking difficult and very tiring.

On the following pages is information to help with bottle and breast-feeding. Another tool to use to help strengthen your baby’s suck is the pacifier. The pacifier strengthens oral motor control and helps develop the muscles needed for drinking, eating solid foods, and talking.

In addition, when your child is a little older, your speech pathologist will probably recommend some type of regular facial and oral stimulation so it is helpful if your child becomes accustomed to touching on the face and in and around the mouth at an early age.
Breast Feeding

BREAST-FEEDING YOUR BABY

Breast-feeding can offer many benefits for a baby with Down syndrome.

Babies with Down syndrome tend to be prone to respiratory infections and digestive upset. Because breast milk has protective immune factors, it can help decrease both the incidence and severity of infections.

Many mothers find that breast-feeding helps strengthen their emotional bond with their babies. Others find that the stimulation of the jaw and oral muscles that occurs with breast-feeding helps to encourage the child’s language development later on.

But breast-feeding a baby with Down syndrome may offer special challenges. If these challenges are met with patience and the support of a qualified lactation consultant (a breast-feeding expert), they generally can be overcome for a satisfying breast-feeding experience.

This article takes a look at some of the common challenges that occur when breastfeeding a baby with Down syndrome. If these suggestions are not helpful, check with your doctor and lactation consultant for advice.

Provide a Mealtime Schedule

Your baby may appear very sleepy and have a “floppy” appearance due to low muscle tone. These babies don’t show a lot of interest in mealtimes and may sleep through them. If so, you may need to take control by putting your baby on a feeding schedule. Begin with a schedule of feeding every 2 to 2-1/2 hours, then stretch longer periods as your baby grows older.

This can help in two ways. First, you are making sure that your baby is getting the nutrition needed for growth, rather than letting the baby sleep through feeding times. Second, you are helping establish and maintain your milk supply. As you may know, your body makes more milk when your baby eats more. Supply depends on demand. If you’re serious about wanting to breast-feed, don’t let your milk production dwindle away by letting your baby sleep through meals.

Many mothers find that short, frequent breast-feeding sessions tend to work out the best. If your baby gets sleepy between breasts, you can take a short break and help increase the baby’s alertness by changing the diaper.

The first few days of breast-feeding should be considered a “getting-to-know-you” period. Your doctor probably will have your baby monitored for weight gain, to make
sure that breast-feeding is providing enough nutrition. Remain calm if complications occur. Notify your doctor, but also use this time to find techniques that work for the individual preferences of your baby.

If your baby has a poor breast-feeding session, express (massage or pump out) your milk afterwards. This will not only keep up your milk supply, but your child can drink it later as a nutritional supplement.

**Alerting Techniques**

You probably will need to find ways to “alert” your baby before feedings. Here are some ideas to try:

- Wash your baby’s hands and face with cool water prior to feeding.
- Have your baby wear just a diaper during feedings. The increased skin contact provides more stimulation.
- Express a few drops of milk into your baby’s mouth to increase interest in the feeding.
- Stroke the side of your baby’s cheek to signal that it’s feeding time.
- A gentle exercise, called the Valsalva maneuver, sometimes is helpful in increasing a baby’s circulation and level of alertness. Gently bring your baby’s knees up to the head, repeating three to five times.

**Positioning Options**

Some babies will remain more alert if they are breast-fed in an upright position.

One position to try is a modified “football hold.” While seated, place your baby in a nearly upright position on your side. You may find it helpful to place a towel behind your baby’s head to help hold the head close to your breast. Offer your breast with your free hand. By bringing your baby’s head up to your breast, you help decrease the baby’s workload and may help the child stay alert longer.

**Baby with a Protruding Tongue**

Breast-feeding can be a challenge when the baby has a protruding tongue. It is important that the baby’s tongue be properly positioned for breast-feeding success.

Insert your finger, with the nail side down, between your baby’s tongue and the roof of the mouth. Next, rotate your finger so that the nail side is toward the roof of your baby’s
mouth. This helps correct an upward tongue position and allows the tongue to go below, rather than above, your nipple during feeding.

Practice this exercise several times before each feeding to help your baby develop a better sucking reflex.

**What if My Baby is Too Weak to Breast-Feed?**

There may be some situations when your doctor advises against breast-feeding. It can be just too exhausting for babies who don’t have a sufficiently strong sucking and swallowing reflex to get enough milk to meet their needs.

This can be a real disappointment for moms who really want to breast-feed. Talk with your doctor about providing your breast milk for tube feedings or through a special bottle as needed. Even if supplemental formulas are used in addition to your breast milk, you may find this a satisfying alternative.

**Support is Important**

Having a good support system of family and friends can make this time much easier. It is also important to consult a qualified lactation consultant if you are experiencing difficulties. Many mothers have found it extremely helpful to talk with other mothers who have breast-fed their babies with Down syndrome. Your lactation consultant, feeding specialist, doctor, or local La Leche League (an organization devoted to assisting breastfeeding mothers) can provide helpful referrals.
BOTTLE-FEEDING YOUR BABY

Most babies with Down syndrome grow properly and do just fine in the eating department. But some young babies with Down syndrome have a harder time sucking efficiently, due to their low, floppy muscle tone. Their mouths may be less “alert” or ready for feeding, and the extra effort they have to put out to eat gives them less endurance for getting through the whole meal.

Breast-fed babies with low muscle tone can lose interest while waiting for the milk to let down. Some babies with Down syndrome find it harder to latch on to the breast or bottle nipple and maintain a good hold throughout the meal. These babies take many more breaks and end up eating less per feeding than you would expect for the amount of time spent. Swallowing excess air is common because the baby has a less efficient hold on the nipple.

Despite these concerns, babies with Down syndrome and their parents usually find a few tricks that make feedings easier for everybody. This article looks at some techniques that often work.

What Can Be Done?

Low-tone babies need to be helped to use the muscle strength and control they have. They often prefer to be fed in a way that requires the least effort, rather than using their muscle control. To help encourage muscle strength, you need to “wake them up” or alert them before and during each feeding. Here are a few wake-up strategies; contact your baby’s doctor and developmental team to review the appropriateness of these activities for your child:

Preparation

Start the feeding when your baby is most awake or alert.

See if playing with your baby just before feeding helps increase attention for the meal. Play gentle tickle games with fingers, toys, or kissing around the face and neck. Dance with your baby so head and upper body control is stimulated.

Bounce your baby gently in your lap. Of course, the dancing and bouncing should be done only if your baby can handle that much stimulation and has the head control necessary to participate without getting hurt.
Some parents have found that a cool or tepid bath wakes up their baby before feedings. Others have found that a brisk towel rub helps.

After waking up your baby’s body, focus the alerting on the face and mouth area. A cool washcloth on the face or gentle tapping around face and mouth may increase readiness for the bottle.

Some parents have found that gently tickling or stretching the muscles around the lips and cheeks helps wake up the mouth. You can use fingers and washcloths.

**Position**

Feed your baby in as upright a position as possible. The more your baby is up against gravity, the more active the muscles become. In addition, babies with Down syndrome seem to be more prone to ear infections. Upright feedings decrease the chance of liquid backing up in the ear canals, reducing the risk of infection.

Be sure that your baby is being fed in a chin tuck position. This position, with the head not too far back and not too far forward, seems to set up the neck and mouth muscles for the strongest sucking response. Try to rest your baby’s head – not neck – on your arm when holding during feedings, which automatically tucks the chin slightly. This position also can be achieved with pillows or arm rests.

An angled bottle, available commercially, may be used to keep the baby’s head at this angle until the end of the feeding. With a regular bottle, children must tip their heads back to get the last few drops. An angled bottle solves this problem.

**Cool the Liquid**

Temperature may affect the efficiency and speed of your baby’s sucking and swallowing. After checking with your doctor, consider starting the baby at room-temperature formula and gradually chilling the formula until your baby can handle it straight from the refrigerator. This can increase not only the baby’s interest in sucking but also the amount that is sucked during the meal.
Cheek and Tongue Involvement

Some babies need to be reminded to suck during the meal by having a little attention drawn to their tongues. To increase tongue involvement, try tapping the nipple on the tongue or pressing up and down on the tongue regularly throughout the meal. This may serve to wake up the tongue, but should be discontinued or decreased if it disrupts the meal too much.

Cheeks can be tickled, squeezed slightly, or tapped to keep them active during a feeding.

Ask for Help

Babies with Down syndrome have all the basic skills necessary for taking a breast or bottle. The suggestions in this article are intended to increase babies’ efficiency and control, so they can progress to more difficult food textures and consistencies.

Some babies with Down syndrome have further medical complications that interfere with good sucking or good nutritional intake. These conditions may require extra assistance. Ask your pediatrician, feeding specialist, or developmental team if you have questions or need more help.
Life is not about how many breaths you take,
but about how many moments that take your breath away.

-UNKNOWN
Proper estate planning is important for any family, but even more so for a family of a child with special needs.

It is extremely important to first seek legal advice from an attorney who has experience in estate planning for children with special needs. The State of Texas has very specific laws that will shape the future for your child, especially if your child continues to receive publicly-funded benefits such as Medicaid.

While DSG cannot offer specific legal advice or recommendations, experts recommend that you establish a will as soon as possible that leaves NO money or property directly to your child. Instead, a Special Needs Trust should be established, and then the trust becomes the beneficiary, not the child.

It is also important that no other relative, however well-meaning, name your child as a beneficiary of any estate.

If your child with special needs receives an inheritance at any age that is outside of a Special Needs Trust, your child could be taken off of public assistance and possibly be responsible for paying the state back for prior expenses.

Some children born with Down syndrome are able to live an independent life as adults. Others, however, are unable to manage without assistance. It is impossible to predict your child’s future, but with proper estate planning, you can feel comfortable that your child’s future needs will be met.

Each family must choose a qualified attorney with whom they are comfortable working.
PLANNING FOR SPECIAL NEEDS PERSONS

OVERVIEW
Summarize key government programs, discuss Special Needs Trust (SNT)

I am not a government benefit program specialist. Like anything that has to do with our government, our public benefit programs are complex and constantly changing. I can’t tell you that I know this area as a government employee would and I am not an expert of what particular benefits your child may receive but I can at least summarize the basics.

What I want to do is try to summarize our major government programs as they exist today and then focus on special needs trust an over of my practice that I spend a consider time in.

I. INTRODUCTION, SPECIAL NEEDS PERSONS.

A. Introduction. As parents of a special need person nobody knows better than you that many special needs persons need a considerable amount of assistance and supervision in order to meet their daily living needs. A special needs person may need (1) full or part-time assistance from an aid in their home, (2) full-time nursing home care, (3) treatment in a residential or mental health facility, (4) health care coverage to pay for extensive and ongoing medical bills, and/or (5) a source of monthly income. For many individuals, government benefit programs provide a necessary safety net, without which they could not meet the needs of their day-to-day existence and medical costs.

Eligibility for many governmental benefit programs is restricted to persons with limited resources and income. Therefore, when special needs persons directly receive assets or income (e.g., through inheritance, gift, or personal injury settlement), the recipient may become ineligible for many public benefit programs. What at first might seem like long-awaited financial relief from an otherwise severely restricted lifestyle, could easily end up being the catalyst responsible for the disruption of a very complicated system of public benefits that holds together the day-to-day support system of a disabled adult or child.

Supplemental Needs Trust (SNT) also referred to as a “Special Needs Trust,” are the main planning device that can be used to hold assets which otherwise would belong to the special needs child, and thereby permit the individual to become qualified or remain eligible for various public benefit programs. Essentially, when such trust are established, maintained, and administered in a proper manner, the assets in the trust are not treated as
disqualifying resources for the beneficiary. Further, if distributions are made properly from the trust, the amounts disbursed will not be counted as disqualifying income to the beneficiary. If we can recognize and respond to the special circumstances associated with benefit program requirements and how these issues interact with establishing and administering the trust, we can insure that our special needs child can get the benefit and use of their trust assets and still qualify for public assistance programs.

II. FEDERAL MEDICAL INSURANCE AND ASSISTANCE PROGRAMS.

In order to do the simplest assessment of a person’s eligibility for state and federal benefits programs, and to understand the rules of those programs, it is necessary to know about the various types of program assistance available. The following sections discuss Medicare and Medicaid, two federal and/or state programs and that provide medical care and other health-related assistance to elderly or disabled people, including minor children.

A. Medicare.

Medicare is a federal health insurance program available to individuals who (1) meet either the disability or age (65 or older) requirements of the program, (2) have paid money into the program through retirement tax payments, and/or (3) have become eligible to receive Social Security Disability or Railroad Retirement Disability benefits, or (4) who have end-state renal disease. Coverage through the Medicare program is automatic when payments have been contributed to the program from the qualifying person’s own income or that of his or her spouse or parent, as is the case with dependent children or survivor coverage. Medicare is a source of health insurance coverage available to a citizen who has paid Social Security taxes and who is drawing either Social Security Retirement or Social Security Disability benefits or Railroad Retirement Disability benefits. Persons who are over age 65 but who have not paid money into the program through federal retirement tax payments or withholding, can elect to enroll in the Medicare program and can get Medicare coverage by signing up for the coverage and paying the required premiums.

In order to receive Medicare insurance coverage then: (1) a person must make an election at age 65 or older for program coverage if they have not paid into a qualifying retirement system which gives them automatic coverage, or (2) for automatic coverage, the claimant or someone whose payments can be credited to the claimant (e.g. the claimant’s spouse or a dependent child), must have made countable payments into the Social Security or Railroad Retirement Systems. 42 U.S.C. §1395c; 42 C.F.R. §§406.20 through 406.26; and 42 C.F.R. §406.10(a). As with any insurance program, some medical services are covered by Medicare and some are not, and a co-payment or deductible amount is normally required for most of the covered expenses.
Eligibility for the Medicare Program is not usually restricted by a person’s access to their assets or income. In other words, when applying for Medicare coverage, it makes no difference what that person’s current income is, what assets she or he may own, or, in most circumstances, whether any or all of the those assets are held in trust or restricted by some other alternative planning device. Therefore, because we typically do not need to consider special trust structures or other estate planning alternatives in order to qualify a special needs person for Medicare.

B. **Medicaid.**

Medicaid is a term usually used to refer to government health care programs that provide medical care and services to indigent (poverty level) persons under title XIX of the Social Security Act, found at 42 U.S.C. §1396 et. seq. In order to be eligible for assistance through a Medicaid program, an applicant must meet **both** the (1) **income**, and (2) **resource** restrictions of the program.

Medicaid program are funded primarily with federal tax dollars that are allocated to each of the fifty states. The states are responsible for administering the allocated dollars along with some state matching funds to provide the program services to state residents. (42 U.S.C. § 1396a and 42 U.S.C. § 1396d.) Currently in Texas, the Medicaid programs are administered and controlled by the Texas Health and Human Services Commission, hereafter referred to as “the Department” or “HHSC.”

The states have some latitude within the federal laws and regulations to establish their own individual guidelines regarding qualifications for program assistance. Therefore, the programs are creatures of both federal and state law, meaning that both must be considered when choosing planning devices for persons with disabilities including the use of special needs trust.

The term “Medicaid” may be used to mean one or more of several different programs administered by the Department. For example (1) “Nursing Home Medicaid,” or “Long-Term Care Medicaid” covers most of the nursing home expenses for persons, including minor children, who reside in qualified nursing facilities and whose medical condition (referred to in program language as “medical necessity”) requires that they receive continuous care of that kind; and (2) “Community Medicaid” refers to comprehensive medical assistance programs that can pay for doctor visits, hospital stays, prescription drugs, and adaptive aids for people not residing in nursing homes. Additionally, there are Community care programs that cover some or all of the cost associated with providing in-home daily living assistance and skilled nursing or medical care for elderly or disabled adults or children while living in their homes.

One Medicaid program that provides in-home assistance and care to disabled or elderly individuals is the Community Based Alternatives (CBA) Program. Under the CBA program, an eligible person has hospitalization, prescription medicine, and
physician coverage and they can also receive (1) adaptive aids and medical supplies, (2) adult foster care, (3) assisted living care services, (4) emergency response services, (5) money for minor home modifications, (6) occupational therapy, (7) personal assistance services, (8) physical therapy, (9) respite care, (10) and speech pathology services. Essentially, the services available to someone who qualifies for the CBA program are similar to those that the person would receive in a skilled nursing facility, but through the CBA program, the goods and services are made available to the recipient in their own home. The goal of the CBA program is to keep as many people in their own homes and in their communities as possible and to reduce the number of disabled or elderly people housed in nursing homes. Similar services are provided to disabled children through the such community based programs as CLASS, MDCP, and Texas Health Steps. For many disabled or incapacitated adults and children, Community Medicaid is the only alternative for health care coverage that they have. It is often the case that disabled people are considered “uninsurable” under conventional health insurance standards. Yet, individuals with debilitating physical or mental conditions are the very person who will most often need expensive medical treatment or assistance with their daily living needs.

