DOWN SYNDROME GUILD
OF DALLAS

Resource Guide for Families of Adults with Down Syndrome

www.downsyndromedallas.org

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Dear Families,

We are constantly transitioning throughout our lives. While all of us handle change in our own way, major transitions often give rise to conflicting feelings. We may look forward to new experiences, yet worry about the unknowns. Taking adequate time to prepare and make a plan is the best way to alleviate the stress that can accompany change. For the families of children with Down syndrome, one of the most important (and challenging) transitions is when our son or daughter is no longer eligible for school services.

While in school, most, if not all, of the resources that make up a student's principle support system of special education and related services are mandated by law. Upon graduation, the student will no longer have an entitlement to many of the services. The process of identifying, applying for, and coordinating appropriate resources will fall mainly upon the family.

In an attempt to assist our member families, the Down Syndrome Guild's Options for Adults committee has prepared this

Resource Guide for Families of Adults with Down Syndrome.

We have attempted to cover the major topics – but the issues are very complex and the numerous programs are difficult to navigate. The resources within the guide are for informational purposes only and are not meant to be legal advice. The Down Syndrome Guild makes every attempt to keep our data current but cannot be responsible for the rapidly changing information on services and programs.

For additional information, clarification or networking, please contact our Executive Director, Becky Slakman, at 214-267-1374 or dsged@sbcglobal.net.

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Resource Guide for Families of Adults with Down Syndrome

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Checklist for Families of Adults (age 18 and older) with Down Syndrome

- ✓ Join the Down Syndrome Guild of Dallas to receive our monthly newsletter, which provides information about local support services, monthly social events, and quarterly networking meetings for parents. To become a member, contact our office at 214-267-1374 or visit our website at www.DownSyndromeDallas.org.

- ✓ Make the necessary contacts with state agencies to ensure that your child has access to the available resources. Many programs have a waiting list. If your child is not on the Home & Community Based Services (HCS) "interest list", do it NOW – there is a 10-year wait.

- ✓ Call the Social Security Administration to apply for Supplemental Security Income (SSI).

- ✓ Make a decision about guardianship or an alternative. Meet with your attorney to update your will and special needs trust.

- ✓ Make sure you have copies of all vocational assessments and other school records.

- ✓ Assist your child to register to vote. For males, registration with the Selective Service is mandatory.

- ✓ Explore post-secondary educational opportunities, vocational options or day activities centers.

- ✓ Find a good primary care physician because most pediatricians will not see patients older than 18.

- ✓ Develop a plan for your child's daily activities and care when you, the parents, are no longer able to coordinate every aspect of his/her life. Write a letter of intent" and share it with family members.

- ✓ Advocate (at the state and federal level) for better funding for community-based service options for adults with Down syndrome.

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Options for Adults Programs and Services

Social Activities - Every month there is an opportunity for adults with Down syndrome to interact in a fun atmosphere – bingo, bowling, dances, board games, etc.

Best Buddies - A partnership with the Best Buddies chapter at Southern Methodist University offers adults with Down syndrome an opportunity to have a one-on-one relationship with a college buddy.

Parent-to-Parent Support - Options for Adults quarterly meetings are offered to discuss topics of interest to families whose children with Down syndrome are no longer receiving school services. Topics include: wills and trusts, services available from agencies, health and wellness, residential options, etc. One-on-one parent-to-parent support is available by calling the DSG office.

Resource Guide - An overview of the resources available for adults with Down syndrome in our community – includes a checklist for families.

Consultation Service - An opportunity to meet one-on-one with our contract consultant to discuss how to best navigate the myriad of state, federal and local agencies that provide funding and/or services for adults with Down syndrome. This program is available at no fee (maximum of four hours of the consultant's time) to any DSG member family whose child is no longer receiving school services.

Agency Collaboration - Staff and parent volunteers regularly network and collaborate with service agencies/organizations (public and private) in our community regarding the needs of adults with Down syndrome. These interactions (formal and informal) benefit all DSG members.

Roommate Registry – Staff maintains a notebook of roommate profiles for those families who are interested in a residential option for their adult child with Down syndrome, providing an opportunity for networking.

Fall Conference - Provides speakers of interest to families who are planning the transition from school to adult life and those who are trying to navigate the agencies which provide services to adults with Down syndrome.

Newsletter - Every month the *DSG News* features an informative article or a notice about events of interest to families of adults with Down syndrome.

Advocacy - Staff and parent volunteers communicate with state and federal legislators about issues that impact the services and programs for adults with Down syndrome. Collaboration with other advocate groups and agencies is also a priority.

Adult Genetics Clinic – A subcommittee is working with this clinic at the University of Texas Southwestern Medical Center (UTSW) to address the complex healthcare needs of adults with Down syndrome. The goal is to develop a model similar to the interdisciplinary team approach used at the Down Syndrome Clinic at the Children's Medical Center in Dallas.

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Glossary of Acronyms

ADA-Americans with Disabilities Act

CBA- Community Based Alternatives

CDS- Consumer Directed Services

CDSA- Consumer Directed Services Agency

CLASS- Community Living Assistance and Support Services

DAC- Disabled Adult Child

DADS- Texas Department of Aging and Disability Services

DARS- Texas Department of Assistive and Rehabilitative Services

HCS- Home and Community Based Services-

ICFMR- Intermediate Care Facility for the Mentally Retarded

IHFS-In-Home and Family Support Program

MRA- Mental Retardation Authority

PASS- Plan for Achieving Self- Support

SES- Supported Employment Service

SHL- Supported Home Living

SSA- Social Security Administration

SSDI- Social Security Disability Insurance

SSI- Supplemental Security Income

TxHml- Texas Home Living Program

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ADVOCACY

From birth until their 22nd birthday, our children with Down syndrome were entitled to services by federal law. After school services end, there are no more entitlements. So even if you were never an advocate before, now is the time!

1. Familiarize yourself with the pertinent legislation – the civil right laws that protect individuals with disabilities from discrimination:
    - Americans with Disabilities Act (ADA)
    - Rehabilitation Act
    - Supreme Court ruling called the *Olmstead* decision

2. Most programs for people with Down syndrome are funded by the Texas legislature and/or Medicaid. Texas consistently ranks LAST in the quantity and quality of services for people with developmental disabilities. Therefore, it is important for DSG families to be informed about the issues when the Texas legislature meets (every other year) and communicate their views to their legislators.

To find out who represents you in the Texas legislature, go to www.legis.state.tx.us Click on "Who represents me?" in the column on the right side of the home page, then enter your home address.

3. The idea of becoming an advocate can seem overwhelming and intimidating, but it need not be. Effecting change almost always happens with the support of a group, so you are not in this alone. Some great resources for more information about the many legislative issues of interest to families of adults with Down syndrome are:

- **Arc of Texas**- provides legislative updates as well as an excellent handbook that can walk you step-by-step through the process of letter writing, calling and visiting legislators, as well as other tips. To find out more, visit their website www.theArcOfTexas.org and click on the Advocacy button.
- **Disability Policy Consortium in Austin, TX-** Visit the website at www.dpctexas.org. To sign up to receive email updates, click on the star icon in the upper right corner of the home page.
- **Advocacy Inc.-** visit their website at www.AdvocacyInc.org

4. One of the biggest issues for Texas advocates is the disproportionate amount of money spent on state schools vs. services for people in the communities where the live. The Down Syndrome Guild collaborates with Community Now! an organization that advocates for the community inclusion of all people. For more information, see the Community Now! website at http://www.CommunityNowFreedom.com/home.

If you would like to receive Legislative updates from the Down Syndrome Guild, please call Becky Slakman at 214-267-1374.

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Important Legislation

Americans with Disabilities Act (ADA)

This legislation was passed by the U. S. Congress in 1990 to prohibit discrimination against people with disabilities and guarantee them equal access to employment, public services, public accommodations, and telecommunications. Several federal agencies – the Equal Employment Opportunity Commission, Department of Justice, Department of Transportation, and the Federal Communications Commission – enforce different provisions of the ADA.

Rehabilitation Act

This legislation was passed by the U.S. Congress in 1973 to authorize grant programs of vocational rehabilitation, supported employment, independent living, and client assistance. It also authorizes a variety of training and service discretionary grants administered by the Rehabilitation Services Administration.

Olmstead Decision

Lois Curtis and Elaine Wilson, two women with disabilities who lived in Georgia nursing homes, asked state officials to allow them to move into their own homes in the community. After the State refused, Atlanta Legal Aid attorney, Susan Jamieson filed a lawsuit on their behalf. After appeals, the case was heard by the U. S. Supreme Court. In July 1999, the Supreme Court issued the *Olmstead v. L.C.* decision.

In *Olmstead*, the Court ruled that Title II of the Americans with Disabilities Act prohibits the unnecessary institutionalization of persons with disabilities. In the words of the Supreme Court, services to persons with disabilities must be provided "in the most integrated setting possible." The Court ruled that there should be community options for Curtis and Wilson.

Disability activists have hailed *Olmstead* as a landmark decision with implications similar to that of another historic ruling: *Brown v. Board of Education*. However, many individuals with disabilities and their families are unaware of the *Olmstead* decision and the full range of community services that are available as alternatives to services provided in an institutionalized setting.

The *Olmstead v. L.C.* decision challenges federal, state, and local governments to develop more opportunities for individuals with disabilities through accessible systems of cost-effective community-based services. Several federal and state initiatives are now underway to expand home and community options and make community living a reality for more people. Medicaid can be an important resource to assist states in meeting these goals.

The scope of the ADA and the *Olmstead* decision is NOT limited to Medicaid beneficiaries or to services financed by the Medicaid program. *Olmstead* is particularly relevant to transition-age youth with significant disabilities who are aging out of government healthcare programs that serve children with disabilities or preparing to exit special education settings and access adult services and participate more fully in the community. Youth, their families, and advocates can use the *Olmstead* decision to advocate that programs and services be provided "in the most integrated setting possible.
For additional information on any of this legislation, go to www.ed.gov.

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Self-Determination, Self-Advocacy and Person-Centered Planning

Adults with Down syndrome have the same rights as all people. However, all too frequently they do not have the same opportunities and experiences that enable them to exert control in their lives and to advocate on their own behalf.