**Medicaid Planning Practice Note** – As will be discussed in detail in Section III, eligibility for the Medicaid programs depends on a special needs person’s monthly income and countable resources. However, assets held in qualifying trusts, are exempted from calculations of available or countable assets. Having “exempt assets” or resources that are not “available” or “countable” because they are held in special trusts means that (1) the value of the assets will not count against the applicant in figuring his or her eligibility for program assistance, and (2) the assets need not be liquidated or “spent down” before programs benefits can begin. Further, while distributing cash to a Medicaid recipient will usually result in the program counting the distribution as income to the recipient in the month it is received, it is possible to avoid that result in certain situations. For example, if Medicaid services are provided to the special needs person through one of the community based programs listed above, a third-party (which includes the special needs person’s trust) can purchase goods and services directly for the special needs person and such “in-kind support and maintenance” payments will not be counted as disqualifying monthly income.

From the perspective of protecting assets in special trusts and making allowable distributions to special needs persons, while staying within the program rules, we must consider the special needs person’s needs and balance those distribution demands against the type of distributions allowed by the program’s guidelines for monthly income. Serious consideration must be given to understanding the interaction between the Department’s controlling rules regarding (1) allowable trust distributions and other payments for Medicaid recipients, on the one hand, and (2) how the Department applies those rules to distributions made from special needs trust or other third-parties, on the other.
III. SUMMARY OF SELECTED MEDICAID PROGRAMS & THEIR ELIGIBILITY REQUIREMENTS

Although the cap on countable income does consistently change and increase slightly every year to adjust for cost of living and inflation, the asset limitation for Medicaid program qualification has remained the same since 1989. The Department publishes its rules for the Medicaid programs in the Medicaid Eligibility handbook (also referred to herein as the “Handbook” or the “MEH”). The MEH is available online at the HHSC website at:  http://www.dads.state.tx.us/handbooks/meh/.

As will be discussed here in more detail, eligibility for SSI and Medicaid may depend on the applicant’s ability to meet numerous requirements, including (1) nationality and Residence requirements, (2) Age, Blindness, or Disability requirements, (3) Medical Necessity Requirements, and (4) Income and Resource Limitations.

A. Nationality and Residence

To qualify for Medicaid, the applicant must be (a) a U.S. Citizen, or (b) an alien lawfully admitted to the U.S. for permanent residence, or (c) otherwise permanently living in the U.S. under color of law (as defined in the regulation). 40 T.A.C. §15.300(a), (b). The applicant must be a resident of Texas, which means that he or she must have established residence in Texas and intend to remain here. 40 T.A.C. § 15.301(a). No specific period of residence in Texas is required, and travel outside Texas does not terminate residency here, so long as the applicant has an intent to return to the state.

B. Age, Blindness, or Disability

An applicant for Nursing Home Medicaid must be either age 65 or older, blind, or disabled (under the Social Security Disability definition discussed below). 40 T.A.C. §15.305(a). In practice, the requirement of being disabled is never an issue, because the “medical necessity” requirement for receiving skilled nursing (nursing home) Medicaid benefits is more stringent than the “disability” requirement of Social Security.

C. “Medical Necessity” & “Disability” for Nursing Home & Community Based Alternatives (CBA) Programs

For some Medicaid programs an applicant must establish they have sufficient physical needs or limitations referred to in program language as “medical necessity,” to qualify for program coverage. Two such programs are (1) the Nursing Home Medicaid Program, and (2) the Community Based Alternatives, or CBA, Program 40 T.A.C. §§ 19.601-19.604. The initial assessments for medical necessity is made on form 3652-A (the CARE form) upon admission to the nursing home or program, and a follow-up is done annually thereafter in most cases.
Essentially, someone (adult or child) meets the “medical necessity” requirement if he or she has a medical disorder or disease necessitating regular attention by registered or licensed vocation nurses. An inability to attend to the “activities of daily living,” such as bathing, grooming, and eating, is not sufficient to meet the standard of medical necessity. See 40 T.A.C. § 19.2402 et seq. for the applicable regulations.

Other Medicaid programs require proof of a “disability,” but not necessarily a “medical necessity” in order to receive program services. One class of Medicaid programs, known as “Community care” programs, provides in-home and community-based services to functionally impaired people who are elderly or have disabilities, allowing them to remain in their own homes or communities. The “disability” requirement for qualifying for most Community Care programs is less stringent than the “Medical Necessity” test required for Nursing Home Medicaid or the CBA program. The Community Care programs require that the applicant meet the definition of being “disabled” as defined by the Social Security Act for the Supplemental Security Income (“SSI”) program, which definition is that the person have the need for assistance in at least some activities of daily living as determined by the assessment interview.

Community Care programs provide assistance with bathing, dressing, toileting, food preparation, housekeeping, etc. The number of assistance hours an applicant will qualify for per week varies based on the caseworker’s determination of the applicant’s needs as gained from the assessment responses given to the caseworker by the applicant, or his or her representative. These “assistance” hours do not include any medical benefits. Medical benefits are provided by the program separately and in addition to assistance hours.

D. **Income & Resource Limitations**

1. **Nursing Home Medicaid.**

As of January 2008, to qualify for Medicaid nursing home program benefits in Texas, an unmarried applicant’s monthly “countable” **income** cannot exceed $2,128, and he or she cannot have more than $2,000.00 in “available” or “countable” **resources** (i.e., cash or property readily convertible to cash, like stocks, bonds, etc.). If an applicant has more “countable assets” than permitted by the particular Medicaid program for which he or she is applying, the applicant generally has to “spend down” the available resources before qualifying for the program.

2. **Community Care Programs.**

For most of the Community Care programs, the **income restrictions** in year 2008 are the same as for Nursing Home Medicaid: $2,128 per month in income for a single person. With the exception of a few programs, the **resource limits** for Community Care programs, including the CBA program,
are also the same as the limits for Nursing Home Medicaid: $2,000.00 for a single person. (See 40 T.A.C. §§ 481.6001-481.6020 for regulations governing the Community Based Alternatives (CBA) Program.) There are a few Community Care Medicaid programs, such as the Adult Foster Care (AFC) program, the Day Activity and Health Services program, the Emergency Response program, and the Family Care program, which have slightly less stringent resource requirements.

E. Available or Countable Resources.

Remember that for most Medicaid programs, including the Nursing Home Medicaid and CBA programs, the resource limits is $2,000 in countable resources for an individual. “Resources are cash, other liquid assets, or any real or personal property or other non-liquid assets owned by a special needs person, his [or her] spouse, or parent, that could be converted to cash.” 40 T.A.C. §15.100, Medicaid Eligibility Handbook § 2310. Instruments that produce income, such as promissory notes and bonds, are counted as resources to the extent of their fair market value; and in addition, the payments received by the special needs person are counted as income in the month received. If there is a mortgage on real property or a security interest on personal property, only the equity value is counted.

Resources are counted only as of 12:01 A.M. on the first day of each month. Changes from that time until one month later do not affect countable resources for that month. Countable resources are reduced by the amount of funds encumbered before 12:01 A.M. of the first day of the month. That is, if a check is outstanding at that time, the bank balance at the time is reduced by the amount of the check for the purpose of determining countable resources. 40 T.A.C. § 15.400(a), (b), 15.435(b)(2), Medicaid Eligibility Handbook § 2310.

To be counted, resources must be both owned (solely or in part) by the applicant and “accessible to” the applicant. “If a special needs person has the right, authority or power to liquidate the property or his [or her] share of it, the property is a resource. If a special needs person would be required to seek court action to access or dispose of property, that property is not considered a resource.” 40 T.A.C. § 15.415(a), (b), Medicaid Eligibility Handbook § 2313. A special needs person’s resources are considered available to him or her when they are being management by a legal guardian, agent under a power of attorney, or other fiduciary agent of the special needs person, unless a court denies the guardian or agent access to the resources. 40 T.A.C. § 15.415(e), (f) Medicaid Eligibility Handbook § 2313.4.

If a special needs person has a joint bank account and he or she can legally withdraw funds from it, all of the funds in the account are considered a resource of the special needs person. However, the rules impose only a presumption that all of the funds in a joint bank account are available to the special needs person and the special needs person must be allowed an opportunity to prove that some or all of the funds are the
property of someone else. Any amount of funds proven to belong to someone else do not count as an available resource against the special needs person. T.A.C. § 15.43(m), Medicaid Eligibility handbook § 2331.3.

If an applicant converts one type of property to another type, the new property may or may not be counted as a “resource.” If the Department policy does not count the type of property that has been acquired by the conversion, then the new property is not a countable resource. Any cash received from the sale of a resource is considered a resource, not income. 40 T.A.C. § 15.420, 15.440(c), Medicaid Eligibility Handbook §§ 2314, 2344. By contrast, a “lump sum payment” other than from conversion of a resource is countable income in the month it is received (so it will usually result in at least one month’s disqualification) and is a countable resource thereafter. 40 T.A.C. § 15.450(b), Medicaid Eligibility Handbook § 2411. Examples of “lump sum payments” are inheritances, death benefits, personal injury awards, and payments of retroactive public benefits. Death benefits are excluded as income when they are used to pay the last illness and burial expenses of the deceased; and they are excluded as resources to the extent they have not been so used by the first day of the second calendar month after the month in which they are received. 40 T.A.C. 15.435(1), Medicaid Eligibility Handbook § 2332.5.

IV. FEDERAL INCOME ASSISTANCE PROGRAMS: SOCIAL SECURITY DISABILITY (SSD), AND SUPPLEMENTAL SECURITY INCOME (SSI)

Two federally funded programs that provide income assistance are the Social Security Disability (SSD) and the Supplemental Security Income (SSI) programs, both of which are administered by the Social Security Administration. The following section provides a general overview of those two programs. The income assistance provided through SSD or SSI generally is relatively small, but it is important to remember that (1) once an individual qualifies for SSD, and receives SSD payments for 24 months, he or she is eligible for the Medicare program, and (2) qualification for the SSI program automatically qualifies an individual for the Medicaid program.

A. Social Security Disability (SSD).

The SSD program is not an income or asset-restrictive program. Similar to the Medicare program in this way, Social Security Disability is paid only to disabled individuals who have made sufficient contributions to Social Security through employment taxes to become insured. An adult is considered “disabled” if he or she is unable to engage in any substantial gainful activity because of a medically determinable physical or mental impairment that can be expected to result in death or that has lasted or can be expected to last for a continuous period of at least 12 months. 42 U.S.C.A. § 1382c(a)(3(A); 20 C.F.R. §416.905. A child under age 18 is considered disabled if he or she has a medically determinable physical or mental impairment that meets the adult definition and that, in addition, result in “marked and severe functional limitations.” Marked and severe function limitations exist “when several activities or functions are
impaired, or even when one is impaired, as long as the degree of limitation is such as to interfere seriously with the ability to function (based on age-appropriate expectations) independently, appropriately, effectively, and on a sustained basis.” 42 U.S.C.A. § 1382c(a)(3)(H) and 20 C.F.R. Part 404 Subpart P, Appendix 1, Part B § 112.00C.

Each insured individual is covered by the program through a specific future date, or the “date last insured.” As the individual continues to work and pay into the system, the date last insured continues to move further ahead. When the individual stops working and paying into Social Security, the date last insured stops moving forward so that the individual eventually will pass the date last insured. In order to qualify for SSD, the individual must be declared disabled before the date last insured.

A person can qualify for SSD if he or she has paid into the Social Security program for at least 10 years and for at least 20 of the 40 preceding work quarters. A person can be eligible with less work history if the person is disabled and under age 31, or if he or she is disabled due to blindness. 20 C.F.R. 404.110 and 20 C.F.R. 404.120.

The amount of benefits paid to a qualifying individual is based on the age of the applicant and the total amount of his or her contributed payments. This means that, like the Medicare program as discussed above, the SSD program is not an income or asset “means tested” program.

SSD benefits are monthly cash payments made to the disabled person. Significantly, after a person is determined to be eligible for SSD benefits, eligibility for the Medicare program often follows. Once an individual qualifies to receive SSD benefits, he or she is also qualified to receive health care coverage through the Medicare program, in most cases, after a term of 24 months.

An applicant must be disabled for five months before he or she will be eligible for SSD benefits, regardless of the severity of disability, except when the disability is blindness. However, SSD benefits may be paid up to one year before filing the individual’s initial application. For applicants who are age 31 or older, to be “fully insured” the applicant must be credited with 40 quarters of coverage. 20 C.F.R. 404.110. The general rule for individuals with a steady work history is that they are insured for five years after they have stopped working.

Since eligibility for SSD benefits is not based upon the resources of the applicant, persons with significant resources do not need special planning in order to qualify.

**B. Supplemental Security Income, SSI.**

SSI is a monthly cash income assistance program intended to help pay for the applicant’s food, clothing, and shelter. 42 U.S.C. § 1381 et seq. As such, the benefits are designed to augment the income or assistance otherwise available to aged (age 65 or
over), blind, or disabled (same definition as stated for SSD) persons, including children, who meet the asset and income restrictions of the program.

1. Income and Resource Limitations.

SSI monthly benefits are based on the total amount of monthly income the person receives, including but not limited to, wages earned, payments available through other government assistance programs, gifts of money or property, and the value in “in-kind” support which can be applied toward food, clothing, or shelter. Although the income guidelines for SSI vary and are more restrictive than those for the Medicaid programs, the program applies the same asset restrictions as are applied for Medicaid as outlined above. Social Security Act § 1902(a)(10)(ii)(V), 42 U.S.C. § 1396a(a)(10)(A)(ii)(V). That is, the available resource limit for an individual is $2,000.00. Payments made from a trust are counted as income in the same way under the SSI rules as payments made to or for the benefit of the beneficiary from any other source.

For SSI purposes, “income” is defined at 20 C.F.R. § 416.1100-416-1182 and is generally regarded as anything the SSI recipient receives in cash, or property readily convertible to cash, or in kind support that can be used to meet his or her needs for food, clothing, and shelter. See also Social Security Administration Programs Operational Manual system (POMS) at SI101120.200J.3. Unlike SSD benefits, eligibility for SSI does not depend on contributions made by the individual in to the Social Security system through specific tax contributions or wage withholding. Significantly, since eligibility for Medicaid is “linked” to eligibility for SSI in Texas, if you qualify for SSI payments you automatically qualify for Community Medicaid coverage.

Income limits in year 2008 for the SSI program state that an unmarried person cannot have more than $637.00 per month in “countable income” and married couples are restricted to a combined amount of not more than $956.00 per month. SSI monthly payments are referred to in the program’s language as “Federal Benefit Rate” (hereinafter “FBR”). As is the case with the Medicaid programs, the amount of allowable monthly income for the SSI program is adjusted yearly in January. 20 C.F.R. § 416.1103. The program counts an individual’s “earned” and “unearned” income when assessing program eligibility. Earned income is gross wages of an employee, and net earnings from self employment (after deduction of business expenses but without allowing for deductions for taxes, or insurance, etc.). Unearned income is all income that is not earned, including without limitation annuities, pensions, alimony, child support payments (including in-kind support and maintenance), dividends, life insurance proceeds, and gifts and inheritances. 42 U.S.C.A. § 1382a(a)(2); 20 C.F.R. § 416.1102, 416.1110, 416.1112, and 416.1120.

Both categories of income, earned and unearned, have several “exclusions” applied when figuring the individual’s applied income and the list should be
consulted when making determinations about trust distributions. 42 U.S.C.A. § 1382a(b); 20 C.F.R. § 416.1124.

2. Treatment of In-Kind Support & Maintenance.

As is the case with Medicaid programs, the SSI program applies specific rules for counting payments of “in-kind support and maintenance.” In-kind support and maintenance is defined by the program as food, clothing, and shelter that is furnished by or paid for by someone other than the SSI recipient and it includes distributions made from a trust. In-kind support and maintenance payments are categorized as unearned income. In the program rules, distributions from special trusts are treated basically in the same manner as payments made by third parties. In general, the value of this type of unearned income payment reduces the amount of the SSI benefit to the recipient dollar-for-dollar.