The principles of self-determination set forth that people with developmental disabilities must:

- Have the opportunity to advocate for themselves with the knowledge that their desires will be heard and respected
- Have opportunities to acquire skills and develop beliefs that enable them to take greater personal control
- Be active participants in decision-making about their lives
- Be supported, assisted, and empowered to vote and become active members and leaders on community boards, committees and agencies
- Have the option to direct their own care and allocate available resources
- Be able to hire, train, manage and fire their own personal assistants

The tool used to ensure that the principles of self-determination and self-advocacy are implemented is called *person-centered planning*. For additional information, visit the following websites:

- www.pacer.org/tatra/resources/personal.asp
- www.ImagineEnterprises.com
- www.TheArcOfTexas.org (click on Real Life and Microboards)
- www.Microboard.org

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What is a Microboard?

A microboard is formed when a small group of committed family and friends joins together with a person with a disability to create a nonprofit organization. The microboard can then plan the support services required by one individual person with disabilities. The biggest benefit of a microboard is that the individual with a disability has control over his or her own life with supports from a nonprofit organization run by those who know and care about him/her most.

The elements of a microboard are:

- Membership of 5-7 family members, friends, and acquaintances who are committed to knowing the person and having a reciprocal relationship with him/her
- Builds bridges between the person with disabilities and his/her community
- Affords the person with disabilities flexibility and more control to achieve his/her goals and dreams
- Manages the support services, such as transportation, medical care, job search, supervising a care-provider in the home, etc. – creating a "circle of support"
- May become an HCS provider for the person with disabilities
- May become the successor guardian or trustee of a special needs trust

The Arc of Texas has introduced the ***Microboard Collaboration*** to Texas, in conjunction with its ***Real Life*** program. The collaboration provides board training, a Texas Microboard Starter Kit, and step by step guidance. For more information see www.TheArcOfTexas.org/programs/reallife.asp .

If you would like to discuss establishing a microboard, contact Lisa Rivers at the Arc of Texas at lrivers@TheArcOfTexas.org or 1-800-252-9729.

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SSI, SSDI and Medicaid/ Medicare- What's the difference?

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. An asset is any money you have in the bank, any property you own other than the home you live in, any vehicles you have over one, and any retirement or investment accounts you have. As the name implies, SSI supplements a person's income up to a certain level. Currently, the maximum amount paid is $674/month. A person who receives SSI benefits automatically is entitled to Medicaid coverage.

Children with Down syndrome can qualify for SSI based on the following:

1 Rules for Children Under 18:

Most children 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.***

2 Rules for Children 18 and Older:

When a child 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 food and shelter, the monthly SSI check may be reduced.

How can I find out if my child is eligible for SSI?

Call the Social Security Administration (SSA) 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- it is usually not necessary to go to a Social Security office.

What is SSDI? SSDI is short for Social Security Disability Insurance. You may hear this term used, but most people with Down syndrome will not qualify for SSDI unless they had a paying job for more than 2 years or one parent has retired or is disabled.

Disabled Adult Child Benefit: An adult disabled before age 22 may be eligible for the DAC benefit if a parent is deceased or starts receiving retirement or disability benefits. The SSA considers this a "child's" benefit because it is paid based on a parent's Social Security earnings record. Based on some DSG parents' experience with this program, if a child with Down syndrome is already receiving SSI (and in some cases SSDI) and their parent (who must be eligible for SS benefits themselves based on their work history) passes away or starts receiving either regular retirement or disability benefits from SSA, this program kicks in. The good part is that if families have already gone through the disability determination process for SSI, that determination will generally be sufficient to support the Disabled Adult Child qualification and the process involves just an SSA administrative move to a different funding source.

The disabled adult loses **automatic** eligibility under Medicaid (but can apply for that separately through the state), and often receives higher monthly SS benefits because benefits are based on a percentage of benefits earned by the parent. After 2 years the disabled adult child is eligible for Medicare benefits.

For more information regarding adult Disabled Adult Child Benefit see:
http://www.ssa.gov:80/dibplan/dacpage.shtml

What is Medicaid? Medicaid is a health *entitlement* program. It 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- this means you do not need to apply. For more information contact the Medicaid Client Hotline (800) 252-8263.

What is Medicare? Medicare is a health *insurance* program (not an entitlement program) for the elderly or those receiving SSDI. It is paid for by the federal government, not the state of Texas.

Note: for one-on-one assistance with Social Security issues, contact:

Mary Sue Welch
Outreach, Advocacy & ADA Specialist
REACH of Dallas
214-630-4796
mwelch@reachcils.org

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Funding Options for Services

Frequently, DSG members call our office to ask how to get services for their child with Down syndrome. Seems like a simple question. However, the answer is very complicated. It depends on the child's age, the family's income level, what kind of services, public or private service providers, availability of funding for existing programs, waiting lists for some programs, rules and regulations that constantly change, etc. Below is a summary of the options:

1. Private health insurance and Medicaid may provide funding for therapies for children and adults with Down syndrome.

2. Some agencies offer "fee for service" therapies and support services for adults with Down syndrome.

3. Texas Department of Aging and Disability Services (DADS) is the state agency which provides funding through the local Mental Retardation Authority (MRA)- see following page

4. Medicaid-waiver programs are funded by a combination of federal and state dollars. Make sure your child is on the "interest list" (or "waiting list") for any and all Medicaid-waiver programs for which he/she is eligible.

5. Some adults with Down syndrome may be eligible for food stamps and Section 8 vouchers from the Department of Housing & Urban Development.

The following pages provide a brief overview of these various funding options.

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The Waiting List- What is it?

In very simple terms "The Waiting List" is for funding for services for people with disabilities, including – but not limited to – children and adults with Down syndrome. The kinds of services include speech therapy, occupational therapy, case management, respite care, supported employment, nursing care and other "individualized" services. The types and frequency of services available are based on an assessment of each person's needs. These services are provided at no cost to the family – that's the good news. The bad news - there is a waiting list of 35,000 people with disabilities in Texas – some families have been waiting for ten years!

"The Waiting List," also called "Interest Lists," is really two lists because there are two different programs that provide almost identical services. Both are referred to as *Medicaid waiver programs* because some of the funding is from federal Medicaid money. An adult or child with Down syndrome is eligible (from the date of birth) for **both** programs, but you have to call and go through the process to get your child's name on each list. The programs are:

Home and Community-based Services (HCS) – contact:
Dallas County – Dallas MetroCare at 214-333-7000
Denton County – Denton County MHMR at 940-565-5244
Collin County – LifePath Systems at 972-727-9133
Ellis, Johnson and Navarro Counties – 903-872-2491, ext. 102

Community Living Assistance Support Services (CLASS) – contact:
Texas Department of Aging and Disability Services at 1-877-438-5658
(also ask if your child is eligible for the Medically Dependent Children's Fund)

When you call, just tell the person who answers that you have a child with Down syndrome and you want to get his/her name on "The Waiting List." You will be asked some basic information and another person will call you back to explain what documentation will be required – in most cases a doctor's statement confirming a diagnosis of Down syndrome is all that is required. At the end of the process, you will receive a letter confirming the date your child's name was added to the list.

**** It is important to verify your child's place on the list annually. Some families report being inadvertently dropped from the list.**

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Department of Aging and Disability Services (DADS)

The primary agency that provides funding (for therapies, respite care, supported home living, etc.) to people with developmental disabilities is the **Texas Department of Aging and Disability Services (DADS).** For many years, the agency was called the Texas Department of Mental Health and Mental Retardation, but about 7 years ago the Texas legislature combined several agencies and renamed them DADS. Each county is served by an office called the *Mental Retardation Authority (MRA).*

The MRA in each county is the gate-keeper for the funding for all the services funded by DADS. There are two types of funding sources: Medicaid waiver (a combination of state and federal dollars) and General Revenue (state dollars). Each family of a child with Down syndrome must contact the MRA in the county where they live and go through the "intake" process to secure services.

Dallas County:
Dallas MetroCare
Eligibility Determination Unit (EDU)
1353 N. Westmoreland, Cottage 4
Dallas, Texas 75211
214-333-7000
www.MetroCareServices.org

Collin County:
LifePath
P.O. Box 828,
McKinney, TX. 75070
972-727-9133
www.LifePathSystems.org

Denton County:
Denton County MHMR Center
PO Box 2346
Denton, Texas 76202
940-381-5000
www.Dentonmhmr.org

Ellis, Johnson & Navarro Counties
Lakes Regional MHMR
800 N. Main Suite N
Corsicana, TX 75116
903-872-2491
www.lrmhmrc.org

*** *DADS – Consumer Rights Hotline- 800-458-9858**

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What types of services are available from DADS?

General Revenue Services - These are primarily intended to help people who are living in their own or their family's homes. Unlike the Medicaid waiver programs (see information beginning on the following page), General Revenue funding is provided through the state only and is non-transferable; if you move out of the county where you currently live, the money will not follow you.

The following services may be available:
- Respite Services
- Occupational/Physical Therapy (OT/PT)
- Speech Therapy
- Psychological/behavioral services
- In-home training
- Nursing/attendant care
- Physical/medical (assistive equipment and medications)
- Recreation/leisure summer programs (camps, etc.)
- Residential placement
- Community living options
- Services for students remaining in the family home
- Supported employment/job coaching/job development
- Sheltered training/workshops and vocational evaluations
- Day programs
- Case management and service coordination

In-Home and Family Support (IHFS) - is a consumer-driven program that provides up to $3,600 per fiscal year to eligible individuals and/or their families as a means of assisting with the purchase of goods or services related to a disability. ***Access to this particular program is on a first-come, first-served basis.*** This is considered "funding of last resort" and is ***not*** a Medicaid waiver program. Services available include:
- Attendant care
- Home health aide or homemaker service
- Respite care
- Transportation services
- Purchase/lease of special equipment or architectural modification of a home

To apply for any of the above services contact your local Mental Retardation Authority (MRA) – see previous page for those in North Texas.

Note: *Many families utilize the above services while waiting for a Medicaid-waiver program "slot" – see information about Medicaid-waiver programs, beginning on the following page*

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What is a Medicaid Waiver?

A Medicaid waiver allows the state to be more flexible in how it allocates money to provide long-term services for some people with disabilities or elderly citizens who are eligible for Medicaid. In the past, people had to be in nursing homes or other large institutions for Medicaid to pay for long-term services.

Important facts about a Medicaid waiver:

- It is an array of support services available to recipients in the communities where they live rather than in institutions or in the traditional 6- person group home.
- **It is *NOT*** an entitlement program – meaning that the number of "slots" available is dependent on the funding from the state legislature. The amount of money appropriated by the state is matched by federal funds.
- Historically, the number of slots available has been fewer than the number of people requesting services, resulting in a "waiting list" or "interest list".
- "Waiver" indicates that certain Medicaid requirements and restrictions do not apply to these programs.
- When services through another government program other than the waiver are available to meet an identified need, those resources must be used first.
- Funding received through a Medicaid waiver program will follow you if you move, unlike General Revenue funding, which may be lost if you move to a different county.

In Texas, there are several different waiver programs that offer a range of home and community-based services to people with disabilities. The most commonly used by those with Down syndrome are HCS and CLASS. There are different rules and funding amounts for each of the different waivers. In general, though, their purpose is to provide funding to help people get the supports they need in the community.

****It is important to note that the HCS program is the only program that offers residential options.**

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Medicaid Waiver Descriptions

Home & Community-based Services Program (HCS)

The HCS Program provides individualized services and supports to persons with intellectual disabilities who are living with their family, in their own home, or in other community settings, such as small group homes. ***Currently HCS is the only residential funding option for people with Down syndrome.***

Eligibility: There is no age limit for enrollment. Individuals must have either intellectual disabilities or a related condition that results in deficits in adaptive behavior and full scale IQ of 75 or below and be eligible for Medicaid. Spending limits are dependent upon the level of need

HCS Services
Case management
Adaptive aids
Minor home modifications
Counseling and therapies (includes audiology, speech/language pathology, occupational therapy, physical therapy, dietary services, social work and psychology)
Dental treatment
Nursing
Residential assistance
Supported home living
Foster/companion care
Supervised living
Residential support
Respite
Day habilitation
Supported employment

Note: Most families of adults with Down syndrome find that the HCS program provides the best selection of services and the highest level of funding. The DSG recommends families use other options (if available) until an HCS "slot" becomes available.

Community Based Alternatives (CBA)

CBA provides home and community-based services to people who are elderly and to adults with disabilities who ***require nursing services***, as an alternative to living in a nursing home.

Eligibility: Individuals must have a need for skilled nursing care; meet at least two nursing facility risk criteria; be eligible for Medicaid; be age 21 or older. Spending limits dependent upon level of need.

Services: Adaptive aids and medical supplies
Adult Foster Care
Assisted Living Residential Care services
Consumer Directed Services (CDS) option
Emergency Response Services
Home-Delivered Meals
Minor home modifications
Nursing services
Occupational therapy services
Personal assistance services
Physical therapy services

(CBA services continued…)
Prescription drugs
Respite care services
Speech and/or language pathology services

Community Living & Support Services (CLASS)

The CLASS program provides home and community based services to people with disabilities or a related condition as an alternative to placement in an intermediate care facility. A related condition is a disability with a primary condition other than an intellectual disability that affects the ability to function in daily life. ***Some consumers may be able to access CLASS services while waiting for an HCS "slot."***

Eligibility: There is no age limit for enrollment; however onset must have been before age 22. To qualify for this service, individuals must have a related condition; be eligible for Medicaid; reside in the CLASS catchments area. Spending limits dependent upon level of need.

Services:
Case Management
Habilitation
Habilitation Training
Respite Care
Nursing Services
Physical Therapy
Speech Pathology
Occupational Therapy
Psychological Services
Adaptive Aides and Medical Supplies (up to $10,000/year)
Minor Home Modifications ($7,500/lifetime)
Specialized Therapies (music therapy, therapeutic horseback riding, massage therapy, and recreational therapy)

Texas Home Living Program (TxHmL)

This program provides selected services and supports to people with cognitive disabilities ***who live in their family homes or their own homes.***

Eligibility: An adult or child is eligible for TxHmL if he or she: has an intellectual disability or a related condition and meets the criteria for a Level of Care I in an ICF-MR; is a current Medicaid recipient, does not require intensive one-to-one supervision to prevent dangerous behavior; has an Individual Plan of Care (IPC) approved by DADS; is not enrolled in another Medicaid waiver program; chooses to participate in the TxHmL program instead of the ICF-MR Program; and lives in his or her own home or family home. Annual spending may not exceed $ 13,000.

Services:
Adaptive aids
Minor home modifications
Specialized therapies (audiology, speech/language pathology, occupational therapy, physical therapy, and dietary services)
Behavioral support
Dental treatment
Nursing
Community support
Respite
Day habilitation
Employment assistance
Supported employment

Consumer Directed Service Option

What is the Consumer Directed Services (CDS) option?

The CDS option allows you the freedom to hire and manage your own employees, set the wages for your employees and give benefits, such as vacation days and bonuses.

How does CDS work?

You select a Consumer Directed Service Agency (CDSA) to do your payroll and federal and state taxes. The CDSA will help you set up an initial budget. In some programs, the CDSA will provide guidance on recruitment, salaries, benefits, and administrative costs.

How do I find a Consumer Directed Service Agency (CDSA)?

Some CDSAs serve the entire state. Others serve certain parts of the state. You can select a CDSA that serves your area. There are currently 2 Consumer Directed Service Agencies in the north Texas area. The only face-to-face meeting you need is the first orientation meeting. All other business can be conducted over the phone or via fax. For a complete list of CDSAs, see DADS website below.

Why would I want to choose CDS?

When you hire your own employees you can often find family, neighbors, or friends to work for you. Within your allotted service budget, you can set your employees' wages and benefits, and you can hire back-up employees for those times when your regular employees are not available to work.

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***** Not all programs and services are eligible for CDS. For more information and to see a complete list of current programs and services available, go to:***
http://www.dads.state.tx.us/providers/CDS/cds-faqs.pdf

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Choosing an HCS Provider That Meets Your Needs

The first step in choosing a provider is identifying your individual needs and the values that are important to you. Once you have identified these things you are on your way to accessing supports that will help you develop a meaningful life for your family member with Down syndrome.

A list of providers can often be obtained upon request from the Texas Department of Aging and Disability (DADS), but it is up to you to choose which person or agency can best meet your needs. Once you have obtained the list you might want to consider visiting two or three different agencies alone or with someone you trust, asking as many questions as you need to feel informed.

In order to make the most of your visit, think about what is most important to you and develop questions that will get you the information you need to make informed decisions. You will also need to be prepared to express your expectations, goals and what you are willing to do to help. The relationship between you and your provider should be a partnership.

Some questions may include:

* What experiences have you had in working for people who have disabilities?
* How many people does your agency serve in supported employment, job development, habilitation, respite, etc?
* Describe some of the factors you consider when matching an individual to an employer, community group, volunteer position, etc.
* What is the average length of time in which your employees stay with your agency?
* Describe the training, if any, which is provided to all employees of your agency.
* Describe the strategies you or your agency use to match a support person to the consumer.
* What type of activities does your agency use to better acquaint the consumer with the support provider?
* Can you explain what strategies you have used to help people develop connections in the community?
* Can you please explain the strategies your agency uses to develop jobs for people with disabilities?
* Describe some competitive based employment jobs and community volunteer opportunities that you have helped persons with a disability obtain and the positions they held.
* How does your agency develop job leads for people?
* What strategies has your agency used to develop natural supports at a job site?
* What strategies has your agency used to develop natural supports in the community?

As you prepare for your meeting, you will begin to think of questions that may be more specifically related to your particular needs and values. Don't hesitate to ask any question you have that assist you in making the best decisions for your family! If you feel the need to request a second meeting, make an additional phone call, etc. Take the extra time. There is no timeline but your own for the selection of a provider. It is a good idea to interview at least 2 or 3 providers before you make a decision.

To see survey results on a comparison of several HCS providers in the Dallas area go to the DADS Long Term care Quality Reporting System at: http://facilityquality.dads.state.tx.us/qrs/public/qrs.do or contact the DSG to network with other families regarding their experiences with HCS providers.

(Adapted from the newsletter of the ARC of North East Tarrant County, February 2007

Funding-Waivers/ July 2009

DOWN SYNDROME GUILD
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Employment Options

One of the greatest challenges faced by adults with Down syndrome is how to stay involved and productive in the community after completing school. One of the ways to accomplish this goal is through employment. The following provides a simple introduction to employment options:

- **Competitive employment -** the individual secures employment in the community – for example, by responding to ads or job postings or proactively approaching businesses – and works independently without any support services.

- **Supported employment -** most commonly used by people with Down syndrome. The individual works in an integrated setting and receives support services from a job coach. Supported employment provides the person with the disability with the long-term support services needed to be successful in competitive employment – training, job matching, job development, job coaching, on-going on-site monitoring, etc. *(See "What is a Quality Supported Employment Program" for more details)*

- **Sheltered employment (also called "enclave" or "workshop") -** individuals work in self-contained settings with others who have disabilities *without* the integration of non-disabled workers. Sheltered employment is often obtained through agencies, and wages for this type of work do not meet minimum wage standards. The "workshop" is usually paid a fee for providing the work and support, virtually negating any wages earned. Sheltered employment typically involves manual labor tasks such as assembling goods.

- **Volunteer employment -** volunteer job that is unpaid. This is sometimes an alternative for those who need more flexibility, or in the event that paid employment is difficult to find. A volunteer position allows a person to continue to improve their skills and build social networks in the community, and may sometimes lead to paid employment

Regardless of the type of employment that is pursued, the challenge will often be locating a job and coordinating appropriate support services. The primary agency that funds employment related programs in Texas is called DARS - Texas Department of Assistive Rehabilitative Services.

Down Syndrome Guild
of Dallas

What is ***DARS***?

DARS – Texas Department of Assistive and Rehabilitative Services

DARS is the name for the state agency that funds work-related programs for people with physical and developmental disabilities. DARS is a merging of several agencies, including the Texas Rehabilitation Commission. There is at least one local DARS office in each county.

- The DARS system is a "rehabilitation" model originally designed for soldiers returning to work after having been wounded in World War I. The system is often difficult to follow and does not provide adequate funding – even after many revisions to the legislation – for people with developmental disabilities who require long-term, on-going support to be successfully employed.