Alternative Planning Devices for In-Kind Support & Maintenance Rules
– Because of the in-kind support and maintenance rules of both the SSI and the Medicaid programs, most fiduciaries believe that they cannot make distributions for these types of costs from special trust if their trust beneficiary receives benefits from the SSI and/or Medicaid programs. However, as will be discussed in more detail in the case studies below, certain SSI income reduction rules and Community Medicaid waiver rules make it possible to avoid program disqualification when in-kind support and maintenance payments are made by third-parties for the benefit of the disabled client.

Obviously in most circumstances it is not possible for a person to pay all of their food, clothing, and shelter costs with only $637.00 per month in allowed income. The following alternative planning devices should be considered when paying for in-kind support and maintenance expenses for SSI recipients.

a. One-Third Reduction Rule: Instead of making a determination of the actual dollar value of in-kind support and maintenance being provided to the SSI recipient and then reducing his or her monthly payment of $637.00 dollar-for-dollar based on that value, if the client or trust beneficiary is living in the household of another person who is providing both food and shelter to the trust beneficiary, we can elect to apply the One-third Reduction Rule to the amount of the beneficiary’s SSI payment. This means that rather than suffering disqualification from the program, or dollar-for-dollar reduction in their monthly payments regardless of the value of the distributions made for this type of in-kind support and maintenance, the recipient will instead be allowed to receive the food and shelter provided and a reduction of only 1/3 of the monthly Federal Benefit Rate (“FBR”) will be applied against them. In year 2008, that means that the reduction amount applied is 1/3 X the FBR of $637.00 which = $214.00. (Another way of viewing it is that $214.00 will be counted as income, in addition to any other countable income the client may have.) As a result, the SSI recipient
would receive a monthly payment of $637.00 minus $214.00, or $377.  20 C.F.R. § 416.1131.

b.  **Presumed Value Rule:** If the One-Third Reduction Rule does not apply to the beneficiary’s circumstances because the beneficiary is not living in another person’s household who is providing both food and shelter for them, but the client is receiving any food, clothing, or shelter from another source, (including payments made for food, clothing, or shelter by a special trust for the benefit of the beneficiary), under this rule, the agency will presume that the maximum value of furnished supports 1/3 of the Federal Benefit Rate plus $20. So, in year 2008, that calculation would be 1/3 of $637.00, which = $214.00 plus $20.00 which = $234.00. This presumption of the maximum value of the provided food, clothing, or shelter is rebuttable by the beneficiary, meaning that if it can be shown that the actual value of the furnished food, clothing, or shelter is less than $214.00, the client can elect to have his or her income reduced by that actual value rather than the “presumed value” of $214.00.

c.  **Exception to the One-Third Reduction and Presumed Value rules:** If the SSI beneficiary live in the household with someone a part of whose income is “deemed” to the beneficiary through the SSI rules (e.g. a minor child living in the household with his or her parent(s), where part of the parents’ income is attributed to the child) then the value of food, clothing, and shelter paid by the parents or anyone else on behalf of the beneficiary is not treated as income to the beneficiary and no reduction in the monthly SSI payment results.  20 C.F.R. § 416.1148 and 416.1160 et seq.

d.  **Business Arrangement.** The SSI rules further hold that a recipient is not receiving in-kind support and maintenance in the form of room or rent if the recipient is paying the amount charged for these costs under a “business arrangement.” This means that there will be no reduction in the beneficiary’s monthly SSI payments if it can be shown, through proper record keeping, that the beneficiary fully pays, or pays his or her pro rata share, of the actual cost of the household expense. A pro rata share is determined by dividing the average monthly household operating expenses by the number of people living in the household, regardless of their age or disability.  20 C.F.R. § 416.1130(b), 416.1133.

e.  **Rent Subsidy – Pay 1/3 FBR to the Landlord.** The rule applied in Texas is that a “business arrangement” will be deemed to exist whenever the rent paid by the SSI recipient equals or exceeds the presumed maximum value amount of $234.00 as discussed above. Therefore, even if the fair market value of the rent is $637.00, there will be no additional “income” attributed to a rent subsidy payment from another source if the beneficiary is paying at least $234.00 to the landlord. This means that a third party or trust can supplement the beneficiary’s rent and other costs, such as utilities and waste.
collection, etc. without the beneficiary losing any of his or her SSI payment. Further, 1) if the property being leased to the beneficiary is owned by the landlord receiving the direct rent payment, and 2) that landlord is not related to the beneficiary in any way, then no amount of rent subsidy paid by the third-party including a qualifying trust will be treated as income against the beneficiary for purpose so SSI qualification.

These considerations are of primary importance to us planners because it provides an opportunity to pay for all of the SSI recipient’s beneficiary’s food, clothing, and shelter, in exchange for a maximum reduction, if any, in the client’s monthly SSI payment of no more than $214.00. These food, clothing, and shelter payments can be made in addition to the unlimited payments the SNT can make to providers for the beneficiary’s “supplemental needs.” The only thing the trust cannot do for the beneficiary is to pay cash directly to the beneficiary. Further, because the beneficiary stays SSI qualified, he or she will also stay Medicaid qualified meaning that the Medicaid program pays for (usually) all of the beneficiary’s medical needs. This leaves the assets of the SNT available to cover the rest of the beneficiary’s needs.

V. USING SPECIAL TRUSTS TO QUALIFY FOR BENEFITS AND MAXIMIZE ALLOWABLE DISTRIBUTIONS.

A. Defining Special or Supplemental Needs Trusts.

As the prior discussions regarding the SSI and Medicaid programs make clear, it often is imperative that a disabled or incapacitated person be eligible for programs that will provide them with medical care and other personal assistance that they need. However, as we are all aware, a person’s disabilities or incapacity most often adds to the costs of their daily lives, and the strict limitations placed on a person’s available resources and income as required by SSI, Medicaid and other programs, such as those administered through the Texas Department of mental health and Mental Retardation (MHMR), can work extreme hardships on our special needs person who so desperately need the medical and/or daily living assistance offered through those programs. By sheltering a special needs person’s assets that exceed those resource limits in a “special needs trust,” (also referred to as “supplemental needs trust” ) or “SNT,” and making proper distributions from the trust so that such distributions are not counted within the program rules as income to the beneficiary, we can ease the financial constraints of the programs and still qualify the special needs person for benefit assistance.

When an SNT is properly established, any property held in the trust, regardless of the value or type of the property, is not counted against the beneficiary during their lifetime, for purposes of qualifying the beneficiary for public benefits programs. See 42 U.S.C.A. § 1396p(d).

B. Consideration of Special Needs Person Circumstances.
There are several questions to consider in deciding which special trust structure, if any, would be best suited to a special needs person’s needs. The following factors are always relevant in making trust structure determinations:

- The age of the special needs person;
- The nature of the special needs person’s disability or incapacity (physical and/or mental impairment);
- Whether or not the special needs person currently owns or has a present right to receive what would be otherwise disqualifying assets;
- The character and value of all the special needs person’s assets;
- The special needs person’s present and future medical and life-skills assistance needs;
- Whether or not the special needs person is under guardianship or is in need of guardianship;
- Whether or not the special needs person is presently involved in a lawsuit that may result in the special needs person’s receipt of money damages;
- Whether or not the special needs person has a surviving parent, grandparent, or legal guardian; and
- Whether or not the law places a primary duty of support on someone else thereby requiring that person(s) to bear the costs of the beneficiary’s health, education, maintenance, and support (e.g. a parent’s obligation to support and care for a child, or a spouse’s obligation to support their spouse.)

These factors are always of primary importance when considering which type of special needs trust will best protect the assets of a disabled or incapacitated beneficiary and the appropriateness of trust distributions and expenditures. See the discussion below regarding parental support obligations and a trustee’s considerations toward trust distributions in those circumstances.

C. **Self-Settled and Nonself-Settled Special Trusts.**

There are really two types of Special Needs Trusts: (1) Self-settled, and (2) Nonself-settled, or third party settled, trusts. Both types work the same way and accomplish the same thing for the special needs person. That is, the trusts insulate the assets placed in the trust so that those otherwise disqualifying assets are not counted as available resources to the trust beneficiary when the beneficiary applies for, or receives, benefits from an asset and/or income-restrictive governmental program such as SSI or Medicaid.

1. **Self-Settled Special Trusts.**

A self-settled SNT is one in which the trust corpus is made up of assets that either belonged to the trust beneficiary, or that the beneficiary had a present right to receive, prior to transferring the assets into the trust. SNTs created on behalf of the
2. Nonself-Settled SNTs.

A nonself-settled (or third-party settled) supplemental needs trust is one in which the trust corpus is made up of assets that did not belong to the trust beneficiary and that the beneficiary never had a present right to receive prior to transferring the assets into the trust. Special needs Trusts created on behalf of the disabled or incapacitated person by a third party, and which are funded with property that passes to the trust by direction of someone’s Will, by gift, or by inter-vivos transfer from the third party, for example, would be considered a non-self-settled, or third party trust. These trusts are often referred to as “common-law” supplemental needs trusts as their validity and use has been established by federal or state statute (i.e. created by the exception allowances of OBRA ’93 legislation), but through sixty-plus years of case law. Because the property in a third-party settled trust did not belong to the trust beneficiary at the time of transfer to the trust, there is no rule requirement that remaining trust assets be used to pay back the State Medicaid program for benefits received by the beneficiary during his or her lifetime as is required by the statutes for self-settled trusts.

VI. THE “PAYBACK PROVISION”.

Perhaps the most significant difference in the required provisions of certain statutory self-settled vs. common law nonself-settled trusts is what is referred to as “the payback provision.” As recited in the trust rules above, the payback rule, found in the provisions of 42 U.S.C. § 1396p(d)(4)(A), requires that qualifying trusts created under that statute must direct that on the death of the beneficiary, the state Medicaid program is entitled to be paid back from any remaining trust assets, an amount that is equal to the cost paid by the program on behalf of the beneficiary. The statutes do not impose this payback provision to third-party settled trusts.

Clearly then, of primary importance to us when deciding which special trust structure to use for a disabled or incapacitated special needs person is the question of whether or not the special needs person already owns, or has a present right to receive, the otherwise disqualifying assets that will be placed in the special trust. If the special needs person is going to receive the asset as a gift or a bequest in a Will, for example, we would want the grantor to create the special needs trust before the property is actually received by the disabled person/beneficiary and then we could avoid having to use a trust structure with any payback provision language in it.

Conversely, if the special needs person already owns the disqualifying asset, and the special needs person meets the other requirements of the state and federal statutes for using a special trust, then we have to include the required payback language in the trust.
agreement or it will not be accepted by SSI or Medicaid as a “qualifying” trust and the assets inside the trust will be counted as an available resource to the beneficiary.

A. Defending the Payback Provision.

One thing that needs to be kept in mind and understood about the payback provision required by 42 U.S.C. § 1396p(d)(4), is that the law places no obligation whatsoever on the trust(ee) to reserve or conserve any trust assets during the beneficiary’s lifetime in order to cover the payback obligation. In fact quite the opposite is true. It is the intent of the OBRA ’93 legislation that the trustee spend any and all amounts necessary from trust assets to improve the quality of life and care available to the trust beneficiary. If the trust has no money remaining in it at the beneficiary’s death, there is no obligation on the trust, the beneficiary, of his or her estate or heirs, to satisfy the payback provision. Or if the remaining assets are insufficient to cover all of the costs of the assistance provided, there is no obligation to satisfy the payback provision in full. If all of the trust assets are spent on the beneficiary’s needs during the beneficiary’s lifetime, the trust is closed when its assets are gone and the state Medicaid program receives no payment at all against the costs of the benefits provided to the beneficiary.

VII. THE RULES TO MAKE QUALIFIED TRUST DISTRIBUTIONS.

A. Managing a Special Trust.

The existing confusion with regard to allowable distributions from SNTs is certainly understandable when you consider all of the various government programs and all of the different program restrictions on counting a beneficiary’s income and assets for program qualification. The confusion provably arises most often because of the sort of program interdependency described above in the discussions about SSI and Medicaid, for example. As was discussed above, if we can qualify our disabled or incapacitated special needs person for SSI, the special needs person will also be qualified to receive Medicaid assistance. However, SNT trust distribution problems may arise because the SSI and Medicaid programs have different rules for counting the special needs person’s support and maintenance income when considering the special needs person’s program eligibility.

B. Medicaid Rules – A Closer Look.

As we discussed above, the MEH rules for applying support and Maintenance payments to persons qualifying for Community Program eligibility state:

Support and maintenance are not counted as income if eligibility is being tested for a waiver program; for example, Community Living Assistance and Support Services (CLADD), the Community Based Alternatives (CBA), Home and Community-Based Services (HCS), and Medically Dependent Children’s Program (MDCP). 40 T.A.C., § 15.455(b)(1), Medicaid Eligibility handbook §2451.
In addition, with regard to special trusts and the treatment of trust assets as a resource, in MEH §2313.45, the Handbook states the following:

The Omnibus Budget Reconciliation Act of 1993 identifies three types of trusts which are exceptions to the trust provisions stated in [Items 23.13.41 through 2313.44]. These exceptions apply only to trusts established on or after August 11, 1993. 40 T.A.C. §15.417(f).

40 T.A.C. §15.417(f)(1) Special needs trust. Description: A special needs trust is a revocable or irrevocable trust established with the assets of a person under age 65 who meets the Supplemental Security Income (SSI) program’s disability criteria. The trust must be established for the special needs person’s benefit by his [or her] parent, grandparent, legal guardian, or a court. The trust must include a provision that the state is designated as the residuary beneficiary to receive, at the special needs person’s death, funds remaining in the trust equal to the total amount of Medicaid paid on his [or her] behalf. This trust exception continues even after a special needs person becomes age 65 if he [or she] continues to meet the disability criteria for the SSI program. However, additions or augmentations to the trust after the special needs person becomes age 65 are a transfer of assets. [See Item 2320, Transfer of Assets.]

40 T.A.C. §15.417(f)(1) – Treatment as Resource: The trust is not counted as a resource.

Treatment as Income: Any distribution to or for the benefit of the special needs person from corpus or income generated by the trust, except payments for medical and social services, is countable income. [See Item 2420, Income Exemptions, for an explanation of medical and social services.] A payment to or for the benefit of the special needs person is counted under trust provisions only if such payment is ordinarily counted as income. MEH §2313.45

VIII. TRUST DISTRIBUTIONS – APPLYING THE SSI AND MEDICAID INCOME EXCEPTIONS

A great number of SNT trust beneficiaries receive SSI benefits and/or community Medicaid assistance. As we have seen, if the beneficiaries’ assets are held in a qualifying SNT then we know that those assets will not be counted as available resources to an SSI or Medicaid recipient. 40 T.A.C. §2313.45, MEH §15.417(f)(1). Therefore, the primary
of the fiduciary who is responsible for making trust distributions for the benefit of an SSI, Medicaid, or MHMR benefits recipient will be those programs’ rules regarding “countable monthly income.” (See discussions above.)

It is possible under both the SSI rules and the Community Medicaid rules to make trust distributions for a beneficiary’s support and maintenance costs, as well as additional medical and social service costs not covered by the medical assistance programs, and still keep the beneficiary qualified for SSI and/or Medicaid assistance. The following case studies will illustrate the applications of the program rules discussed above to two different special needs persons’ circumstances taken from active case files in my firm’s practice.

A. Planning Strategy – Case Study – Trust Distributions Medicaid’s CBA Program.

1. Medicaid CBA Program Rules Restated.

In the above discussions on the rules of the CBA Medicaid Program, we outlined the Medicaid SNT rules and the support and maintenance exceptions applied to a special needs person’s countable monthly income.

There are two important rules that must be read together in the MEH that, when applied correctly, will allow a qualified trust beneficiary to receive distribution payments for in-kind support and maintenance expenses without counting those payments as disqualifying income to the beneficiary. Equal in importance to the support and maintenance exceptions found in the SSI rules, these Medicaid exclusions should not be overlooked by the trustee when making special trust distributions.

As the emphasized language regarding trust distributions in rules quoted above shows, in order to determine if a trust distribution would be counted as income to the beneficiary, the fiduciary must ascertain which types of payments are ordinarily counted as income for special needs persons of the particular Medicaid program. Therefore, the rules regarding countable income must be cross-referenced with the rules applied to specific Medicaid programs.