- Before approving any client to receive funding, DARS will require a vocational assessment. For clients with developmental disabilities, standardized vocational assessments generally lead to a recommendation that a sheltered workshop is the best option. Therefore, families should go to DARS with vocational assessments done by the school district showing a summary of performance and a listing of specific skills demonstrated during internships, in-school jobs, previous jobs, etc. A good vocational assessment should emphasize the client's likes and acknowledge his/her dislikes.

- DARS has a list of "vendors" that provide Supported Employment Services (SES). These vendors are paid through DARS based on "benchmarks" of success for the employee (length of time employed, etc).

- The goal of DARS is to close each competitive employment job case after 90 days of employment or supported employment after 117 days. In supported employment, the vendor/ employer *may* continue to provide on-going support and follow up, but typically this involves only one visit to the job site per month. Families need to ask their SES vendor: "What is your commitment to my child after DARS funding is gone?"

For additional information, see: **www.dars.state.tx.us.**

Or contact the Down Syndrome Guild DARS liaison:
Margo Wheeler Rye
214-778-4938
Margo.Rye@dars.state.tx.us

DOWN SYNDROME GUILD
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Employment and Social Security

How do we pay for employment services?

The state agency that provides funding for employment services for people with disabilities is the Department of Assistive and Rehabilitative Services (DARS). If your child is still in school, you should connect with the DARS Transition Counselor assigned to each campus. If your child is out of school, you should make an appointment to meet with the DARS Vocational Counselor assigned to your area of the Metroplex. To assist families in making the necessary connections, DARS has assigned a "liaison" to the Down Syndrome Guild. You may contact
Margo Wheeler Rye at 214-778-4938 or email Margo.Rye@dars.state.tx.us

Can my child with Down syndrome work and keep Social Security benefits?

YES, many adults with disabilities earn wages and are able to keep at least a portion of their monthly Social Security check and their eligibility for Medicaid – but you have to know the rules and regulations. It is a complicated system but help is available through a **FREE** program called **"Work Incentives Planning and Assistance."**

A community work incentives coordinator will meet with you and your child to develop a personalized, written benefits report that provides detailed information about the various options, including Earned Income Exclusion; SSI Continuation; Student Earned Income Exclusion; Work Expenses Exclusion; Protection of Medicaid 1619B; and Plan for Achieving Self-Support *(PASS- for more details on this program PASS information page)*. This valuable information allows a person with a disability to make an informed decision about seeking employment.

Easter Seals of North Texas has received a grant from the Social Security Administration to provide this service to 21 North Texas counties through 2010. For more information, contact Cindy Herzog, Director of the Work Incentives Planning and Assistance program for Dallas and Denton counties, at 888-617-7171 ext. 1038 or email Cindy at cherzog@ntx.easterseals.com. For Collin, Grayson, Hunt, and Cook Counties, contact Lucy Endermark at 469-742-0887.

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PASS - Plan for Achieving Self-Support

PASS is an SSI work incentive under which persons with disabilities can set aside income and/or resources to be used to achieve specific work goals. A PASS can be established to cover the costs of obtaining an education, receiving vocational training, starting a business, or purchasing support services that enable individuals to work and result in reduction/cessation of benefits (SSI/SSDI). PASS is meant to assist a person in competing in the job market. PASS makes it financially feasible for individuals to set aside or save income and/or resources. These can be used to achieve their vocational goals by enabling them to receive higher SSI payments as they work toward self-sufficiency. These support services may include:

- The purchase of coaching/job advocacy supports needed to obtain, maintain employment
- Vocational evaluation
- The payment of transportation-related expenses
- The purchase of job-related equipment, uniforms, etc.
- The mechanism for allowing individuals or groups of individuals to purchase a business;
- Any other services/equipment needed to support individuals in a work-related manner.

PASS is just the means to acquire the services and items needed for ***starting*** work, not the means to make income or resources available for ongoing costs. For a PASS to be approved by SSA, there must be a reasonable chance that individuals can achieve their vocational goal. There must also be a clear connection between the vocational goals and the increased or maintained earning capacities.

For free assistance on this and other Social Security/employment related issues, contact Cindy Herzog, Director of the Work Incentives Planning and Assistance program, at 888-617-7171 ext. 1038.

What is a Quality Supported Employment Program?

If you want a job in the community, here are some guide lines for deciding whether a program is the right one for you. No program is going to meet all these perfectly, but programs should recognize these as important things they should work toward.

Eligibility

Everyone has the right to a job in the community, without regard to label or severity of disability.

Individual Choice

The individual receiving services helps decide what services are provided, how they are provided, and which staff provides them.

Service Setting

Services are provided in integrated community settings (e.g., businesses in the community), with the chance to spend time, communicate and develop friendships with people without disabilities. Services respect and try to accommodate diverse cultural and linguistic preferences.

Assessment

Assessment (evaluation) is not done to figure out "what's wrong" and how to "fix it," or to see if the person is "ready" to work. The agency helps the person figure out their dreams, hopes, interests and capabilities. Jobs and support services are developed in response to what the person wants and needs. Community settings (i.e., real employers) are used for all assessments.

Service and Placement Design

Rather than "fitting" people into existing programs, people are helped to find their own jobs (not group situations), and are paid directly by the employer at the competitive wage for the job. For example, a program may give options such as, "You can go in our janitorial training or food service training program" or "You can go to our enclave at the supermarket or the packaging company." What they should be saying is, "Let's find out what kind of job you would really be happy doing, and we'll help you find it."

Use of Community Resources

The program makes every effort to help people use services and resources used by all community members (people with and without disabilities). "Special" services for people with disabilities (such as special transportation) are used only when there are no other possibilities. For example, a person who wants to learn office skills or English as a second language would be provided help to take a course at the local community college, rather than receiving the training from a disability agency.

Behavior Challenges

A good provider realizes that people have a right to work in the community, even if they act differently or have behavior problems. Instead of controlling or modifying behavior before a person is given a chance at a job, emphasis is placed on matching the person in a situation which meets their needs and/ or lessens the impact of the behavior. People are placed in jobs where their behavior is acceptable (e.g., an individual who speaks in a loud tone of voice is placed in an active, noisy work environment), in places which will not cause behavior problems (e.g., an individual with a compulsive eating disorder is placed in a job with no access to food), or simply in environments where they are given more control, thus reducing problem behavior over time.

Training and Staff Role

Training is done to the fullest extent possible by the employer. Agency staff see their role as providing consultation to supervisors, co-workers and other community members, to help the person with a disability succeed on the job. Staff do not replace typical employer training and support, but only add to it if necessary.

Training on the Job

Training and support are customized to the specific needs of the individual, the employer, and the social aspects of the job. Training and accommodations are always done in ways that are respectful of the individual, and encourage integration into the job environment. For example, co-workers interact and give feedback directly to the employee, and not through the job coach; the job coach does not speak for the employee.

Skills and Social Match

In developing jobs, the agency not only looks for a job which is a good match to the skills, culture, and interests of the individual, but also finds jobs which a person is comfortable in socially. For example, a person who is naturally quiet and likes to keep to themselves would not be placed in a job which requires lots of personal interactions and where everyone else is outgoing.

Social Inclusion

Jobs are developed and services provided so that people not only get a job, but also get the chance to make friends and participate in social activities connected with the job. People are encouraged and provided assistance to participate in such activities as: going to lunch with co-workers, coffee club, birthday celebrations, social gatherings and parties outside of work, and company sports teams.

Career Development

Services are provided in a way that supports ongoing career development. Individuals have the opportunity to improve their skills, change positions and jobs, and change careers. Career development includes the opportunity for increased hours, benefits, and employment on a full-time basis with financial independence.

Holistic Approach

Having a good job is seen as one part of your life that relates to other things, including social relationships, recreation, and where you live. Services are provided so that a person is able to experience all aspects of community life.

Employment is about people:

- ✓ *Reaching their full potential*
- ✓ *Becoming participating community members*
- ✓ *Having a valued role, with the same rights and responsibilities as everyone else*
- ✓ *Experiencing and enjoying all that life has to offer*
- ✓ *Defining themselves and their place in the world*

DOWN SYNDROME GUILD
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For those adults with Down syndrome for whom competitive employment or a volunteer job is not a desired option, the choices include day habilitation centers, sheltered workshops, and recreation centers. Below are some local resources:
(Inclusion on the list is not an endorsement by the Down Syndrome Guild.)

Day Habilitation Programming

Achievement Center of Texas (ACT) - Garland
(972) 414-7700
http://www.AchievementCenterOfTexas.org/

Coventry - Wylie
(214) 498-7298
http://www.CoventryReserve.org/

Easter Seals of North Texas- Carrollton
(817) 759-7930
http://ntx.EasterSeals.com/site/PageServer?pagename=TXNW_Habilitation_Services

My Possibilities - Plano
(469) 241-9100
http://www.MyPossibilities.org/

UCP of Metropolitan Dallas (formerly United Cerebral Palsy) Dallas
(214) 351-2500
www.UCPDallas.org

**** Many providers of HCS services also offer a day habilitation option.***

Sheltered Workshops

Alternative Business Services (formerly Community Voices, Inc.)- Arlington
(817) 695-1417 or (817) 695-1422

Calab Learning Center - Grand Prairie
(972) 522-5900
http://www.CalabInc.com/

Citizens Development Center (CDC) - Dallas
(214) 637-2911
www.CDCDallas.org

Dallas Center for Developmentally Disabled – Dallas (*offers day program and sheltered workshop)*
(214) 328-4309
www.DallasCenterForDD.org

Mosaic Vocational Center/Document Destruction Service - Carrollton
972-866-9989 ext. 302

North Texas Rehabilitation Service, Inc. - Garland (*offers day program and sheltered workshop)*
(972) 272-6526
www.ntrsinc.com

Recreational & Leisure

The ARC of Dallas L.I.F.E Program- Dallas
(214) 634-9810, extension 108
http://www.ArcDallas.org/adult.htm

Bachman Recreation Center - Dallas
(214) 670-6266

Plano Parks & Recreation Department - Plano
972-941-7272
http://www.Plano.gov/Departments/ParksAndRecreation/Therapeutic+Recreation

***For additional information on day activities see the ARC of Dallas Resource Directory at www.ArcDallas.org or call (214) 634-9810**

DOWN SYNDROME GUILD
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Post-Secondary Education Opportunities

Receiving a college education and experiencing that very exciting time in life is as beneficial for students with Down syndrome as for students without. The growth that students experience in college can be measured in a number of areas, including academic and personal skill-building, employment, independence, self-advocacy, and self-confidence.

Programs and schools vary widely in terms of what they offer with respect to academics, independent living skills training, residential options and the type of diploma or certificate earned. Deciding which program to enroll in is just like researching any college or program. It is important to find a good fit between the individual and the school. We have included some tips to help in this endeavor:

- ✓ Determine what your intended outcome is- does the student want to be more independent and experience college life away from home in a dorm-like environment, gain employability skills, join extra-curricular activities, etc.? This will be important in deciding which school is best.

- ✓ When contacting a school, note that in most cases, the Office of Disability Services is **not** related to curriculum. It is only to provide accommodations such as tutoring, note takers, etc. Most programming information will be found through the Continuing Education office.

- ✓ Funding is typically paid for by the family, but may be paid for by DARS, depending on each individual circumstance. Contact your DARS representative to find out if this is an option for you.

- ✓ You ***must*** apply for federal student financial aid (FAFSA) whether or not you think you will get it or need it, in order to receive any funding through DARS for education. See http://www.fafsa.ed.gov/ to fill out an application.

- ✓ If your child is interested in a course, but not able to meet entrance requirements, they may be able to "audit" a class. Check with an advisor for guidance.

- ✓ Many schools that offer opportunities for students with cognitive disabilities do not post these options on their general website. Do not assume because it's not listed, that it is not offered. Call and ask questions!

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The following are highlights of some of the post-secondary options available and links to further information. Use the contact information provided to find the program that will work best for your student.

El Centro College (Dallas, TX) - currently offers two classes specifically designed for students with developmental disabilities:
The Next Step program is designed for individuals with severe reading or learning disabilities. The class also teaches how to perform basic office-computer tasks, and works to improve basic reading, writing, and math skills. A job placement counselor also works with them in this period to help them to find work alternatives.
The Moving On program is designed for individuals who have learning disabilities but read at a minimum of fifth grade level. The program works to improve basic work skills and computer skills in Microsoft Office, and works to improve basic academics, job seeking skills, and problem solving skills. This program also includes working with a job placement counselor. Contact Steven Carter, Program Director/Instructor in Workforce Education at 214-860-5940 or e-mail sc5753@dcccd.edu

Richland College (Dallas, TX) - offers a variety of continuing education classes focused on an employability outcome. Some courses may include job search skills, workplace safety, computer skills. They also offer an "Employability Certificate" program which includes an internship following completion of classes. Please contact Melinda Weaver- Director of Continuing Education @ 972-238-3750 or MWeaver@dcccd.edu

Northlake College - a new program called CAPS - Career Action Pathways to Success- currently offers one 4-week class through Disability Services that addresses employability skills. This class is only offered in the summer. For more information contact Tony Miller, Disability Services Coordinator at 972- 273-3166.

Tarrant County Community College -currently offers three different programs: The Transitional Skills program on the Northeast campus (817-515-6657), The First Choice Program on the Southeast campus (817- 515-3020), and College Explorations on the South campus (817-515-4592).

Transitional Skills Program at North Central Texas College (Corinth, Texas) — classes are offered through the Division of Lifelong Learning. Course studies include phonics, reading, spelling, grammar, math, computers, history, and Spanish. The curriculum is designed to meet the academic needs of the individual with the emphasis on improving behavior patterns and developing living-life skills. Schedule options include two-day or four-day schedules. For more information call 940-498-6270.

Vocat (Austin, TX) - The program is a collaboration between Technology and Inclusion and Austin Community College (ACC) offering adult continuing education courses in Vocational Occupational Skills, Vocational Academic Skills and Vocational Technology Skills, designed to provide a community college experience for adults with moderate to severe disabilities. For more information call: 512-223-7515 or see: www.austincc.edu/ce/bii/vocat

College Living Experience (CLE) (Austin, TX) - They also have several other locations throughout the U.S. CLE is a post-secondary program for students who require additional support with academic, social and independent living skills. Students live in independent apartments with support and may enroll in several different schools in the Austin area. Academic assistance includes helping students choose their classes, ensuring students receive the accommodations to which they are entitled, intensive one-on-one tutoring with content experts, and staff supervised study halls. Within the realm of independent living, CLE students are taught how to pay their own bills, live within a budget, manage their own checking accounts, keep their apartments clean and organized, and plan/ prepare meals. The extensive social skills program encourages students to make healthy choices and provides the skills necessary to make and keep friends. For more information see: www.cleinc.net

Houston Community College (Houston, TX) - The Vocational Advancement and Social Skills Training program (V.A.S.T.) provides educational opportunities to individuals with intellectual and other learning differences that prepare them to enter Workforce Certificate Programs and to receive many of the skills needed to become competitively employed as well as live more independently in the community. Contact the V.A.S.T. program at 713-718-6000.

Eastern New Mexico University Roswell (Roswell, NM) - Occupational Training Program- provides a unique opportunity for students to experience college life while living on campus and attending classes focused on occupational and vocational training. A few of the certificate programs offered include, auto mechanics, child care, nursing assistant, and office skills, among others. For more information, contact: the Special Services Office @ (575) 624-7286 or see www.roswell.enmu.edu/special_services/occupational_training_program.php

ClemsonLIFE at Clemson University (Clemson, South Carolina) – ClemsonLIFE is a full-time two-year program including coursework and job internships developed in partnership with The National Down Syndrome Society (NDSS). The program includes peer mentor support, certified faculty, field-based job experiences, employment portfolio development, independent living experiences with built in support, and extracurricular activities. For more information see www.clemson.edu/culife.

Next Step Program at Vanderbilt University (Nashville, TN) – Next Step is a 2-year certification program with peer mentors and individual programs of study. The goal of the program is to broaden the career options and opportunities for individuals with intellectual disabilities in inclusive, age-appropriate settings. For more information see: www.kc.vanderbilt.edu/site/nextstep.

Pathway at UCLA (Los Angeles, CA) – Pathway is a two-year certificate program for students with intellectual disabilities, providing a blend of educational, social, and vocational experiences, taught and supervised by an expertly trained staff that is sensitive to the individual needs of our students. The program includes a residential component. For more information see: https://www.uclaextension.edu, go to *Fields of Study* and click on *Pathway Programs*.

The Career & Community Studies Program (College of New Jersey- Ewing, NJ)-The **CCS** is a full time, 4 year program featuring coursework in four central areas: liberal studies, vocational development, independent life and socialization. Students receive support through trained mentors (specific to this program) while they participate in a variety of coursework and field-based experiences on and off campus. This program is endorsed by the National Down Syndrome Society. For more information see: www.tcnj.edu/~ccs/index.html

For more helpful information also see: www.thinkcollege.net

DOWN SYNDROME GUILD
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INCLUSIVE Community Living

Over the last 25 years, the Down Syndrome Guild has been a strong voice in our community for including students with disabilities in regular education classes with their non-disabled peers at their neighborhood schools. When young adults with Down syndrome and other developmental disabilities finish their education and vocational training, where will they live? Housing choices have been limited to six-person group homes or large "disabled only" communities in rural areas of Texas. The Down Syndrome Guild advocates for "inclusive" community living.

What you should look for:

- Safe location in the community where the person with Down syndrome grew up and has a network of people who know him/her
- Appropriate level of supervision to ensure safety but allow for the person to grow and become more independent
- Ability for a person to have some choices regarding roommates, activities, staff, schedule, etc.
- Accessibility to jobs, recreational activities, grocery shopping, worship opportunities, and public transportation
- Staff who will assist in organizing activities in the community and facilitate the participation by a person with Down syndrome–not the "disabled only" rec center, Special Ed Sunday school class, day habilitation facility, 6-person van to leisure outings, etc.
- "Circle of friends" or a team of family and friends who are NOT PAID to interact with the person who has Down syndrome
- Permanency provided by a system of supervision so that a person can maintain the same lifestyle even when his/her parents are not involved due to death or disability
- Flexibility to change living arrangements as the person ages
- Resources (special needs trust and/or government program) that will not be depleted before the death of the person with Down syndrome

DOWN SYNDROME GUILD
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Residential Services

Individuals with Down syndrome and their families often explore possible changes in living arrangements as part of the transition to adulthood and the move toward greater independence. Not every person will want, need or be able to move from the family's home to more independent housing. Still, the question of where the individual will live must be addressed in planning. *Be prepared- finding a quality residential option for your child can be very difficult.*

Group Home –a house in which six people with intellectual disabilities live together. The property is usually owned and maintained by a provider agency. Shift staff provides 24-hour/day supervision. The following are types of group homes:

- **Private pay** -at a cost of approximately $40,000+ per year
- **Intermediate Care Facility for the Mentally Retarded (ICFMR) -** these are Medicaid funded. However***, no funding is available for new ICFMR slots, but an open ICFMR bed that already exists may be available.***

Home and Community-based Services (HCS) is the funding stream known as a Medicaid waiver program and is a combination of federal and state dollars. There is a 10-12 year waiting list for a slot. The slot belongs to the person with a disability and he/she can choose a provider from the numerous for-profit and non-profit agencies. The following are residential options which can be funded through an HCS slot:

- **HCS Home** – the house is operated (can be a rental) by the HCS provider agency. The residents pay room and board from their earnings or SSI check. The support services are paid at a reimbursement rate that varies, depending on the resident's "level of need."

  There are two types of HCS homes:
  1. ***Residential support*** – staff changes shift at least one time per day and at least one resident requires awake staff at night. No more than four people with intellectual disabilities can live together.
  2. ***Supervised living*** – no more that three people with intellectual disabilities can live together – none of whom require awake staff at night.

- **Supported Home Living** – a person with an intellectual disability lives in a house or apartment of his/her choosing. The number of hours/day of support staff depends on the resident's needs – a maximum of 20 hours/week and NO overnight supervision.

- **Foster/Companion Care -** a person with a disability lives with a companion in the companion's home or the home of the person with a disability. The Foster/Companion Care provider may be a family member. No more than 3 people with disabilities may live with one Foster/Companion Care provider. The provider pay varies, depending on the client's "level of need."

Independent or Semi-independent Living Apartments– a complex of apartments or condos for individuals with intellectual disabilities who require minimal supervision. A private agency provides the support services, based on the person's individual needs. Funding is provided by private-pay or Medicaid-waiver program's Supported Home Living services (see above).