B. Case Study – Trust Distributions & the SSI Program.

1. SSI Eligibility Rules Restated.

As discussed above, SSI is available to individuals who are either disabled, blind, or over the age of 65, and who meet the program’s stringent asset and resource limitations. Remember that one of the most important reasons for qualifying an individual for SSI is that an SSI recipient is automatically qualified for Medicaid. Therefore, even though the SSI program pays only a small amount per month in cash assistance, qualifying a disabled individual for SSI will automatically qualify that
individual for health care coverage and other public assistance to meet the individual’s daily needs. For an individual with extensive medical needs, qualification for SSI can man access to thousands of dollars in medical and personal care assistance.

2. Terry’s Case.

Terry is 25 years old and he has Down’s Syndrome. Terry is eligible for a small amount of SSD, based on the fact that he is disabled and his deceased father worked and paid into the Social Security System for a sufficient number of quarters. The SSD benefit receive by Terry is approximately $100 per month, and since the SSD is Terry’s sole source of income, he is well under the income limit of $637.00 for a single person receiving SSI. Terry is the beneficiary of a trust, which was established by his father as part of his estate plan. Since the trust is a properly established SNT, the assets of the trust are not countable resources that would disqualify Terry from receiving SSI. Further, since the assets of the trust are inherited property and not property that ever belonged to Terry, there is no requirement that the trust contain a reimbursement payback provision to the state of Texas. Terry receives $100 per month in SSD, plus $537.00 from SSI which brings his total monthly income up to $637. Because he is eligible for SSI, he is also eligible for Medicaid. The issue in Terry’s case is how to make distributions from his trust to take care of his support needs, including the costs of his food, clothing and shelter either in his home or at a residential facility, without disturbing his SSI and Medicaid eligibility. (Note that the following analysis would be the same if Terry were still a minor child.)

3. Distributions from Terry’s Trust.

As explained above, when an individual receives assistance with food, clothing, and shelter from another source, that assistance is called “in kind support and maintenance.” A distribution from Terry’s trust for his food, clothing, and shelter each month would ordinarily be considered as a distribution of “in kind support and maintenance.” In-kind support and maintenance is treated as income for purposes of eligibility for the SSI program. However, under the following situations applying the 1/3 reduction rules, or the business arrangement rule there are different alternatives for making distributions from Terry’s trust that would allow him to continue to be eligible for SSI, and consequently, receive his Medicaid coverage.


Remember that if Terry is living with a family member, so long as he pays his “pro rata share” of the actual cost of his food and shelter, as proven by household record keeping, then the receipt of the value of food and shelter is not counted as income to Terry and it, therefore, does not reduce his SSI benefit.

b. Rent Subsidy & the One-third Reduction Rule.
An alternative approach for Terry, if reliable records are not kept, or if the value of Terry’s rent exceeds $637.00 per month, would be for Terry to pay at least $234.00 (1/3 of the Maximum Monthly Federal benefit Rate, plus $20.00) towards his monthly household expenses. He would then fall within the requirements of the business arrangement rule and his SNT could pay the rest of his monthly household expenses and make distributions for any of his other supplemental needs. In this manner, Terry would continue to receive his SSI and he would remain eligible for Medicaid as well.

c. Rent Subsidy When Landlord is Not related to Beneficiary.

Now let’s assume that Terry resides in a residential facility where he is charged a monthly rental amount for his room. Terry is not related in any way to people who own the facility and his SNT pays the full cost of Terry’s monthly rental. Making direct payments to the facility from Terry’s SNT means that no rent subsidy paid by the trust will be counted as income to reduce Terry’s SSI check. Alternatively, Terry’s SNT could pay all of the costs of his provided food, clothing and shelter at the facility and allow SSA to reduce his check by 1/3 of the federal benefit rate or $214.00. Therefore, the trustee of Terry’s SNT makes distributions for Terry’s food, clothing, shelter and other services provided by the facility meaning he gets the benefit of payments far in excess of $214.00 in exchange for a reduction of just $214 in his SSI benefit. Additionally, Terry continues to remain eligible for SSI, and consequently, eligible for Medicaid.

The above scenarios change if Terry is a disabled minor child. If Terry is a minor child living in the household with his parent(s) and is subject to SSI deeming rules, his SSI benefits will not decrease if his trust payments are being made as contributions toward the actual costs of his food, clothing, and shelter.

A portion of these materials are reprinted with the permission of Deborah Green, Esq. from her publication “Oh I think I Need An SST”.
“THERE ARE NO SEVEN WONDERS OF THE WORLD IN THE EYES OF A CHILD. THERE ARE SEVEN MILLION.”

-WALT STREIGHTIFF
**Down Syndrome Guild of Dallas**  
**New Parent Checklist**

- Get connected with the Down Syndrome Guild of Dallas to receive a new parent packet and begin receiving the newsletter to learn about local support services, events and information. Membership is free to parents with children 12 months or younger. 214-267-1374; [www.downsyndromedallas.org](http://www.downsyndromedallas.org)

- Contact your local Early Childhood Intervention (ECI) provider to arrange for services. To determine which agency services your home area, see the list of agencies at the back of the Down Syndrome Guild phone directory or call the ECI Care Line at 1-800-628-5115.

- Make an appointment for you and your child to visit the Down Syndrome Clinic at Children’s Medical Center Dallas - call 214-456-2357. See enclosed brochure. There is typically a three month wait to get an appointment.

- Find a good pediatrician. Contact the Down Syndrome Clinic at Children’s Medical Center Dallas (Joanna Spahis 214-456-2327) or the Down Syndrome Guild for a referral. The American Academy of Pediatrics document entitled “Health Supervision for Children with Down Syndrome” is included in this guide and is designed to assist your pediatrician in caring for a child diagnosed with Down syndrome.

- Attend a new parent gathering sponsored by the Down Syndrome Guild of Dallas. These are informal gatherings for parents/families of children with Down syndrome ages 0-18 months, yet families with children of any age are welcome. They occur once per quarter generally in the months of February, May, August & November. You will receive an invitation in the mail.

- Familiarize yourself with the government programs available. See the “Programs in Texas offering Family Support and Services” document in this guide. Other than ECI, there are programs available to families of children with Special Needs. Because some of these programs have long waiting lists, it is beneficial to sign your child up for these services as soon as possible.

- Community Living and Support Services (CLASS). Provides a broad array of services to individuals with physical disabilities and related conditions occurring before the age of 21 years. Telephone number for information and to place a name on the waiting/interest list: (877) 438-5658.
✓ Home and Community based Services Program (HCS). Provides a broad array of services to both children and adults who have mental retardation and certain related conditions. To find the center nearest you call (512) 794-9268, or go to the web at http://www.dads.state.tx.us/contact/mra/index.cfm.
BIBLIOGRAPHY
FOR PARENTS OF NEWBORNS

PARENTING

An overview for new parents and professionals of children with Down syndrome.


Written for fathers, by fathers of diverse backgrounds. 800-843-7323; www.woodbinehouse.com.

A comprehensive reference book especially for new parents, but useful and informative for "seasoned" parents as well. Topics include: history of Down syndrome; developmental expectations; early intervention; the school years; recreation; adolescence and adulthood; vocational training and employment. 800-638-3775; www.pbrookes.com.

Gene Stallings recounts his life as a football coach and a father, focusing on his relationship with his son Johnny, who has Down syndrome.


A routine ultrasound reveals that the baby Tierney carries has a major heart defect, leading doctors to suspect Down syndrome. This book follows the Fairchild family and the decisions they must make regarding their unborn baby. 617-742-2110; www.beacon.org.
DEVELOPMENT
A practical and accessible guide to understanding and developing fine motor skills in children with Down syndrome. 800-843-7323; www.woodbinehouse.com.

Focuses on speech and language development from birth through the stage of making three-word phrases. Covers problem areas and treatment. 800-843-7323. www.woodbinehouse.com.

Provides parents and professionals with essential information about motor development associated with Down syndrome. 800-843-7323; www.woodbinehouse.com.

FAMILY SUPPORT
Case studies of families woven in a clear, readable fashion, followed by practical suggestions to help both parents and professionals alike. 303-757-2579; www.lovepublishing.com.

MEDICAL ISSUES
A guide for parents providing detailed, easy-to-understand information on a wide range of medical conditions. 800-843-7323; www.woodbinehouse.com.

BOOKS FOR CHILDREN
A day in the life of Russ, who happens to have Down syndrome. 800-843-7323; www.woodbinehouse.com. (other titles in this series are: Russ and the Firehouse and Russ and the Almost Perfect Day.)
A mother helps her daughter understand that a child who looks or acts differently, is much more like her, than different. www.twbookmark.com.
**Stuve-Bodeen, Stephanie.** *We'll Paint The Octopus Red.* Bethesda, MD: Woodbine House. 1998.

A simple repetitive story told with warmth and directness puts young siblings minds at ease, and helps them develop a positive outlook for their brother or sister with Down syndrome. 800-843-7323; www.woodbinehouse.com.


Isabelle and Charlie are friends who don’t have to be just alike to enjoy being with each other. Isabelle has Down syndrome. www.woodbinehouse.com.

For additional resources, please contact the National Down Syndrome Congress at 1-800-232-6372 or www.ndsccenter.org
A small group of thoughtful people can change the world. Indeed, it is the only thing that ever has.

- MARGARET MEAD
SSI and Medicaid
For Children with Down Syndrome

What is SSI?
Supplemental Security Income is a program that pays a monthly benefits check to people with low incomes and limited assets (less than $2,000) who are 65 or older, blind or disabled. As the name implies, SSI supplements a person’s income up to a certain level. Currently, the maximum amount paid is $674/month. Children with Down syndrome can qualify for SSI based on the following:

- **Rules for Children with Down syndrome Under 18:**
  Most children with Down syndrome do not have their own income and do not have assets (bank accounts, cars, jewelry, etc.). However, when children under 18 live at home, the Social Security Administration considers the parents’ income and assets when they decide if the child qualifies.

- **Rules for Children 18 and Older:**
  When a child with Down syndrome turns 18, the Social Security Administration no longer considers the parents’ income and assets when deciding if he/she can get SSI. A child with Down syndrome who was not eligible for SSI before his/her 18th birthday will become eligible at 18 (depending on the amount of wages earned, if he/she is working).

On the other hand, if a child with Down syndrome receiving SSI turns 18, and continues to live with his/her parents but does not pay for his/her portion of the household food and shelter, the monthly SSI check may be reduced.

What is Medicaid?
Medicaid is a health entitlement program - pays for doctor visits and hospital stays - for people with low incomes and limited assets (less than $2,000). Children and adults who get an SSI benefits check automatically qualify for Medicaid coverage.

How can I find out if my child is eligible for SSI?
Call the Social Security Administration at 1-800-772-1213. An application for SSI can be filed on the phone - the documents that must be filled out can be sent to your house - there is no need to go to a Social Security office.
Programs in Texas Offering Family Supports and Services

Medicaid

Medicaid was established in 1967 under the Social Security Act. It provides medical assistance for low income families and many individuals with disabilities, including children. Approximately 60% of those on Medicaid in Texas are children. Medicaid is an entitlement program, meaning that if you meet the eligibility requirements, the state must provide certain services within federal guidelines. In Texas, children receiving Medicaid services have the advantage of a comprehensive service package through the Comprehensive Care Program known as Texas Health Steps. This program requires that children receive whatever medical care is determined to be “medically necessary.” The Medicaid Comprehensive Care Program often becomes a lifeline for children with disabilities. The ability to access Medicaid healthcare can be the deciding factor as to whether a family can keep their child with disabilities at home. Without Medicaid services, some families are faced with the possibility of institutionalizing their child. The Texas Medicaid program is administered through the Health and Human Services Commission. Information on eligibility criteria and the application process can be obtained on-line at http://www.hhsc.state.tx.us/Programs/how_to.html, by calling 211, or by contacting your local Department of Aging and Disability Services Office (formerly Department of Human Services Office). To find the office nearest you, visit http://www.dads.state.tx.us/contact/dads_offices.html.

Medicaid Home and Community-Based Waiver Programs

Texas currently has seven different Medicaid waiver programs designed to allow Medicaid funds to be available to provide individuals with disabilities the opportunity to receive supports and services in their community as an alternative to institutional care. These waivers are administered through the Texas Department of Aging and Disability Services (DADS). Medicaid waiver services can be especially helpful to families caring for children with disabilities. Services can include nursing care, attendant care, respite, home modifications, medical equipment and supplies, therapies, service coordination, pre-vocational services, community living supports, assistive technology, and more. In addition to the services provided through the waiver program, a child who is in a Medicaid waiver program also has access to Medicaid healthcare benefits. Medicaid waivers, however, are not entitlements. This means that the number of individuals that can receive Medicaid waiver services depends on the willingness of the state legislature to fund these services. When the Texas Legislature meets every two years, they appropriate funding for a certain number of waiver “slots.” The “slots” appropriated translate into the number of people who will receive services. The number of “slots” funded, historically, has been well under the
number of individuals and families requesting those services. Consequently, waiver waiting/interest lists are used to provide services as they become available on a first-come, first-serve basis. To be eligible for Medicaid waiver services, children and adults must meet both financial eligibility requirements as well as functional eligibility requirements. In all but one of the seven waiver programs (Texas Home Living Waiver), financial eligibility for children is based on the child’s income rather than the family income, making it possible for many struggling families to obtain services that enable them to keep their child at home and prevent institutionalization. Due to the existence of extensive waiting/interest lists for Medicaid waiver services, it is important for families to place their child’s name on the waiting lists for all programs for which their child may be eligible as soon as possible. Eligibility assessments will not be done until a waiver slot becomes available, which may be several years. As it is often impossible to know what children may need in the future, it is better to have your child’s name on the list(s) so the option for services in the future remains available. Putting your child’s name on a waiver waiting list does not obligate you to accept those services in the future. It simply makes the option of supports and services available in the future. The following list of Texas Medicaid waivers is intended to provide basic information on each of the programs. Additional information can be obtained by contacting the agencies or the disability advocacy organizations listed in the resource section.
<table>
<thead>
<tr>
<th>Medicaid Waiver</th>
<th>Description</th>
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</table>
| Community Living and Support Services (CLASS)       | • Provides a broad array of services to individuals with physical disabilities and related conditions occurring before the age of 21 years;  
• Individuals with mental retardation may be eligible, but this waiver is not intended to serve those with a primary diagnosis of mental retardation;  
• Not currently available statewide, but expansion of existing service areas is expected;  
• Website: http://www.dads.state.tx.us/services/index.html;  
• Telephone number for information and to place a name on the waiting/interest list: (877) 438-5658. |
| Medically Dependent Children’s Program (MDCP)       | • Serves children and youth under the age of 21 years who have significant medical disabilities and would typically be eligible for nursing home care; provides respite, nursing, and home modifications;  
• Available statewide;  
• Website: http://www.dads.state.tx.us/services/index.html;  
• Telephone number for information and to place a name on the waiting/interest list: (877) 438-5658. |
| Home and Community based Services Program (HCS)     | • Provides a broad array of services to both children and adults who have mental retardation and certain related conditions;  
• Must meet functional eligibility requirements for intermediate care facilities for the mentally retarded;  
• Services are available statewide;  
• Website: http://www.dads.state.tx.us/services/dads_help/mental_retardation/index.html;  
• For information and to place a name on the waiting/interest list, contact your local Mental Health/Mental Retardation Community Center. To find the center nearest you call (512) 794-9268, or go to the web directory at http://www.dads.state.tx.us/contact/mra/index.cfm. |
| Community Based Alternatives (CBA)                  | • Provides supports and services to individuals over the age of 21 years with physical disabilities;  
• Must meet medical necessity criteria for nursing home care;  
• Services are available statewide;  
• Website: http://www.dads.state.tx.us/services/index.html;  
• For additional information and to place a name on the waiting/interest list contact your local DADS (Dept. of Aging & Disability Services) office (formerly Dept. of Human Services) or call (512) 438-4882. To find the office nearest you, visit http://www.dads.state.tx.us/contact/dads_offices.html. |
| Deaf-Blind Multiple Disabilities Program (DB/MD)     | • Serves individuals who are deaf and blind and have additional disabilities, over the age of 18 years;  
• Must meet functional eligibility requirements for intermediate care facilities for the mentally retarded;  
• Services are available statewide;  
• Website: http://www.dads.state.tx.us/services/index.html;  
• Telephone number for information and to place a name on the waiting/interest list: (877) 438-5658. |
| Consolidated Waiver Program (CWP)                   | • This is a Bexar County Pilot Program serving individuals of all ages, with varying disabilities; no specific waiting list exists as referrals for these slots come from the HCS, CLASS, MDCP, DBMD, and CBA waiting lists;  
• Must meet eligibility criteria for nursing home care or for intermediate care facilities for the mentally retarded;  
• Website: http://www.dads.state.tx.us/services/index.html;  
• Telephone number for information and to place a name on the waiting/interest list: (512) 438-3444. |
| Texas Home Living (TxHmL)                           | • Serves children and adults with mental retardation;  
• Must meet functional eligibility requirements for intermediate care facilities for the mentally retarded;  
• Services are available statewide;  
• Website: http://www.dads.state.tx.us/services/dads_help/mental_retardation/index.html;  
• For information contact your local Mental Health/Mental Retardation Community Center. To find the center nearest you call (512) 794-9268, or go to the web directory at http://www.dads.state.tx.us/contact/mra/index.cfm |
Other State-Administered Community Care Programs

In addition to Medicaid and Medicaid waiver programs, there are other state programs that offer services to children with disabilities. These programs are typically funded through state dollars or, like Medicaid programs, through a combination of state and federal dollars. These programs are referred to as “community care” programs and are intended to help individuals with disabilities remain in families and in their communities. Some family support services are available through these various programs, but benefit levels and the types of services offered are generally more limited than in the Medicaid waiver programs.