Residential Facility – a campus-like setting where 7 to 200+ people with intellectual disabilities live together with shift staff on the grounds 24 hours/day. The Texas State Schools are residential facilities but there are also private-pay residential facilities.

DOWN SYNDROME GUILD
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Residential Options in Texas

Down Syndrome Guild families have recommended the following agencies, based on their personal experiences. These resources are provided for information purposes only. Inclusion on this list should NOT be considered an endorsement of any kind by the Down Syndrome Guild of Dallas, either express or implied.

Association for Independent Living (Dallas) **214-351-0798** **www.afildallas.org**
AFIL is a private pay only, non-profit organization. Residents live in a "training house" environment to learn and practice basic living skills required for self-sufficiency. Once they have mastered the basic skills required, they move into efficiency apartments while still under the guidance of staff. There are also several buildings with condominiums where a lower level of supervision is provided.

Breckenridge Village (Tyler) **903-596-8100** **www.breckenridgevillage.com**
Breckenridge is a private pay only, non-profit Christian faith-based 70-acre campus located just west of Tyler, Texas. This is a segregated community in which residents live, work, play and participate in daily Bible studies within the "Village." Residents may not hold competitive employment but may work in the vocational training shops or participate in the day program provided.

Brookwood Community (Katy) **1-800-726-3234** **www.brookwoodcommunity.com**
Brookwood is a private pay only, non-profit organization on a 475-acre self-contained campus. The residents work in one or more of several on-site enterprises, exercise and play in the indoor swimming pool and gymnasium, can worship in the interfaith worship center, and when necessary receive care in the on-site clinic. The residential section is composed of seven large group homes and two staff homes.

Calab, Inc. (Dallas & Tarrant Counties) **817-633-8511** **www.calabinc.com**
A non profit agency, Calab offers ICFMR group homes in Mesquite & Grand Prairie and HCS homes in Arlington & Grand Prairie.

Community Homes for Adults, Inc. (CHAI) (Dallas) **214-373-8600** **www.chaidallas.org**
A non-profit, non-sectarian organization operated under Jewish auspices which provides 6-person private pay group homes and HCS group homes.

Community Options, Inc. (Dallas) **972-503-3901** **www.comop.org**
A non-profit agency, which offers HCS group homes in Northern Texas.

Cornerstone (McKinney) **214-223-9387** **www.cornerstonegrouphomes.com**
Cornerstone is private pay only, gated 42-acre segregated ranch. Christian-based with mandatory daily Bible studies (although all faiths welcome). Daily scheduled activities as a group. There are no competitive employment options- residents do community service work instead of seeking paid employment. The staff is mostly volunteers; it was founded and is run by an individual couple. This facility is currently unlicensed and is not regulated through the Texas Department of Aging and Disability Services (DADS).

Dallas MetroCare Services (Dallas County) **214-333-7000** **www.metrocareservices.org**
A nonprofit agency that offers a variety of residential services including ICFMR group and HCS group homes.

Daybreak (Dallas & Tarrant Counties) **1-800-299-5161** **www.daybreak-hcs.com**
A for-profit agency that offers HCS group homes. Homes are located in the Lancaster/ Desoto/Duncanville area.

Disability Resources, Inc. (Abilene) **325-677-6815** **www.driabilene.org**
A nonprofit agency that provides ICFMR group homes and assisted living. They also have vocational training and sheltered employment. At the present time, DRI operates four residential facilities.

Down Home Ranch (Elgin) **512-856-0128** **www.downhomeranch.org**
A nonprofit agency that provides ICFMR group homes on a working ranch. Residents live and work on the ranch with staff but may be employed outside of the ranch if they desire. They also provide vocational training and summer camp programs. The majority of residents have Down syndrome but others are welcome.

EduCare Community Living (Dallas & Tarrant Counties) **972-929-5000** **www.educaretexas.com**
A for-profit organization that provides ICFMR and HCS group homes in Dallas and Tarrant counties, as well as a larger campus setting in San Antonio and Austin for individuals with complex medical needs. .

Evergreen Presbyterian Ministries (Dallas) **972-386-4834** **www.epmi.org**
Louisiana-based nonprofit organization. The North Central Texas Division offers ICF/MR and HCS group homes.

LifePath Systems (Collin County) **972-727-9133** **www.lifepathsystems.org**
A nonprofit agency that offers a variety of residential services including ICFMR group and HCS group homes.

Marbridge Ranch (Austin) **512-282-1144** **www.marbridge.org**
A private pay only, nonprofit campus setting with semi-independent living "cottages," dorm facilities, or fully-supervised facility with 24-hour medical care for older residents and those residents who require professional nursing and/or rehabilitative medical care. Provides a variety of training opportunities including therapy, life skills, recreational activities, and, when possible, employment.

Mission Road Ministries (San Antonio) **210-924-9265** **www.missionroadministries.org**
A nonprofit HCS provider of semi-independent living apartments along with day programming and vocational services.

Mosaic (Dallas) **972-866-9989** **www.mosaicinfo.org**
A nonprofit agency offering five ICFMR group homes and one HCS group home in the Dallas area.

N. TX Special Needs Assistance Partners (SNAP)(Tarrant County) 817-481-652 www.ntxsnap.org
A private pay only nonprofit organization begun and currently run by family members and volunteers, SNAP leases condominiums to people with disabilities at a subsidized rate. A longer range project will include housing for those needing a greater level of supervision or care. They also provide some daily living support. The success of the program is dependent on the involvement of families using the services.

United Cerebral Palsy of Metro Dallas (Dallas) 214-351-2500 www.ucpdallas.org
A nonprofit agency that operates both HCS and ICFMR group homes in the North Texas area.

Volunteers of America (VOA) (Dallas, Collin, & Tarrant Counties) 817-529-7300 www.voatx.org
A nonprofit agency that operates both HCS and ICFMR group homes in the North Texas area.

*** Note: any agency or organization which offers HCS group homes is an HCS provider and must also offer or contract with others to offer the full array of HCS services.**

DOWN SYNDROME GUILD
OF DALLAS

Health Resources

The Down Syndrome Guild of Dallas has developed a relationship with some local physicians who have agreed to see adults with Down syndrome:

1. Dr Amer Shakil is an assistant professor in the Department of Family Practice and Community Medicine at the University of Texas Southwestern Medical Center at Dallas (UTSW). Because this clinic is associated with the medical school, Dr. Shakil will always be assisted by interns and residents.

To make an appointment with Dr. Shakil, please call:

Family Practice Clinic
6263 Harry Hines Blvd., Bldg #1,
Dallas 75390
214-645-3900 - tell the receptionist that the patient has Down syndrome and request to see Dr. Shakil.

2. Dr. Joseph Maher is board certified in medical genetics and internal medicine and is also an associate professor of medical genetics at the UTSW Medical School. While Dr. Maher does not consider himself an expert in DS, he is willing to build his expertise and network with/refer to other departments in the UTSW system, as warranted by the patient's needs. As the number of patients grows, Dr. Maher will be able to add the staff required to replicate the Adult Down Syndrome Clinic model used in other major cities. Dr. Maher will provide consultation and referrals – he will not provide primary care for adults with Down syndrome.

To discuss scheduling an appointment with Dr. Maher, please contact:

Stacy Utay, Genetics Counselor
Adult Genetics Clinic-Aston Center at UTSW
5303 Harry Hines Boulevard
8th Floor, Suite 400
Dallas, TX 75390
214-648-5964

Note: The UTSW Adults Genetics and Family Practice Clinic accepts Medicaid, Medicare and most private insurance. However, some specialists to whom patients may be referred will not accept patients with Medicaid only.

DOWN SYNDROME HEALTH CARE GUIDELINES

(Based on 1999 Down Syndrome Health Care Guidelines)*

Adulthood (More than 18 Years)

- TSH and T4-Thyroid Function Test (annual)
- Auditory testing (every 2 years)
- Cervical spine x-rays (as needed for sports); check for atlanto-axial dislocation
- Opthalmologic exam, looking especially for keratoconus & cataracts (every 2 yrs)
- Clinical evaluation of the heart to rule out mitral/aortic valve problems. Echocardiogram-ECHO(as indicated)
- Reinforce the need for subacute bacterial endocarditis prophylaxis (SBE) in susceptible adults with cardiac disease
- Baseline Mammography (40 yrs; follow up every other yr until 50, then annual)
- Pap smear and pelvic exam (every 1-3 yrs. after first intercourse). If not sexually active, single finger bimanual exam with finger-directed cytology exam. If unable to perform, screen pelvic ultrasound (every 2-3 years). Breast exam (annually)
- General physical/neurological exam. Routine adult care
- Clinical evaluation for sleep apnea

  Note: research shows that many adults with Down syndrome have sleep apnea even in the absence of symptoms
- Low calorie, high-fiber diet. Regular exercise. Monitor for obesity
- Health, abuse-prevention and sexuality education. Smoking, drug & alcohol education
- Clinical evaluation of functional abilities (consider accelerated aging); monitor loss of independent living skills
- Neurological referral for early symptoms of dementia: decline in function, memory loss, ataxia, seizures and incontinence of urine and/or stool

  Note: National Down Syndrome Society recommends a neuropsychological baseline exam at age 30
- Monitor for behavior/emotional/mental health. Psych referral (as needed)
- Continue speech and language therapy (as indicated).

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* [HEALTH CARE GUIDELINES FOR INDIVIDUALS WITH DOWN SYNDROME: 1999 REVISION (Down Syndrome Preventive Medical Check List) is published in **Down Syndrome Quarterly** (Volume 4, Number 3, September, 1999, pp. 1-16) and is reprinted, duplicated, and/or transmitted with permission of the Editor.

Down Syndrome Guild
of Dallas

Book Review: Mental Wellness in Adults with Down Syndrome

We talk to many DSG families about many issues. The most difficult phone call is when a family member asks about resources to evaluate a change in the behavior and/or functioning level of an adult with Down syndrome; unfortunately, the resources are meager. We recommend the following book: Mental Wellness in Adults with Down Syndrome.

Mental Wellness is an invaluable resource for parents, mental health professionals, case managers, and caregivers who want to understand how to promote good mental health and resolve psychosocial problems in people with Down syndrome. The authors are Dennis McGuire, Ph. D., and Brian Chicoine, M.D., both of whom are founding directors of the Adult Down Syndrome Center at Lutheran General Hospital in Park Ridge, IL. This facility was established almost 30 years ago and its multi-disciplinary team has treated more than 3,000 adolescents and adults with Down syndrome ages 12 to 83.

Mental Wellness - an authoritative, easy-to-read guide - clarifies what are the common behavioral characteristics of people with Down syndrome, how some can be mistaken for mental illness, and what are the bona fide mental health problems that occur more commonly in people with Down syndrome. The authors discuss the importance of regular assessment and how behavior and mental well-being can be affected by environmental conditions, social opportunities, and physical health.

A copy of Mental Wellness has been purchased for the DSG's lending library. To check on availability, call the DSG office at 214-267-1374.

HEALTH ISSUES FOR ADULTS WITH DOWN SYNDROME

Brian Chicoine, MD
Adult Down Syndrome Center of Lutheran General Hospital

Dennis McGuire, PhD
Adult Down Syndrome Center of Lutheran General Hospital
www.advocatehealth .com/adultdown

Health is more than the absence of disease. Health is a sense of physical, mental and spiritual well being. It is a process that involves health promotion, health monitoring, and early intervention for health problems. Understanding what is typical or in the normal range for a person with Down syndrome is essential for providing health care.

I. Understanding Normal/Typical

Adults with Down syndrome have a number of typical behavioral issues that are important to understand so as not to over-diagnose disease states.

A. Self-talk and imaginary friends

These appear to be developmental stage-appropriate behaviors that are used as coping strategies, defense mechanisms, and to alleviate boredom.

B. The Groove

People with Down syndrome often show a tendency towards needing sameness, repetition and order in their lives. It can be very functional.

C. Grief

A delayed response to grief is often seen and it may be demonstrated in alternative ways.

D. Pain Tolerance

People with Down syndrome may have an increased tolerance to pain. However, limited communication skills may also limit the ability to express/convey pain that can lead to the pain being expressed in alternative ways.

E. Behavioral change as a potential communication device

Sometimes a behavioral change may be an attempt to communicate physical or psychological discomfort. A thorough medical evaluation is indicated when a person with DS presents with a behavioral change to assess for an underlying physical condition.

II. Health Promotion

A. Regular exercise. We have found that adults with Down syndrome are more likely to be closer to their ideal body weight if they have opportunities for recreational and social activities (not necessarily exercise). We generally recommend 20-30 minutes of exercise at least 3-5 times per week. In addition, (or alternatively) social activities like shopping, visiting museums, etc. that involve walking can be very beneficial. Increasing energy expenditure by parking a little farther away, taking the stairs, and working in the house and yard are all beneficial. Generally, turning off the television and being more active is beneficial.

B. Recreational Activities - As noted above, recreational activities can have a benefit for physical health. In addition, they are an important part of mental health as well as part of life's enjoyment. Sometimes as parents naturally slow down with age or the adult with Down syndrome ages out of the school system, fewer activities are available. That is a particularly important time to seek other reliable people who can assist in participation in recreational activities.

C. Nutrition - Obesity is the most common nutrition-related disorder.

Attention to a healthy diet as well as regular activity and exercise are required to prevent and treat obesity.

D. Opportunities for Accomplishment and Sense of Worth - Adults with Down syndrome have the same need as others to feel a sense of accomplishment and worth. For some, that may be a repetitive job that fulfills their need for order and regimen. For others, it may be a particular sense of being needed achieved through doing for others. An assessment of what the individual would like to get from a job, as well what his skills are to do the job is encouraged.

E. Immunizations - (These recommendations assume all childhood immunizations were given appropriately.)

Diphtheria - Tetanus- Pertussis- recommended every 10 years

Influenza — consider annually each fall especially if exposure to many people. Recommended annually for persons with certain other health problems.

Pneumonia - We recommend considering the pneumonia vaccine at age 50 for adults with Down syndrome. Recommended at a younger age for persons with certain other health problems and then repeat in 5 years.

Varicella (Chicken Pox) - recommended testing for immunity by blood tests if there is no history of having had chicken pox. Recommend the 2-shot series if not immune.

Hepatitis B - recommended for people living in group facilities. We also recommend it for persons working in a group setting (e.g. workshop) and considering it for all others. We recommend a blood test before administering the vaccine for adults with Down syndrome to see if they have immunity (thus, they do not need the vaccine). In addition, we recommend drawing a blood test (hepatitis B surface antibody) to document attaining immune status 4 to 6-weeks after the third shot.

F. Osteoporosis prevention-Osteoporosis is more common in adults with Down syndrome. Adequate calcium intake throughout life is essential. Recommend 1000 mg a day of calcium for men and non-menopausal females and 1500 mg a day for menopausal females (by diet or supplement). Recommend taking Calcium with vitamin D to promote absorption. Consider bone density scanning to screen for osteoporosis. Consider appropriate medical therapy for prevention or treatment of osteoporosis.

III. Health monitoring

A. Health Screening - History and Physical exam recommended annually.

B. Some important aspects of the history:

Decline in skills
Memory impairment
Swallowing difficulties, choking
Change in gait, unsteadiness
Incontinence of urine and/or stool
Change in appetite
Change in weight
Behavioral issues
Psychological concerns Change in mood Change
    in interest in life

C. Thyroid — Recommended annual thyroid blood testing.

D. Celiac Disease - Consider blood testing (anti-endomysial antibody or anti tissue-transglutaminase antibody and antigliadin IgA and IgG).

E. Neck x-ray - once in a lifetime; (additional neck x-ray if previous abnormal or symptoms develop).

F. Cancer of the cervix - Recommend pap smear every 3 years (after two annual tests normal) if not sexually active and asymptomatic. If sexually active, may want to do annually.

G. Breast cancer - Recommend mammogram every other year from 40-50 and annually after 50. Annual breast exam and teach/encourage breast self-exam (if possible).

H. Cancer of the testicle - Recommend annual testicular exam and teach self-exam (if possible).

I. Vision - Recommend exam every 1 -2 years.

J. Hearing - Recommend audiogram every 1-2 years.

Down Syndrome Guild
of Dallas

Sleep Apnea in People with Down Syndrome

Sleep apnea is a serious health problem that is common in people with Down syndrome of all ages. If not treated it can lead to heart and lung damage and can also contribute to behavioral and psychological problems. Sleep apnea is defined as a complete cessation of breathing from any cause during sleep, resulting in decreased oxygen in the blood or increased carbon dioxide (greater increase than what would be seen in normal sleep). For people with Down syndrome, it is commonly caused by obstruction of the airway.

Inadequate sleep, particularly if it is a chronic problem, has a huge effect on a person's ability to function in her daily activities. It can lead to irritation, problems controlling emotions, loss of concentration, attention problems, and apparent loss of cognitive skills. There has even been evidence that psychotic behavior has improved with the treatment of sleep apnea. In adults with Down syndrome, symptoms such as these may lead to misdiagnosis of dementia or Alzheimer's disease, or the assumption that the person is simply regressing in their skills.

Due to the high incidence of sleep apnea in people with Down syndrome, symptoms such as a long history of snoring combined with restless sleep, excessive daytime sleepiness, and early morning headaches, a physical exam should always include questions designed to determine if sleep apnea may be present.

Reprinted from Mental Wellness in Adults with Down Syndrome by Dennis McGuire, Ph.D. & Brian Chicoine, M.D.

Local Resource:

The Sleep and Breathing Disorders Center at the University of Texas Southwestern Medical Center offers a comprehensive team of experts in pulmonary medicine, neurology, psychiatry, pediatrics, otolaryngology, surgery and rehabilitation medicine to manage all sleep problems and breathing difficulties including sleep apnea. To schedule an appointment for an evaluation contact:

Sleep and Breathing Disorders Center
5939 Harry Hines Blvd
2nd Floor, Suite 110
Dallas, Tx 75390
214-645-5337

Aging and its Consequences for People with Down Syndrome

Adapted from the booklet written by Prof. Tony Holland & Marie Benton

For each one of us, getting older is associated with many changes, both biological and social. For someone with Down syndrome these changes can be particularly daunting and difficult. There is evidence to suggest that some biological problems related to aging can occur earlier in people with Down syndrome than in the general population.

These pages aim to highlight some of the issues that may prove particularly relevant to people with Down syndrome and to their parents and caregivers as they get older. Although reference has often been made to the link between Down syndrome and Alzheimer's disease, it is not by any means inevitable that the person you care for will develop any form of dementia. Very often an apparent decline in a person's abilities will be diagnosed as something else that can be easily treated.

Dementia is the name given to a collection of illnesses, one of which is Alzheimer's disease that have a characteristic pattern of symptoms and signs and generally occur later in life. The main symptoms of dementia are deterioration in the person's memory (usually of recent events) and loss of other abilities such as finding one's way around, communicating through language and performing particular tasks, such as getting dressed. The incidence of Alzheimer's disease in the Down syndrome population is estimated to be 3 to 5 times higher than in the general population, and it is thought to occur 30-40 years earlier. Far too often in the past the symptoms of dementia would be ascribed to the person's disability rather than their dementia (particularly when being assessed by strangers). These days far more is known about the subject; however, there is still a danger that the person with Down syndrome will be given a diagnosis of dementia when it could be something else that would show similar symptoms but is easily treatable. ***A diagnosis of dementia cannot therefore be made without first eliminating the other possibilities.***

▪ SOCIAL CHANGE

Sometimes the most obvious cause of a change in someone's behavior can be overlooked, particularly if that person has difficulties with communication. Often a doctor will rely on evidence from someone who has known them for a long time. The following are some of the social changes that can affect people as they get older. It is by no means a comprehensive list and the possibilities for each individual will of course vary enormously.

- Moving- to new environment or returning home after living on their own
- Job change- new people, new environment can cause anxiety
- Bereavement- loss of friend or family member
- Retirement- work is a wonderful way to stay connected to the community- retirement may not be seen as a good thing

▪ BIOLOGICAL CHANGE

The following are all health problems that can show similar symptoms to dementia: -

Depression

It is not generally appreciated that the risk of depression increases as people get older. There is also evidence that people with Down syndrome may be more prone to depression than those in the general population. Depression in later life, if it is severe, can mimic the features of dementia and it is sometimes referred to as 'pseudo-dementia'. The main features of depression are:

- Change in mood: the person may become more withdrawn, perhaps irritable, easily tearful or tearful for no obvious reason. This may be worse at particular times of day, specifically in the early morning. Sometimes this can be associated with increased anxiety or obsessive behavior.
- Loss of interest in a previously enjoyed activity, such as a hobby, sport, or a particular TV program.
- Deterioration in the ability to concentrate; the person can no longer easily focus on something that previously they could do well, and is easily distracted.
- Change in sleep pattern – usually waking earlier in the morning, but can include sleeping excessively.