<table>
<thead>
<tr>
<th>Program</th>
<th>Description</th>
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</thead>
</table>
| In-Home and Family Support Programs | • Provides limited funding for family support services;  
 • Available statewide to children (and adults) with both physical and cognitive disabilities (currently, two separate programs exist – one serving those with mental retardation, and the other serving individuals with physical disabilities);  
 • Website: http://www.dads.state.tx.us/business/mental_retardation/in-home/;  
 • For information or to place a name on the waiting list, contact your local DADS office. To find the office nearest you, visit http://www.dads.state.tx.us/contact/dads_offices.html. |
| Children with Special Health Care Needs (CSHCN) | • Aimed at providing services to uninsured or underinsured children with special health care needs;  
 • Administered through the Texas Department of State Health Services; includes both medical and family support services;  
 • Website: http://www.dshs.state.tx.us/cshcn/default.shtml;  
 • Telephone number for information and to place a name on the waiting list: (800) 252-8023. |
| Primary Home Care (PHC) | • Provides personal care services to adults and children to assist with performing activities of daily living;  
 • Services are available statewide;  
 • Website: http://www.dads.state.tx.us/services/index.html;  
 • For additional information contact your local DADS (Dept. of Aging & Disability Services) office (formerly Dept. of Human Services). To find the office nearest you, visit http://www.dads.state.tx.us/contact/dads_offices.html. |
| Early Childhood Intervention (ECI) | • Provides early intervention services such as therapies, parent training, assessment and evaluation, and more;  
 • Available to children from birth to three years with disabilities or developmental delays;  
 • Services are available statewide;  
 • ECI services are an entitlement to eligible children, therefore no waiting lists exist;  
 • Website: http://www.dars.state.tx.us/ecis/index.shtml;  
 • For screening information contact (800) 250-2246. |
| Children’s Health Insurance Program (CHIP) | • Designed to provide healthcare benefits for children in families who earn too much to qualify for Medicaid, yet cannot afford to buy private insurance; provides medical care only;  
 • Does not offer family support services;  
 • Is available to children with disabilities and children with special health care needs;  
 • Website: http://www.hhsc.state.tx.us/chip/;  
 • Telephone number for additional information or to obtain an application: (800) 647-6558. |

**Women, Infants and Children Program (WIC)**

Your child may automatically qualify for WIC if he/she receives Medicaid, Temporary Assistance to Needy Families or Food Stamps. WIC provides free formula and nutritious foods for pregnant women and children from birth to age 5. Gross income must fall at or below 185% of federal poverty income levels to qualify. Call the toll free number or check the website to see what type of documentation you need to bring to your appointment.

Call 1-800-942-3678 to find a WIC clinic near you. Check out the website dshs.state.tx.us/wichd/default.shtm
Early Intervention

ECI is a statewide program for families with children, birth to three, with disabilities and developmental delays. ECI supports families to help their children reach their potential through developmental services. Services are provided by a variety of local agencies and organizations across Texas.

Early Childhood Intervention (ECI) services are provided by a network of non-profit organizations. The services provided include:

- Therapies, parent training, assessment and evaluation
- Available to children from birth to three years with disabilities or developmental delays
- Services are available statewide
- Services are an entitlement to eligible children, therefore no waiting lists exist
- Website: http://www.dars.state.tx.us/ecis/index.shtml

Locate the ECI agency that serves your area by calling the ECI “Care Line” at (1-800-628-5115)

Life isn’t a matter of milestones, but of moments.
ECI Provider Network

Following is an alphabetical listing by city of the ECI Provider Network for our area:

**Dallas Center For Developmentally Disabled ECI**
Dallas, TX
(214) 328-4309

**Project KIDS-ECI**
Dallas, TX
(972) 581-4133

**ECI of Special Care and Career Services**
Farmers Branch, TX
(972) 991-6777

**Parents in Partnership (PIP) ECI**
Garland, TX
(972) 926-2671

**ECI of Dallas Metrocare Services**
Irving, TX
(972) 870-5900

**LifePath Systems ECI**
McKinney, TX
(972) 359-1110

**Region 8 ESC ECI**
Mount Pleasant, TX
(903) 572-8551

**Infant & Toddler Intervention Program of North Texas ECI**
Plano, TX
(972) 599-6125

**ECI of Richardson**
Richardson, TX
(972) 490-9055
### ECI Local Public Awareness Contacts (Child Find Coordinators)

<table>
<thead>
<tr>
<th>Host Agency</th>
<th>Child Find Coordinators/Primary Child Contacts</th>
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<tbody>
<tr>
<td><strong>Dallas Center for Developmentally Disabled (023)</strong>&lt;br&gt;Dallas Center for Developmentally Disabled ECI</td>
<td>Susan Bart&lt;br&gt;8550 Cadenza Lane&lt;br&gt;Dallas, TX 75228&lt;br&gt;(214) 328-4309&lt;br&gt;(214) 328-7486 (F)&lt;br&gt;<a href="mailto:sbart@dallascenterfordd.org">sbart@dallascenterfordd.org</a></td>
</tr>
<tr>
<td><strong>Dallas Independent School District (025)</strong>&lt;br&gt;Project KIDS-ECI</td>
<td>Helen Vogel&lt;br&gt;9911 N Morocco&lt;br&gt;Dallas, TX 75211&lt;br&gt;(972) 794-4569&lt;br&gt;(972) 794-4573 (F)&lt;br&gt;<a href="mailto:hvogel@dallasisd.org">hvogel@dallasisd.org</a></td>
</tr>
<tr>
<td><strong>Dallas Metrocare Services (024)</strong>&lt;br&gt;ECI of Dallas Metrocare Services</td>
<td>Yvette Serventi-Aguilar&lt;br&gt;1353 N. Westmoreland, Bldg. F&lt;br&gt;Dallas, TX 75211&lt;br&gt;(214) 333-0109&lt;br&gt;(214) 333-7097 (F)&lt;br&gt;<a href="mailto:yvette.serventi-aguilar@metrocareservices.com">yvette.serventi-aguilar@metrocareservices.com</a></td>
</tr>
<tr>
<td><strong>Garland Independent School District (035)</strong>&lt;br&gt;Parents in Partnership (PIP) ECI Program</td>
<td>Janet Centola, LCSW&lt;br&gt;2625 Anita Drive&lt;br&gt;Garland, TX 75041&lt;br&gt;(972) 926-2671&lt;br&gt;(972) 926-2679 (F)&lt;br&gt;<a href="mailto:jccentol@garlandisd.net">jccentol@garlandisd.net</a>&lt;br&gt;Sarah Simpson&lt;br&gt;2625 Anita Drive&lt;br&gt;Garland, TX 75041&lt;br&gt;(972) 926-2671&lt;br&gt;(972) 926-2679 (F)&lt;br&gt;<a href="mailto:ssimpson@garlandisd.net">ssimpson@garlandisd.net</a></td>
</tr>
<tr>
<td><strong>LifePath Systems (020)</strong>&lt;br&gt;ECI of LifePath Systems</td>
<td>D. Kazlow&lt;br&gt;P.O. Box 828&lt;br&gt;McKinney, TX 75070&lt;br&gt;(972) 359-1110&lt;br&gt;(972) 547-6801 (F)&lt;br&gt;<a href="mailto:dkazlow@lifepathsystems.org">dkazlow@lifepathsystems.org</a>&lt;br&gt;Janna Fitzhugh&lt;br&gt;P.O. Box 2244&lt;br&gt;Rockwall, TX 75087</td>
</tr>
<tr>
<td>Organization</td>
<td>Contact Information</td>
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<tr>
<td>---------------------------------------------------</td>
<td>-----------------------------------------------------------</td>
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<tr>
<td>ReadyStart-ECI (066)</td>
<td>Vicki Deaver&lt;br&gt;1701 North Collins Blvd. Ste. 100&lt;br&gt;Richardson, TX 75080&lt;br&gt;(866) 619-5660&lt;br&gt;(469) 385-4915 (F)&lt;br&gt;<a href="mailto:vickid@readystart.org">vickid@readystart.org</a></td>
</tr>
<tr>
<td>ReadyStart, Inc.</td>
<td>Maria Avitia&lt;br&gt;1701 North Collins Blvd. Ste. 100&lt;br&gt;Richardson, TX 75080&lt;br&gt;Plano ISD&lt;br&gt;(469) 385-4256&lt;br&gt;(469) 385-2982 (F)&lt;br&gt;<a href="mailto:mariaa@itipnt.org">mariaa@itipnt.org</a></td>
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<tr>
<td></td>
<td>Rebecca Clark&lt;br&gt;ReadyStart, Inc.&lt;br&gt;807 W. Main Street&lt;br&gt;Decatur, TX 76234&lt;br&gt;(940) 627-7300&lt;br&gt;<a href="mailto:rebeccac@readystart.org">rebeccac@readystart.org</a></td>
</tr>
<tr>
<td>The Warren Center&lt;br&gt;ECI of Richardson/North Dallas</td>
<td>Kay Hopper&lt;br&gt;320 Custer Road&lt;br&gt;Richardson, TX 75080&lt;br&gt;(972) 490-9055&lt;br&gt;(972) 490-9058 (F)&lt;br&gt;<a href="mailto:center@thewarrencenter.org">center@thewarrencenter.org</a></td>
</tr>
<tr>
<td>LaunchAbility&lt;br&gt;ECI of Special Care and Career Services</td>
<td>4350 Sigma, Ste. 100&lt;br&gt;Dallas, TX 75244&lt;br&gt;(972) 991-6777&lt;br&gt;(972) 991-6361 (F)&lt;br&gt;<a href="mailto:marnies@launchability.org">marnies@launchability.org</a></td>
</tr>
<tr>
<td>UT Medical Branch at Galveston (076)&lt;br&gt;ECI LAUNCH</td>
<td>Stacey Monroe&lt;br&gt;301 University Boulevard Route 1025&lt;br&gt;Galveston, TX 77555-1025&lt;br&gt;(409) 772-0887&lt;br&gt;(409) 772-0866 (F)&lt;br&gt;<a href="mailto:swmonroe@utmb.edu">swmonroe@utmb.edu</a></td>
</tr>
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</table>
Other Helpful Resources

ARC of Dallas
12700 Hillcrest, Suite 200, Dallas, TX 75230
(214) 634-9810
www.arcdallas.org
*Salvage Pick-up:* (214) 337-8900

ARC of Texas
8001 Centre Park Dr., Suite 100, Austin, TX 78754
(800) 252-9729
www.thearcoftexas.org

Adult Down Syndrome Center (Chicago) Website
www.advocatehealth.com/adultdown

Advocacy, Inc.
1420 W. Mockingbird, Dallas, TX 75247
(214) 630-0916
Austin Office: (800) 252-9108
www.advocacyinc.org

Autism Society of America
7910 Woodmont Avenue, Suite 350, Bethesda, MD 20814-3067
(800) 3AUTISM (800-328-8476)
http://www.autism-society.org/site/PageServer
Local chapters in Dallas, Fort Worth, Plano and Austin

Celiac Disease Foundation
(818) 990-2354
www.celiac.org

Child Care Group (*Daycare resources and referrals for 14 counties*)
8585 No. Stemmons Freeway, Suite 600, Dallas, TX 75247
(214) 630-5949
www.childcaregroup.org

Dallas MetroCare Services (*MHMR Center serving Dallas County*)
1380 River Bend, Dallas, TX 75247
(214) 743-1200
www.metrocareservices.org
other helpful resources

Denton County MHMR Center
P. O. Box 2346, Denton, TX 76202
(940) 565-5244
Contact: Susan Hines
Crisis Hotline: 800-762-0157
www.dentonmhmr.org

Down Syndrome Clinic at Children’s Medical Center Dallas
1935 Motor Street, Dallas, TX 75235
Clinic location: 4th Floor, Pavilion
(214) 456-2357
Contact: Joanna Spahis, RN
Email: Joanna.spahis@childrens.com

Down Syndrome Health Issues Website
www.ds-health.com

Down Syndrome Partnership of Tarrant County
1506 Pioneer Parkway, Suite 103
Arlington, TX 76013
(817) 277-7064
www.dsptc.org

Down Syndrome Research and Treatment Foundation
www.DSRTF.org

East Texas Down Syndrome Support Group
P. O. Box 6604, Longview, TX 75608
(903) 757-3516
Contact: Leslie Stevens
www.etds.org

LifePath Systems (MHMR center serving Collin County)
1416 North Church Street
P.O. Box 828, McKinney, TX 75070
(972) 562-0190
www.lifepaths.org

Special Olympics of Texas
Greater Dallas
400 South Zang, Suite 926
Dallas, TX 75208
(214) 943-9981
resources

Red River Valley Down Syndrome Society  
6325 Lamar Road, Reno, TX 75462  
P.O. Box 6455, Paris, TX 75461  
(903) 783-1922  
www.redriverdss.org

Texas Council for Developmental Disabilities  
(800) 262-0334  
www.txddc.state.tx.us

Texas Department of Aging and Disability Services (DADS) - formerly MHMR  
Medically Dependent Children Program  
Home and Community-Based Services Program  
In-Home Family Support Program  
(800) 262-0334  
www.dads.state.tx.us

Texas Department of Assistive and Rehabilitative Services (DARS) - formerly Texas Rehab Commission  
(800) 628-5115  
www.dars.state.tx.us

Texas Department of State Health Services  
Children with Special Health Care Needs Program  
Children’s Health Insurance Program  
Health Insurance Premium Payment Reimbursement Program  
(800) 252-8023  
www.dshs.state.tx.us

Texas Education Agency (TEA)  
Special Education Infoline: (800) 252-9668  
Region X Education Service Center  
(972) 348-1536  
Contact: Gloria Key, Director of Special Education

Texas Parent-to-Parent  
(866) 896-6001  
www.txp2p.org

UT Southwestern Medical Center at Dallas – Family Medicine Clinic  
(Healthcare for adults with Down syndrome)  
6263 Harry Hines Blvd., Clinical 1 Building, Dallas, TX 75390-9067  
(214) 645-3900  
Contact: Amer Shakil, M. D.
WrightsLaw (special education issues)
www.wrightslaw.com

Yahoo Groups:
DownSyndromeGuild-subscribe@yahoogroups.com
DS-Autism-subscribe@yahoogroups.com (dual diagnosis)
HKDS-subscribe@yahoogroups.com (for home schoolers)
SPED_Discussion-subscribe@yahoogroups.com (special education issues)
Dallasarearock-subscribe@yahoogroups.com (celiac disease)
National Organizations

**ARC – US**
www.thearc.org

**National Academy for Child Development (NACD)**
801-621-8606
www.nacd.org

**National Down Syndrome Congress (NDSC)**
1370 Center Drive, Suite 102, Atlanta, GA 30338
800-232-NDSC
www.ndsccenter.org

**National Down Syndrome Society (NDSS)**
666 Broadway, New York, NY 10012
800-221-4602
www.ndss.org

**National Information Center for Children and Youth with Disabilities (NICHCY)**
800-695-0285
www.nichcy.org

Additional Websites

**www.ds-health.com**
This website was created by Len Leshin, M.D., pediatrician and father of a son with Down syndrome. It contains great information on health-related issues faced by children with Down syndrome.

**www.chask.org**
Christian Homes and Special Kids (CHASK) provides an adoption program. CHASK is an organization whose purpose is to find Christian homes for children with special needs.

**www.nathhan.com**
National Challenged Homeschoolers Associated Network (NATHHAN). NATHHAN’s purpose is to provide support and information for homeschooling families with special needs children.
www.denison.edu/dsq/
Down Syndrome Quarterly is an interdisciplinary journal devoted to advancing the state of knowledge on Down syndrome and covers all areas of medical, behavioral, and social scientific research. It is published quarterly and is distributed by subscription to individuals, organizations, and libraries. Some of the articles from the journal are published on this website.
Suggested Professionals
Attorney Specializing in Special Needs Trusts/Wills

Inclusion on this list should NOT be considered an endorsement of any kind by the Down Syndrome Guild of Dallas, either express or implied. Down Syndrome Guild families have recommended these resources, which are provided for information purposes only.

Karen C. Cathey
206 S. Tennessee
McKinney, TX 75070
972-562-0777

Richard O’Connor
Blankenship, Willard & O’Connor, PC
8111 Preston Road, Suite 950
Dallas, TX 75225
214-691-3400

Chris Mims
2929 Carlisle, Suite 170
Dallas, TX 75204
214-855-5160

John C. Wray
200A North Rogers Street
Waxahachie, TX 75165
972-938-1850

J. Mitchell Miller
Haynes & Boone, LLP
2505 N. Plano Road, Suite 400
Richardson, TX 75082
972-680-7560

Legal Clinic
SMU School of Law
214-768-2562

Legal Services of North Texas
(Serving Dallas & Ellis Counties)
214-748-1234
(Serving Collin, Grayson, Kaufman & Rockwall Counties)
972-542-9405

Lawyer Referral Service
Dallas Bar Association
Advocacy, Inc.
214-630-0916
www.advocacyinc.org

This is a non-profit agency that advocates for the legal rights of people with disabilities. They provide free information on guardianship, wills, estate planning, special education, law, etc. They do NOT represent individuals but are a great source of information.

The Arc of Texas Master Pooled Trust
Chris Oglesby, JD, Trust Manager
1-800-252-9729

A trust fund, established under the auspices of the Arc of Texas that provides people with disabilities an ongoing source of money for supplemental wants and needs. The trust manager assists families in establishing trust accounts, keeping up with current Medicaid regulations, and approving and reporting trust disbursements.

The Down Syndrome Guild recommends no financial planners and suggests that families seeking this service visit: www.cfp.net.
“WE FIND THE DELIGHT IN THE BEAUTY AND HAPPINESS OF CHILDREN THAT MAKES THE HEART TOO BIG FOR THE BODY.”

- RALPH WALDO EMERSON
Alana Patricia Drablos is my first born 23 year-old daughter. I was 26 and my husband, Scott, was 29 on February 8, 1985, when she arrived six weeks early weighing 4 pounds, 11 ounces. We learned she had a heart defect when she was two days old, and a group of doctors told us she had Down syndrome four days later when the definitive test results were in hand. My delivery was a Caesarian because Alana was breech and premature. She actually did very well and breathed on her own from birth, but needed to stay in the hospital for 16 days to establish a pattern of gaining weight.

Our doctors were well intentioned, but poorly informed in many ways. The lead neonatologist assured us that Alana would walk and run and play, for heaven’s sake! Granted this was more than 20 years ago and times have changed, but it is almost silly to think of it given what Alana has accomplished and all that she can and will do in the future. Our shining star at the time was Alana’s pediatric cardiologist, Damaris Wright, who is passionately attached to her patients with Down syndrome and a high energy super positive happy individual. Dr. Wright went through all of Alana’s heart issues with us including successful surgery at 10 months.

Scott and I were referred to the Down Syndrome Guild of Dallas. We met other families with children with Down syndrome. I read everything I could find that seemed relevant trying to understand what it really meant to have Down syndrome. Alana was a perfect baby, easy going and very attached to her dad. She started home based therapy at six weeks. I became an advocate for full inclusion of people with Down syndrome in all communities, including the public schools. I became a board member of the Guild. Our family grew. Her sister Katie was born, then her brother, Thomas, and finally, her second sister, Maeve. All four children attended Montessori school in Dallas and then public school in Fairview, where we had moved when Alana was entering fourth grade.

Alana accomplished almost all the typical childhood milestones, just at a slower pace and in her own way. In grade school she was in an Indian Princess tribe, took dance and gymnastics lessons, played the piano, was in a Girl Scout troop, played basketball on a team Scott coached, sang in the church children’s choir, and was fully included in typical classes at Lovejoy elementary.

Middle school and high school in Allen brought new challenges and enriching experiences. Alana managed girls basketball teams, was a staff photographer for the
yearbook and newspaper, took trips with the photography department to national conferences without her parents, and was very much a part of the school community with good friends and supportive teachers. She was assisted by peer tutors in some of her academic subjects where curriculum was modified. Alana herself was able to be a peer tutor for a student in a wheelchair her senior year. She was very active in the Life Teen program at our church.

After graduation from Allen High school Alana received a Special Services Certificate in Office Skills from Eastern New Mexico University in Roswell, New Mexico, upon completion of a one year program of study there. She lived in a college dormitory away from her family and came home more confident and independent. She has been successfully and very happily employed as a courtesy clerk at Kroger since she was sixteen. She is now taking one class a semester at Collin County Community College in their office technology division and working about 30 hours a week. She has a cute boyfriend, Chad Turner, who she met in Roswell and sees about once a month. He has Down syndrome as well, and lives on his own in Colleyville.

Alana loves her family and friends, the Dallas Mavericks (especially Dirk Nowitzki), Broadway musicals, sushi, playing cards and keeping score, the television show “Friends”, purses, texting her siblings from her IPhone, listening to music, working out to her Denise Austin tape, babies in the checkout line at work, and helping out, among many other things. Her sophistication in some areas is amazing. She reads very well, balances her own checkbook, and knows as much about sports as any typical avid fan addicted to Sports Center on ESPN. At the same time she can be very sweet and innocent. Her siblings adore her. She makes all of us smile. She teaches us patience and determination and is a terrific example of good self esteem.

The path we have traveled from February 8, 1985, to the present has sometimes been very hard and challenging. It has been full of surprises, successes, and setbacks. Often, perhaps ironically, Alana has been my easy kid. Please know that the Guild exists to support your family in your journey, wherever it may take you. Give yourself time to adjust. Ignore the well intentioned but poorly informed. Come meet us when you are ready. You are most welcome.

Scott and Kelly Drablos  
(972)562-8997  
sdrablos@aol.com
Hi, we are the Longworth’s – Greg, Elizabeth and Katie Longworth. Katie, our daughter, is a delightful, sassy, impish 7 year old! Katie loves to go down the slide, head-first, laughing all the way. She has a wonderful smile that lights up the room and a twinkle in her eyes I pray she never loses. She gives the best hugs and loves to laugh. She loves her friends, family and music. Katie loves school and has great friends. You can usually find her at school outside running around with the boys. She’s taken swimming lessons, horseback riding and music classes. What a joy and blessing she is to all who know her. I can’t imagine what our life would be like without her. By the way, Katie has Down syndrome and mild-moderate hearing loss.

We found out Katie had Down syndrome through amniocentesis. We had heard the statistics, but we really didn’t think that applied to us. The results of the amnio were not going to change anything for us – we just wanted to be prepared or if there was something that could be done prenatally to help – we would do it.

After receiving the news, we were stunned, probably shocked and scared is more accurate. How had the world suddenly turned upside down?? How were we going to face this? Handle this? What do we do?? That night as Greg and I lay holding each other in bed, I remember wondering if we would ever laugh again – what was our life going to be like? What was ahead for our daughter??

We were very blessed to have wonderful doctors, friends and family who were very encouraging and supportive. I was induced 2 weeks early and Katie spent 3 weeks and 5 scary days in NICU. Katie struggled with various issues during her stay in NICU – some mysterious, some frightening and others more mundane. How well I remember pumping in NICU and at home so she would have her breast milk! Katie was prenatally diagnosed with a serious heart defect and we met with the pediatric surgeon to discuss the problem and when they would repair her heart. After delivery, her heart was fine. She had some minor heart issues, but nothing requiring surgery. She was born with a cleft palate – which should have been an indication of her personality!! The little imp – full of surprises! Because of the lower muscle tone and hole in the roof of her mouth, she couldn’t suck well – so she had a g-button put in her stomach so that she could get nourishment.

As we were going through the process of getting the cleft palate repaired, we discovered that she had mild to moderate hearing loss. We were quite devastated at this news, but as
usual, Katie was undeterred, and then so were we! Katie had her cleft palate repaired at nine months and followed with hearing aids. What a challenge to keep the hearing aids in!! I used to call them the most expensive chew toys!!

The double edge sword of modern technology was that we were able to find out while I was pregnant that Katie has Down syndrome. It gave us the time to read and best prepare and plan for her. The scary part was that I didn’t yet have my baby to hold and that beautiful little face to look at me – I could only imagine. After 9-11, as we all were scared and uncertain of what lay ahead, I’ll never forget holding Katie on our couch and looking at her. I had just finished tube feeding her and was so scared. I really wondered what kind of world had I brought her into?? She looked up at me and just smiled and her eyes gave me the look that said – “Mommy, what’s the problem?? Everything will be okay - I’ll be fine, we’ll be fine.” And a peace came over me and I knew we all would be fine together.

Katie is such a blessing to our family! When I look back at the hurdles we encountered, cleft palate, g-button, hearing loss – that seems so long ago. As parents, we just did what we needed to do for our daughter. The cleft palate was repaired at nine months, she was off the g-button by age 2, finally wearing her hearing aids without tossing them by 3ish – ok maybe longer!! Yes, it was painful at first, because we didn’t know what to expect – not that you can know what to expect from a typical child either! And yes, it was scary, but she was our baby and depended on us. We would do everything we could to give her the best advantages – early therapy, the best doctors, great nutrition, love and most importantly, setting high expectations. We treat Katie just like we would if she were a typical child – lots of love, discipline and high expectations. As I have said to many a legislator when advocating, we are raising Katie to be a happy, productive, fulfilled, voting tax payer, not a tax burden.

Katie reminds us what is truly important in life – love, joy, family and friends. It’s valuing life’s little accomplishments and wonders, along with the big. Slowing down to treasure the enormous hug that your daughter decides you need. Katie has made me a better person, more compassionate and understanding of differences, truly looking at the bigger picture. She sees true joy and revels in it. I do believe there is a higher power who blessed us with Katie – and in that blessing an obligation to advocate for her and others and to hopefully, help make the world a better, kinder place.

And back to that original fear, would we ever laugh again?? Yes, oh how we laugh!!! Yes indeed, our life is so much richer with Katie!

Greg and Elizabeth Longworth
(972) 831-0665
eglongworth@sbcglobal.net
Austin Davenport

About a self advocate

Our son, Austin, just had his thirtieth birthday.

It was one of those events that we didn’t think about the day he was born. We probably didn’t think about it on his fifth birthday either, or even his fifteenth. It is unlikely at times such as those that we would imagine any of our children with Down syndrome having birthdays as significant as that. Our minds just don’t go there.

To our surprise though, the years continued to plow by and our youngest had sixty of “his closest friends” for dinner and dancing to the music of his favorite DJ a few weeks ago.

It’s funny that even though we never imagined Austin having a thirtieth birthday, we did imagine him growing up and being on his own. Once we got over the initial surprise of who he was when he was born, we never kept our eyes off that goal of his independence. Occasionally, a well-meaning teacher or a friend or a relative or a doctor unintentionally tried to discourage us. This was usually with the thought of protecting Austin from the world or protecting him from failure. Sometimes Austin himself discouraged us when he did something or could not do something that appeared at the moment to be a dead end to a life with independence as a goal. At times like that we wanted to take him and hide him and protect him.

We always came around though to asking the questions:

*How will he ever learn about the world without being constantly in it?*

*How will he ever learn how to overcome failure without experiencing it?*

So Austin struggled his way through growing up, with his family and friends occasionally picking him up and dusting him off. He gradually learned what worked for him to live life in the world with peers who allegedly don’t have learning difficulties. If he found an insurmountable obstacle (often a person), we simply helped him find a way to go around it. It was seldom easy, and it was a long road.

And it’s a road he is still on. Although he has lived almost completely independently for eight years—working full time, living
in his own place—life constantly throws in his path new things to learn. At this stage, that object is almost always a relational issue.

As a result we are SO glad we insisted that he be fully included with his more-able peers in school and church and scouts and life. We did not accept token inclusion. If we had, he would never have had the tools to sort out the intricacies of challenging relationships. He would never be planning, as he is right now, how he is going to pay for a wedding ring set for the girl he has loved for four years. He also would never have gathered together a few weeks ago such the delightful group of close friends of all ability levels with whom to dance.

----Dick and Nancy Davenport
Casey Jane O’Brien

What is Different, Anyway?

Casey Jane loves to copy her big brother, say ‘no’ to mom, and sing every song she’s ever heard. She’s 4 going on 14. Her favorite color is pink, she gets timeouts at school for erasing the calendar board, and does a mean punch-and-front-kick combo in Tae Kwon Do. She is a far different little girl than the one I pictured as I held her for the first time, hours after she was born, while they told me she had Down syndrome. I can’t even write down what I thought she would be like – a mother is not supposed to have those thoughts about her child, especially on what is supposed to be a joyous day. Yet I did, and still bear a little guilt about it 4½ years later. But one thought I still have and probably always will. That day, the day she came into our lives, our family became “different.”

I know that “all families are special.” Maybe it’s just my need to feel ‘extra–special,’ or to counter the self-pity that sometimes creeps into my bones when I watch her lick the window at her gymnastics class in front of all the other parents. But the truth is, we are different now. We are going through life experiencing something most people never will. Our daughter has a disability. One look at her face and people immediately know. For us, the experiences that have come with raising Casey have resulted in changes to our family that neither my husband nor I would have ever predicted.

I once caught my dad, Casey’s beloved PopPop – the tough, non-emotional, corporate executive – comforting her after a fall. He had swooped her up before I could even get near her. I heard him whispering little sweet nothings in her ear and that he would always be there to protect her, no matter what. I don’t think my dad has ever whispered those words before or since. My husband and I, both brought up to ”follow the job” and “keep your options open” left our wonderful house, beloved neighborhood, and comfortable job in Maryland to move to Dallas, only because we finally recognized the value in having our kids grow up around grandparents, aunts, uncles and cousins. We followed no job, just our hearts.

I think what has changed most about our family though, is our determination. Casey pushes herself to figure out how Lego’s fit together, how to draw shapes, and how to get her shoes on without Mommy’s help. Those things just don’t come naturally to her like they do to her brother or her typical friends. This fighting spirit in her is what pushes me
to bring her to every one of Danny’s soccer games, even though I spend most of the game chasing her around the field, just so that she can cheer when her brother scores a goal. It pushes me to sign her up for karate and gymnastics with her typical peers even though she might be the smallest and the slowest. It pushes my husband to show tremendous patience as he teaches both kids how to make pancakes every weekend. It even pushes Danny to practice the piano more often just because he knows Casey enjoys hearing his music so much. Seeing how hard she fights, makes us fight harder to make sure she is included and successful in whatever she does.

We are not the same family as before. We are different. We have evolved. We are better than we once were. So, while I strive everyday to teach Casey to do things that make her ‘more normal’ like everyone else, I secretly cherish the thought that I, as her mother, am made special; that our family is forever different, because of her.

*Michael and Angela O’Brien*
*parents to Casey Jane*
*aobrien1997@gmail.com*
One of the biggest mistakes I ever made was on August 14, 1999, when my sweet baby nephew was born. I tried to encourage and assure my rock of a sister that everything would be okay after the birth of her son Eric, with Down syndrome, and said all the wrong things. I told her he would someday be a divine gift, a blessing, a wonder to everyone he met, but my timing for those words – though well intentioned – was bad.

Immediately though it seemed my assurances became reality as my sister Anita, her husband Ed and daughter Mandy recognized the true miracle of Eric. His demeanor, smile, and development were infectious, motivating and exciting. It wasn’t long before everyone considered our little “Eric the Incredible” just a normal little boy. Don’t get me wrong . . . though he is a remarkable young man, he is today who he is and capable of being because of his family. They never gave up, complained or fell short of providing every benefit, opportunity or resource for Eric’s advancement. He is adored everywhere he goes and never hesitates to tackle anything. He is one amazing gift.

He wasn’t voted captain of “Eric’s Incredibles” for nothing:

- He loves adventure and trying new things
- He does it all with a smile on his face and seldom fails
- He never forgets a name or a face; he’s never met a stranger
- He has every characteristic of a future politician or Rock Star, because he shakes hands with everyone he meets, with a smile on his face and a “My name’s Eric.”
- He gives a mean massage!
- He has excelled at every game or activity he has ever tackled. Do you have any idea how frustrating it is to be beat by him at Wii bowling? He bowls a 222 or higher!
- He performs a mean Rap, takes interesting photographs, loves to do “rabbit ears” over others’ heads in photos and enjoys tickling
- He dresses purely GQ and struts when he’s looking fine
- He is becoming quite the Tae Kwon Do student and can shoot a water pistol further than anyone
- He never waivers in his “inclusive” classes at school and has more girlfriends than most boys could handle
He loves his family with a huge heart, greets everyone with a hug and challenges those around him to be their very best . . .

And he does it all with a giggle. Infectious – that’s what he is. Today he IS that divine gift, a blessing and a wonder. His future is bright and his potential is impressive. If you haven’t yet met young Eric Ford, you’re missing out.

Aunt Angela Knapp
Who would have imagined life could be so great? It was 18 years ago and we awaited the birth of our son. We had a daughter already and my husband had adopted my children from a previous marriage. He was a very successful CFO for an international airline, which provided us an exceptional lifestyle with many benefits. The school year was spent overseas and the summers in Dallas, my previous home and where my husband had completed some post-graduate work.

Christmas 1989, we came to Dallas for the holidays. The kids and I arrived first mid-month, followed by my husband (who only had a short time with us – 7 days to be exact). We arrived to a flooded house – a pipe had frozen and broken…. We should have known this trip would be more eventful than usual! We celebrated Christmas and Bader returned to Kuwait. I stayed behind to finish the repairs on the house. Then the real Christmas present: a baby was coming!!!

It had been a rocky pregnancy to say the least. I was stranded in Dallas because my doctor considered the pregnancy “high risk”. At the age of 38, I was pressed hard by my OB doctor to have amino; I had some breakthrough bleeding and extremely low progesterone (which was combated with daily injections). I opted not to have the amino – what difference would it make? I wouldn’t have eliminated a baby we wanted so much. We had been through a lot though. After 2 failed marriages, I had my tubes cauterized; then married the perfect man (who had never been married and no children of his own), I felt compelled to have his children. So, I underwent tubal repair, which was unsuccessful. Off to England to the best IVF doctor in the world: Patrick Steptoe. Pregnant the first time with triplets, one was born – our daughter Manal. IVF attempts (7 to be exact) were unproductive – now, no IVF or any other infertility intervention, certainly unexpected, I get pregnant! God wanted us to have this baby. So, we waited.

Our plan? I was to spend the summer of 1990 in Dallas like always; get ready for the next school year; baby due in September; October/November go back overseas to Kuwait where life would resume. Then it was the beginning of change, when the phone rang late on August 2, 1990. It was my husband calling from London; he was there on a business trip. He said, “Iraq invaded Kuwait.” I was standing by our bed, still up late, taking advantage of the long summer nights. I remember so well, holding the phone with what must have been the strangest look on my face, because I had no idea what that meant for us. I just stood there, saying, “So, what does that mean?” That was the start of another new chapter in our lives.
A month later my husband was still in London, trying to hold together the national airline and to keep the symbolic Kuwaiti logo at the forefront of the news. Everything was going to be all right?? My husband was going to be here in just 2 days so that he would be present at the scheduled C-section. Then, as unexpected as our future, my water broke! As I was wheeled off to the delivery room, I said to my cousin standing there for support, “Please don’t let him have IT!” The fear of Down syndrome had haunted me for the last nine months. My worst fear: Having a child with DS. Don’t ask me why the fear was DS, it just was!!!! About 1 hour later, a baby was born. The news hummed in the delivery room; since I had eaten earlier, there was no general anesthetic, so I was semi-awake during the section. I could hear people muttering, but nothing specific. Then, I heard something, “…symptoms of Down syndrome.” OH MY GOSH! MY GREATEST AND ONLY FEAR – A baby with Down syndrome? This could NOT be happening to me! What had I ever done to deserve this? My girlfriend (the replacement for my husband’s absence), holding the new baby, squealing with delight said, “Here don’t you want to look at him?” There in my face screaming DOWN SYNDROME, my girlfriend held a baby, unlike any I had given birth to prior! I thought, “Who does that baby belong too?” How could I have imagined what greatness lay in front of me?

And that was the beginning of a new life. Our Yousef, our light, the freshness of every, single day had arrived. I had yet to accept this greatness....After a few weeks had passed, I was still uncertain about our future; I hesitantly opened the DSG New Parent packet. Still shaken by the events in my husband’s homeland (Kuwait) which was under siege and occupation, I felt semi-unconscious, sinking into quick-sand: a new baby; Down syndrome acceptance and “what now” questions.

When Yousef was about 6 weeks old I finally faced the reality of having a baby with Down syndrome; it happened at a DSG New Parents Coffee. I asked my girlfriend to go with me; it was a club that I wasn’t keen on being inducted into, but had faced the inevitable reality... it was time. Again, a new chapter. Nervous to the point of sweat pouring down my back, I was so surprised and overcome with emotion by what I saw: toddlers, walking, talking and they LOOKED like their parents and their siblings! So, you mean Yousef who has DS looks like our family?? Everything changed from that moment – the blindness was taken from my eyes and my heart opened and embraced this loving infant who was mine.

Now 17 □ years later, Yousef is a brother, uncle, cousin, son and companion. He has traveled through the school system in Coppell and is currently a junior at Coppell High
He plays snare drum in the band, which proudly marches 350 band students. He is a history buff who would die to meet Benjamin Franklin. He knows more about The Alamo than I do! He attends as many Dallas Stars hockey games as he can, always willing to contribute his Kroger earnings for tickets. He hates vegetables and loves hamburgers with lots of French fries. He loves travel to anywhere and is set on going to Kuwait this summer on his own. He wants to go to college and move to an apartment. He has been playing TOPS soccer since he was 6; swimming on his own since he was 5, plays Special Olympics basketball, cooks, cleans, does his chores, hates homework as much as any 17 year old boy, has several girlfriends (all typical), goes to the movies and dinners with his peers, travels on band trips and spring getaways, oh and did I mention, LOVES THE PRETTY GIRLS!

Someone asked me “How’s puberty going for ya’ll?” Oh that’s funny, I thought! Puberty is as complicated as it is with any other teen! I knew we were in trouble one day, when one of my friends was at the house, attractively wearing a form fitting t-shirt. Never shy Yousef greeted her with his friendly smile and handshake, “I L-O-V-E your t-shirt!” My friend replied, “Oh thank you, Yousef.” Then we both laughed when I said, “Yousef, look at her eyes, look at her eyes!” Need I say more about puberty?!

So what is the secret to Yousef’s success? The only thing I can attribute it to is being treated like any other kid! It’s simple. Why have different expectations for him, just because he has Down syndrome? He’s a typical teenager! Oh, did I mention that he just happens to have Down syndrome? Down syndrome is a condition – it doesn’t define who Yousef is! That is THE number one message we have lived by – it’s the message our family, his teachers, his friends, his co-workers, everyone who is around Yousef hears. HAVE EXPECTATIONS! Wow, what a unique concept: having expectations! I believe that combined with Yousef’s unique personality and ability, Yousef has surprised even the most doubtful.

Did someone say this has been easy? I wouldn’t say difficult, so it must have been pretty easy. I learned early on, it’s about being an advocate – knowing the law, making sure educators are aware of your expectations of your child and what expectations you have of them. Our daughter, Emily, who is a successful Occupational Therapist said to me a long time ago, “You, Mom, you have to make it happen for Yousef. The teachers aren’t going to be the ones who are going to be responsible for him at the end of school; it’s you and dad. It’s what you want for Yousef – to be as independent as possible.”

Yousef, by far, has given us more pleasure than anything we could have ever done for him. He has been the “giver” and us the “receiver.” We have learned more from him than any book or educator could have ever taught us. He is celebrated by everyone in our family and all of our friends. He is supported with kindness from his high school peers and band members. His teachers adore his politeness, genuine kindness and his eagerness to participate, contribute and learn.
If it’s already been 18 wonderful years, I can only imagine how wonderful the next 18 will be with our Yousef!

Phyllis and Bader Malallah
Our son is Yousef Malallah
533 Meadowood Lane, Coppell 75019
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cmcphyllis@aol.com

By request; written for the Down Syndrome Guild of Dallas
Phyllis A. Malallah, May 1, 2008
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I was an only child until I was 13, and had desperately wanted a sibling my whole life. When I found out that my wish had finally come true, it came with a twist. The little sister I had always hoped and dreamed for was going to have Down syndrome. I didn't really know what to think of it at the time...I was sort of indifferent to the situation because I didn't know what to expect. I never could have imagined what Kallen and her spirit would bring to my life or how she would touch me so completely. I never expected that she would mold my perceptions of different people and situations to teach me the true meaning and importance of acceptance. I never expected that one, young life could not only make me appreciate the difference in people, but see it as a blessing. Having a sibling with Down syndrome has been one of the most eye-opening experiences of my life. It has showed me that the simple things in life are often our greatest joys and that there is nothing better in the world than selfless, unconditional love. Although I have helped Kallen take her first steps, speak her first words, write her name, and everything else on the endless list of things people teach children to do, no amount of what I have taught her can even compare to what I have learned from her. Kallen has taught me that patience really is a virtue, and that the longer you have to wait for something to happen, the sweeter it is when it finally does happen. She has helped me realize the amazing power of encouragement, support and love. She has shown me what it truly means to be a family because no matter how many mistakes I make, she loves me with reckless abandon. She has taught me so many important virtues that I fear I would otherwise be without, and for that I think she has made me a better person. Although she has helped me realize so many of the things that make someone a "good" person, the one and constant thing that I know has made me a better person is her love. I cannot properly express with words how it makes me feel to hear her say, "Goober, I love you", to see her sweet smile when I walk into a room, or to get a big hug from her. It is my great hope that she will touch others lives even a fraction of the way she has touched mine, and that people will be able to grow with and learn from her as I have.

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On the morning of July 13, 2006, my wife Paige was almost 8 months pregnant. As I was getting ready to run out the door for an early appointment, she told me that she didn’t feel right. She said that the baby hadn’t moved since the night before, and she had a bad feeling. After getting us in quickly to a Perinatologist the doctor saw that the flow in the cord was very little, there was little amniotic fluid and recommended that our doctor deliver the baby as soon as possible. He also said that he saw a possible heart defect, but the main thing was to get the baby out as soon as possible. About an hour later we had our baby girl, Shelby Kate Strawn. I thought that she was beautiful and tiny. Other than her being little, I didn’t see anything different about her. However, Paige knew that she had Down syndrome immediately. I think they call this a mother’s intuition. They took her into the NICU and that is where we would spend the first two weeks of her life. During that first day we learned that Shelby had a VSD, and that she did have Down syndrome. By the luck of the draw we found Dr. Kao who would become our cardiologist, and a couple of months later her VSD was repaired by Dr Mendelhoff, at Medical City.

After her surgery, Shelby really began eating and growing faster. She also began to develop her personality, which is a combination of standup comedian and a demanding actress. We have also had her in a lot of physical, occupational, and speech therapy. Almost from the start her fine motor skills and speech have been good. However, she has had a more difficult time with gross motor skills. In July, Shelby will turn two and she is very close to walking on her own. She feeds herself and even uses a spoon and fork some of the time. She loves trying to get into the bathroom and pull all the toilet paper off the roll. Although Sesame Street is her favorite show she enjoys watching sports with her Dada on the couch. But when times are tough she always opts for her Mama.

Shelby also has a very close relationship with her big brother, Turner. They are truly best friends and love to play and dance together. Their relationship seems different than most siblings, at this point in their lives. Almost from the time we brought Shelby home, her brother has known that there is something different about her. That he needed to watch out for her and help take care of her. I believe that God gave us a son like Turner, because he knew Shelby would come along later.
We are blessed to have many friends and family. All of them will tell you that they have a special relationship with Shelby, because that is the way she makes you feel. The other kids in the neighborhood love her and always want to hang out with her. She also has Casey, Chloe, Brittany and Grover that are her buddies, and they have Down syndrome as well. It has been a big help to us, to have their families in our lives.

I know that there will be many times that we have to fight for Shelby, and that she will need our support for the rest of our lives. But there is something that makes you feel very special to be the parent of a child like Shelby.

Paige & Luke Strawn
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“Mom, I feel like God is trying to tell me something.” “What dear?” “I feel like my baby may have some sort of special need.” “Oh Polly, don’t worry sweetie, everything will be just fine. I think you are just nervous.” Little did I know that only 24 hours later, I would get God’s message loud and clear. This was a conversation between my mom & me one day before I went into labor with my son. We were at the State Fair of Texas and I could not keep my eyes off every person I saw with some sort of special need. I knew deep down that my life was about to change.

You could have heard a pin drop when the on-call pediatrician delivered the news later that cool October day. Bennett Peoples Redden was born only a couple of hours and was having trouble breathing. He was in the special care nursery as Ross & I were resting in our room. We were exhausted from over 20 hours of labor that lasted throughout the night. “What?” I said. “Your son shows signs of Down syndrome.” I literally sat there with my mouth wide open for no telling how long. What in the world was this lady talking about? Who was she? I hated her at that moment. She certainly didn’t seem to be bothered by the news she was delivering to us – coming in waking us up, tossing her purse ever so carelessly on the floor, invading our room and privacy. The NICU doctor was with her and he began to give us an update on Bennett. I have no idea what words were coming out of his mouth. I was in shock. I could hear him speak but I was already gone to someplace else. I had to then make the dreaded phone call to my parents, which was one of the hardest calls I’ve ever made.

I knew when I first laid eyes on Bennett that something was wrong. I felt it from the very beginning. Ross & I declined any prenatal testing offered to us simply because we agreed that whatever the results, we would not end the pregnancy. I second-guessed my decision once we declined but quickly decided to let it go. That was probably the best decision I ever made. I enjoyed my pregnancy and chose not to worry about anything. I laughed, sang, read and talked to Bennett while he was growing inside me. I always tell people that my hell lasted only a few hours because I didn’t find out early on. To me, that is much better than months of knowing.

Bennett was admitted into the NICU before the afternoon was over and immediately put under a halo, which is an oxygen tent. He was sleeping ever so peacefully when my sweet husband wheeled me downstairs so I could see him. It was at that moment that I fell in love with him. He was my son and I loved him dearly no matter what the doctors told us. Before the morning, he was
put on a CPAP, which gave him more oxygen than the halo. We were assigned a primary care nurse and told he would be given the first round of tests to see if he was positive for DS. Several days later we received what we prayed would be negative results but turned out to be positive. What a coincidence being that Bennett has brought so many positives to our lives since he was born.

I can’t tell you the number of people who have said to us, “I’m sorry” when we’ve told them Bennett has Down syndrome. Our comeback is always the same, “please don’t be, we aren’t.” He is still a little boy, with big bright blue eyes and a smile and laugh that will tattoo itself on your heart.

Bennett is among the percentage of children born without a heart defect. So we consider ourselves very lucky. We spent a total of 21 days in the NICU at Presby Dallas and made lifelong friends with other families, nurses, and doctors. We love to stop and visit when we are close by.

Ross told me early on that we had 2 choices to make, either we could feel sorry for ourselves or take this opportunity and be joyous about it. After all, we have been given a “child for life” and doesn’t that make us among the luckiest people of all? What a joy Bennett is to our family. Little sister Hattie Grace joined our family in March of 2008 and Bennett already brings smiles to her face. Thank you God for the journey we are on!

Ross & Polly Redden
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Introduction:
Abby is my sister by all but biological means. From day one, Abby and I have been best friends and have grown up side by side. Over the years, we have spent holidays together and gone on vacations. Together, we were Indian princesses, Brownies, and Girl Scouts; we were in choir and on sports teams, but most importantly, together we went through our first thirteen years of school.

Abby was born with Down syndrome and her parents were immediately faced with decisions and difficulties that they had not experienced with their other two children. After advice and insistence from their four and six year olds, Abby’s parents decided that she would attend school with her peers, that inclusion was the way to go for their family. In making this decision, Abby’s parents believed they were providing her with a better learning environment and a place to grow socially; but what her parents did not realize at the time was the impact that Abby would have on every classmate, friend, and teacher that she encountered.

Through her inclusive education, Abby became the epitome of independence. At an orientation before the first day of middle school, I told Abby I would help her find her way around our new school. She was appalled at my offer. She took my face in her hands and let me know that she knew as much about the school as I did and did not need my help. Instead of accepting my offer, she studied a map of the school to prove to me that she could do it on her own. It was at that point I realized that Abby could do it on her own, that she did not need my help, and that the only thing she needed was my friendship. I realized that Abby was no different from my other friends. Yes, I might have to explain something an extra time, or watch my language for fear of being scolded, but Abby is not my inferior; in fact, in many aspects Abby is my role model.

Abby has taught me not to take anything as a disadvantage. She has taught me to put a smile on my face through the hard times. Abby is always there to give me a hug when
she knows I am feeling down, or to yell at me when she thinks I am acting inappropriately. Abby faces every challenge in her life with confidence and has taught me, as well as many of our peers, to do the same. Abby has taught us all that anything is possible, given the right attitude.

Abby graduated from high school with me last May and now attends a community college close to home. Though Abby does not have her driver’s license, she goes by herself to class every day, independently taking a bus and a train. Abby would not have the independence that she has today, and I would not be the person that I am today, if she had not been an integral part of my education.

**An Assessment of the Benefits of Inclusive Education**

As more public school systems begin to adopt inclusive methods of education, experts and parents are becoming skeptical, often questioning whether the benefits of inclusive classrooms really do outweigh the consequences. Inclusion is defined as establishing an educational system in which all students, including those with disabilities, are educated together, in a general education classroom, for the entirety of the school day. Inclusion is different from mainstreaming because all students remain in the general education class for the whole school day, instead of only participating for specific subjects.

Much of the adoption of this teaching method is due to the Individuals with Disabilities Education Act (IDEA) of 1990 which states that, "each state must establish procedures to assure that, to the maximum extent appropriate, children with disabilities… are educated with children who are not disabled and that special education, separate schooling or other removal of children with disabilities from the regular educational environment occurs only when the nature of the severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily" (NDSS 2). Following the ideals set forth by the IDEA, many children, including those with Down syndrome, who would at one time have been put in separate special education classrooms, are being placed into general education classrooms.

Though the IDEA and many other similar acts and initiatives exist, many critics, teachers, administrators, and especially parents still resist inclusive methods of teaching. Inclusion critic and former president of the American Federation of Teachers, Albert Shanker, has argued that "requiring all disabled children to be included in regular classrooms is both unrealistic and downright harmful to the children themselves" (Peltier 1). Teachers worry about whether they will be able to give the extra attention and spend the extra time necessary to execute an effective inclusion program. Administrators worry about having to ensure extra funding for aides, or extra training workshops. But most of all, parents of non-disabled students often worry about inclusive education having a negative impact on the learning and classroom opportunities of their children. It is common for these members of the education community to have the belief that, "accommodating the needs of a few may place at risk the learning opportunities of the majority" (Peltlier 1). After doing research on this topic, I believe that not only is an inclusive education environment
not detrimental to other students, but that it is beneficial to all involved, including the teachers, parents, peers, and special needs students.

Inclusion, particularly the inclusion of pupils with Down syndrome, promotes a successful learning environment for those involved, causing teachers to adjust their classroom methodology in ways that are positive for all students, promoting extra help in the classroom, and promoting more teacher and parent fulfillment as all students noticeably benefit from the program.

A study done by Gloria Wolpert showed that in order for inclusive education to be entirely successful, a teacher needed to be prepared for and flexible to formatting curriculum to address the special needs of a Down syndrome child. While adjustments to the classroom curriculum instigated by the presence of a Down syndrome student sound as if they would be detrimental to the learning of the other students, they have actually proved to be beneficial (Banerji, Dailey 511-521; Davis, Farrell, Fox 188-189; Johnson 27-29; Peltier 1-4; Wolpert 1-20). Many teachers undergo special training and/or workshops in order to better prepare themselves to teach in an inclusive environment. I believe that this extra training also helps to keep teachers up-to-date with all teaching methods and modern student problems. Many schools with successful inclusion programs allow more time for teachers to plan out classroom activities and to assess work, as well as to facilitate teacher communication about students (Banerji, Dailey 512). With the extra planning and training for inclusive educators, they are more prepared to teach all children in the classroom and to create a positive learning environment (Banerji, Dailey 518; Wolpert 5-11).

Successful inclusive classrooms often have a very positive atmosphere. Teacher praise, being the best motivator for a child with Down syndrome, becomes a prevalent part of the classroom. As quoted in Wolpert's study, one teacher states that "my children with Down syndrome soak up praise - the more they get, the more they want and the harder they will work to get it," but isn't this true of all children? "A child is a person first and their difficulties are add-ons which, although posing difficulties, can be overcome by a good teacher with… a positive attitude" (Johnson 22). The positive atmosphere is also promoted by the lack of "emotional outbursts and punishments" as methods of controlling inappropriate behavior, with the idea that "these cause bad feelings for everyone" (Wolpert 8). In this context, everyone can be interpreted to be not only students with Down syndrome, but those without, including teachers. More encouragement and less scolding create a supportive classroom, one that is conducive to the learning of all children.

Teachers also support more hands-on teaching methods because they are "reported to be highly successful catalysts of achievement for students with Down syndrome" (Wolpert 5). Personally, I believe that hands-on learning is advantageous for all students, keeping them active and interested in what they are learning. When teaching hands-on activities, as well as other activities around the classroom, teachers have the ability to slightly alter the assignment for the Down syndrome student, without noticeably setting them apart from the class. In Wolpert's study, "one teacher reported that while the rest of her first
grade class used Uniflex (small, colored) cubes for counting and adding, her student with Down syndrome sorted the cubes by color" (Wolpert 7). This active teaching approach is applied in testing and grading methods within the classroom as well. I agree with the idea that "performance in a workbook does not adequately reflect the knowledge and abilities of students," that instead, "teachers [have] found that daily physical performances or participation in class, and effort of the student [are] much better indicator[s] of learning or grades for students" (Wolpert 8). Here the teachers are speaking specifically of students with Down syndrome, though, from personal experience, I believe this to be true for all students, especially in elementary school. Another teaching method strongly advocated by inclusion supporters is group work and peer interaction. Having students work together helps everyone learn; top students help tutor needier students, while reinforcing their own knowledge. One parent in Wolpert's study said, "I love it that my son works with a top student in class. He tries to be more independent and do more on his own to be accepted by his peer tutor" (Wolpert 10). Sherri Munn, another parent of a child with Down syndrome, said that when her daughter, Abby, was in first grade, she was paired with a fellow student who was having trouble reading; after working together, Abby’s partner, Brooke, gained confidence in her reading, while Abby learned how to read, which in the first grade is a major accomplishment for a child with Down syndrome (Munn). As both students gain academic knowledge, they are also learning social skills that will help them succeed throughout the rest of their lives. The teaching methods and environment of inclusive classrooms are opportune for students with and without special needs.

Often full inclusion calls for the presence of a special education supporter within the context of the general education classroom (Banerji, Dailey 512). An extra teacher available in the room can allow for more one-on-one activity with not only the student with Down syndrome, but with the other students as well. In a study done by Banerji and Dailey, the researchers found that, "all the students want[ed] to work with the [special needs] teacher…I think they think it is special" (Banerji, Dailey 518). The ability of the special needs teacher of making students feel 'special' rather than stigmatized is important in their ability to help out rather than to cause problems. There can be problems that stem from the presence of an aide, such as giving one-on-one attention to only the special needs child or in causing distractions in the classroom (Wolpert 4-9). In order to prevent these problems from occurring, aides and teachers need to communicate and work together well, working more as a team instead of as two individual teachers. The aide also needs to be aware of all of the children in the classroom, helping all students who are struggling with a lesson or assignment, so that no one student feels singled out. Despite complications that can arise because of the presence of a classroom aide, overall, the extra help in the classroom can help to relieve the stress of the teacher and to give each child more individualized attention.

Inclusive classrooms are not only beneficial for the students, they are also beneficial for the teachers and parents. Teaching in an inclusive setting does require more work from both teachers and parents, but both groups find the process to be more fulfilling and worthwhile.
Teachers report that inclusion causes extra work in areas of modifying homework, class assignments, tests, grading procedures and communicating with parents (Wolpert 7). They agree that, “the benefits [are] well-worth the extra effort” (Wolpert 11). In another study, teachers also reported positive experiences working in inclusive settings and even high levels of professional fulfillment (NDSS 9). Parents placing their children in inclusive education have the responsibility of being in greater communication with their child's teacher in order to facilitate learning outside of the classroom walls. Though there are extra demands, parents describe having positive attitudes about inclusion (Johnson 26; NDSS 5-6; Wolpert 5-11). From my experiences, I believe that the parental involvement that inclusion requires helps to promote a better relationship between the parent and child and a more conducive home environment.

Teachers and parents could be pleased by inclusive education because of the growth, personally and academically, that all students experience in an inclusive classroom. Students with Down syndrome placed in inclusive classrooms experience “increased self-esteem, independence in daily living skills, social interaction, speech and communication and academic achievement,” becoming more prepared to move forward with their lives and to find their places in a heterogeneous society (Wolpert 3). The students without Down syndrome show benefits from inclusion, including openness to human differences, along with comfort and awareness of the physical and cognitive differences of people. They also experience improved feelings about themselves after helping classmates with severe disabilities. All students, through inclusion, improve their abilities to develop warm and caring friendships with both people to whom they are similar and with people with whom they have differences (Peltier 3).

As shown from the evidence above, inclusive education can be beneficial for parents, for teachers, and for all students. No student should be left out because of their disability, because of their differences. Every member of a classroom has something to bring that helps transform the class into a medley of personalities, talents, experiences, and abilities, an environment in which both academic and social personal learning are cultivated.
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I knew something was wrong...I could sense it, but little did I know that this feeling would soon turn out to be a reality, and this reality would soon turn out to be a nightmare.

Just as the excitement of the newest edition of the White family began to stir it was quickly shot down by "the news" and left a state of depression hanging over my family.

My pop, (what we call our dad), tried to tell us as gently as possible- Alex has Down syndrome- the news pierced my heart. I felt unbearable pain for my brother, who had just been born a day earlier and I had yet to meet.

My pop tried to explain what Down syndrome meant. All we wanted to know was when we could see him...when or if we could hold him. My pop said we could go to the hospital that night to see mom and Alex but he was intensive care so we would only be able to stay a little while.

Mom needed a hug so I hugged really tight and told her not to worry because we would all help...we would all be there for Alex...she was not alone. He was so cute but we could not hold him because he had a lot of tubes and things hooked up to him. We all told him we loved him.

What I thought would be a nightmare has turned out to be what seems like a dream if you think about how lucky we are to have Alex. He is healthy and smart. There could have been tons of challenges for Alex- but there was only one besides Down syndrome. One of his eye muscles were extremely weak, he could barely focus on an object without one of his eyes straying away. The day he had surgery I cried, I was scared that he wasn’t going to be okay. When I came home from school that day, his eyes looked bloody, but after awhile they cleared and he could see a lot better. He was a fighter.

Almost immediately after his surgery Alex began to crawl, slow or fast he crawled. The next thing I knew he started walking. I couldn’t believe it, could this really be the little brother I used to cradle and hold in my arms? He was going to be able to do anything.

Despite everything that has happened to Alex, he still keeps going--he never gives up and he never will. We have learned so much from him.

I love Alex just the way he is. When I look at him he doesn’t seem any different than any other child his age, but what I worry about is if someone tries to tell him he is different- I worry about the first time he feels hurt or pain.
I know that Alex will go through a lot of hard times in the future, but what ever challenge life brings to Alex I will be there for him…we all will. We love him very much and our family would never be the same without Alex.

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It is hard to believe that nearly a decade has passed since we were blessed with the birth of our Eric. It is even harder to believe that where we once were told not to expect much of Eric that we now see endless possibilities for him. It is our hope that this guide will not only give you the resources you and your family need to cope with the birth of your new born but that it will also give you confidence that there are limitless possibilities for your son or daughter as well.

Like many parents, we were not allowed the luxury of enjoying the birth of our new baby before we were hit with the news that our son had Down syndrome. Along with the news came some cold, hard, alleged facts about Down syndrome and what we could expect and not expect from our son. I can still remember a nurse telling me: “…And he will not be able to kiss you goodnight.” Most of Eric’s first year or so was spent searching for information about Down syndrome, sifting through piles of information and sorting what was helpful and what was rather misleading, in a quest to answer the many questions coursing through our brains. We were not fortunate to have a resource book at our fingertips or a support group to help guide us in the right direction. We felt lost and alone. And there were many family members and friends that wanted to help but didn’t know how or what Eric and our family needed.

One day, a friend gave me the book Another Season. This book gave me a new perspective on Down syndrome and gave me the courage and hope that I could expect much more from Eric. The book is the story about Johnny Stalling, the son of the famous football coach Gene Stalling and his wife Ruth Ann, and the family’s resiliency and fortitude to help Johnny overcome the many challenges of Down syndrome. As Johnny was born in 1962, there were virtually no resources or medical treatments available to support the Stalling family. Through love and perseverance, the Stallings pioneered a new path for people with Down syndrome and proved that there were options for Johnny and others. Today, there are more and more resources and possibilities for people with Down syndrome, especially in the medical and development fields. A research study conducted in 2002 showed that the life expectancy of individuals with Down syndrome nearly doubled from 25 to 49 years in the previous two decades.

While I did not specifically set out to find ways how to open up more possibilities for Eric, what Another Season encouraged me to do was to get involved in his activities, to seek support from others, and most of all, to love my son as I would any child of mine.
Sometimes the perfect person for you, is the one you least expect.

Unknown.
In Eric’s early years, most of my time was spent finding out what interested him. Consequently, I spent many an evening watching “Veggie Tales”, pushing the ball back and forth to each other and acting like “rock stars” while we played on his electric drums and guitar.

As Eric grew older, his interests turned to sports and other outdoor activities. We were fortunate to come across several sports programs for Eric in Lafayette, Louisiana: swimming, soccer and T-Ball. I was amazed at how many people wanted to help Eric and offered their knowledge and time without asking for anything in return. What I learned was that they did get a lot in return and it is what I get great satisfaction in seeing everyday – Eric’s beaming smile when he accomplishes a new task no matter how small. In swimming, it was getting his face in the water. In soccer, it was stopping the ball with his foot. In T-Ball, it was running to first base by himself.

Over the past several years, Eric has progressed in his sports. He continues his swim lessons and is now diving under water for objects on the pool floor. In T-Ball, Eric had his first hit off a coach’s pitch this season; his smile was a mile wide. Eric has traded in his soccer ball for a Taekwondo Gi; he is now working towards his red belt. He also has taken on many new interests and tasks. Eric and Dad have enjoyed two camping trips, the Pinewood Derby and selling popcorn as part of the Cub Scouts. Eric is also an avid PSP™ and Wii™ player and is many times the champion for the night. He has also taken on more responsibility around the house and he routinely sets and clears the dining table including the cleaning of the glass tabletop.

In the next decade, we have visions of Eric graduating from high school, getting his black belt in Taekwondo, having a girl friend, driving a car, going to college and starting a work career. Isn’t this what we would want for any of our children? It is only now, through the encouragement of the Stalling family story and with the resources and support from many wonderful people that these dreams are possible as well as all the other endless possibilities. With love, perseverance and support, anything is possible.

By the way, Eric is one of the best goodnight kissers that I know.

*It is not enough to give the handicapped life; they must be given a life worth living.* – Helen Keller

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This book has been furnished to you by the Down Syndrome Guild of Dallas (DSG). DSG is a non-profit organization dedicated to providing accurate and current information, resources, and support for people with Down syndrome, their families, and the community.

If you would like to be included on our mailing list so that you’ll know about upcoming DSG educational and social events, please fill out the form at the bottom of this page, and mail to:

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