- Change in appetite – usually a loss of appetite, which can lead to significant weight loss, but it can occasionally be an increase in appetite.

Depression is diagnosed primarily on the history of the person changing in the ways listed above. While many people with Down syndrome will be able to describe how they feel and if very depressed, may report some suicidal tendencies, for some it may be difficult for them to describe their inner thoughts and feelings. Under these circumstances others, who know the person well, may have observed changes such as an increase in tearfulness or loss of interest or deterioration in concentration. Changes in appetite and sleep may be very important markers of depression. Treatment has become increasingly effective. Severe depression is initially best treated usually through the use of the newer anti-depressant medications, but in addition it is important to deal with any other major issues in a person's life, such as the quality of the environment, or bereavement, if it has occurred. If you suspect that the person you care for is suffering from depression, your first port of call should be his/her General Practitioner. If the GP cannot treat the symptoms personally, he/she will refer you on to someone who can.

Thyroid Disorders

The thyroid gland is situated in the neck and produces the hormone thyroxin, which is one of the factors that control the body's metabolic rate. The gland can either become over-active (hyperthyroidism) or under-active (hypothyroidism). It is the latter that is more common in later life and the percentage of people with Down syndrome affected increases with age. The development of under-activity of the thyroid gland can occur slowly and go unnoticed. The key changes that should lead to a suspicion that someone may have hypothyroidism are:

- Dry skin/ brittle hair
- General mental and physical slowing
- Mood changes
- Increased intolerance of cold
- Unexplained weight increase

Some or all of the above symptoms may cause your doctor to suspect under-activity of the thyroid gland. The diagnosis is confirmed through a blood test. This blood test measures the levels of two substances; thyroxin (the hormone produced by the thyroid gland) and another hormone (Thyroid Stimulating Hormone - TSH), which is produced by the pituitary gland (situated at the base of the brain) and drives the thyroid gland to make thyroxin. If the former is low and the latter is high this confirms the diagnosis. Giving the patient replacement thyroxin daily, in tablet form, can treat hypothyroidism. We know of many people who have deteriorated quite considerably because of undiagnosed hypothyroidism, but once it was recognized and treated, many of the symptoms disappeared. As under-activity of the thyroid gland is relatively common in people with Down syndrome and its presence can be difficult to detect, yearly blood tests to test for this are recommended.

Sensory Impairment

Another possible cause of a decline in abilities in later life is that the person in question simply cannot see or hear as well as he/she used to. Some people with Down syndrome will recognize this. However, others may not be able to communicate or understand the fact that their hearing or vision is getting worse. This fact, and the deterioration itself, may leave him/her feeling isolated and vulnerable. Regular testing of hearing and vision once every 1-2 years is recommended.

Hearing Loss

With all hearing problems a person may seem confused, display a loss of interest in the world around them or a decline in his/her abilities. The hearing loss may be caused by a variety of things, including:

- Build-up of earwax-This is a common occurrence in people with Down syndrome. If you suspect that the person with Down's syndrome that you care for has a hearing problem, always first consult his/her GP. It may be necessary for the excess wax to be removed by a simple irrigation or suction process.
- Fluid behind the eardrum-This may require draining the fluid through a tube that is placed through the eardrum. It is a simple process usually performed at the ENT (Ear, Nose and Throat) department of your local hospital. A referral would be made by your GP, so again the GP should be your first port of call.
- Inner Ear problems- As these cannot be detected by examination of the outer ear or eardrum, your GP will refer the patient for a comprehensive hearing evaluation. Some adults with Down syndrome will develop

a decline in their ability to hear high-pitched sounds, including some speech consonants. A hearing aid can often correct this.

Visual Impairment

Just as in the general population, a person with Down syndrome's eyesight is likely to deteriorate as he/she gets older. As with hearing loss, deterioration in someone's vision is likely to make him or her feel confused and vulnerable. The sight loss can be a gradual decline or can be fairly rapid (often for women, it is triggered by menopause). As well as checking regularly (doctors recommend once every 2 years) whether glasses are required for reading or long distance, you optometrist should also be checking for the following:

- Cataracts- The occurrence of cataracts (opaque formations in the lens of the eye) in people with Down syndrome in later life is well established. These can be removed and artificial lenses put in place instead, under local anesthetic.
- Glaucoma-This is a condition where pressure builds up in the chamber of the eye and causes damage to its main nerve. If the pressure is higher than usual treatment is available in the form of surgery and/or medication. While glaucoma can come on suddenly with severe pain in the eye and loss of vision it more commonly in later life develops slowly and therefore goes unnoticed, certainly in the early stages. Symptoms to watch out for can include enlarged or differently sized pupils.

Orthopedic Problems

All of us can be affected by increasing stiffness and degeneration of our joints as we get older. However, people with Down syndrome do seem to suffer an increased sensitivity to instability in the neck joint. This is known as atlantoaxial instability as it occurs where the atlas (first vertebra) meets the axis (second vertebra). The vertebrae can slip, causing compression of the spinal cord. Doctors recommend yearly physical examinations to check for changes that would be consistent with spinal cord compression.
As a caregiver you should watch out for the following symptoms:

- Difficulty holding up the head
- Neck pain
- Weakness of arms or legs
- New onset of urinary or stool incontinence
- Difficulty walking
- Loss of fine motor control

Menopause

It is now thought that women with Down syndrome reach menopause 5-6 years earlier than other women. The average age is thought to be 46 (as opposed to 51 in the general population). They will go through the same stages and experience the same symptoms as any other woman.

Often the emotional symptoms of the menopause will be dismissed as challenging behavior caused by the woman's disability, rather than being correctly diagnosed. This difficulty can be compounded by the fact that women with Down syndrome often have problems describing their symptoms. They are often not aware of a "hot flash"; being unable to tell the difference between a flash and feeling hot due to the weather, for example. The better informed the woman is the better she will be able to recognize her own symptoms, and the easier a diagnosis will be. It is therefore essential that women with Down syndrome be educated about what will happen to their bodies as they get older, before it begins to affect them. Often people with a disability don't "pick up" this sort of information socially as other people would, so the information given must be clear and unambiguous.

The early onset of the menopause is often associated with osteoporosis, and it is true that women with Down syndrome are more susceptible to this disease. It affects the bones; over the years bones become thinner, more porous and therefore weaker. The bones are therefore more susceptible to fracture, which can create serious complications for the older, less able woman.

DOWN SYNDROME GUILD
OF DALLAS

Alzheimer's Disease and Down Syndrome

Alzheimer's disease, a degenerative neurological disorder characterized by progressive memory loss, personality changes and loss of functional motor capabilities, is far more common in individuals with Down syndrome than the general population. However, not all individuals with Down syndrome will develop Alzheimer's disease, and even those showing Alzheimer's-type symptoms may not have Alzheimer's disease since other conditions can mimic the symptoms.

How common is Alzheimer's disease in individuals with Down syndrome?

Estimates vary, but a reasonable conclusion is that 25 percent or more of individuals with Down syndrome over age 35 show clinical signs and symptoms of Alzheimer's-type dementia. The percentage increases with age. In the general population, Alzheimer's disease does not usually develop before age 50, and the highest incidence (in people over age 65) is between five and 10 percent. The incidence of Alzheimer's disease in the Down syndrome population is estimated to be three to five times greater than in the general population, and oftentimes, symptoms begin much earlier.

What are the symptoms of Alzheimer's disease?

Early symptoms include loss of memory and logical thinking, personality change, decline in daily living skills, new onset of seizures, changes in coordination and gait, and loss of continence in bladder and bowel habits.

How is a final diagnosis made?

Alzheimer's disease is difficult to diagnose. It is important to be certain Alzheimer's-type symptoms do not arise from other conditions, namely thyroid disorders, clinical depression, brain tumor, recurrent brain strokes, metabolic imbalances and various neurological conditions.

The diagnosis of Alzheimer's disease is made on the basis of clinical history, showing a slow, steady decrease in cognitive function and a variety of laboratory tests which provide contributory evidence, including electroencephalogram, brain stem auditory evoked response, computerized transaxial tomography and magnetic resonance imaging, among other tests and measurements.

Is there a baseline test that can be repeated at intervals to determine specific decrease in cognitive function?

Psychologists often use questionnaires answered by family members, companions or caretakers that assist in the early detection of dementia. It is recommended that individuals with Down syndrome be tested at age 30 to provide a baseline reading, and periodically thereafter. If the tests show deterioration, further tests must be made to rule out conditions that present similar or overlapping symptoms.

What information has research yielded about a link between Alzheimer's disease and Down syndrome?

Current research investigating how certain genes on Chromosome 21 may predispose individuals with Down syndrome to Alzheimer's disease. A number of centers are testing therapies in Down syndrome that appear to benefit patients with Alzheimer's disease in the general population.

Alzheimer's Disease and Down Syndrome Resource List

Alzheimer’s Association (National Office)
225 North Michigan Avenue, Fl. 17
Chicago, IL 60601-7633
Telephone: (800) 272-3900 (24 hour hotline)
Website: http://www.alz.org

Alzheimer’s Disease International’s fact sheet on dementia and intellectual disabilities.
http://www.alz.co.uk/adi/publications.html

Alzheimer’s disease and people with mental retardation.
http://www.thearc.org/NetCommunity/Document.Doc

Developmental disabilities and Alzheimer’s disease: what you should know.
http://www.thearc.org/publications

Books on Alzheimer’s Disease and Dementia

Holland, A. “Down Syndrome and Dementia”. In Dementia. London, UK: Oxford University Press (2000). http://www.oup.co.uk

Janicki, M. Dalton, A.J.P. Dementia, Aging, and Intellectual Disabilities: A Handbook. Brunner/Mazel Publisher (1999). Now Routledge Mental Health.

McGuire, D & Chicoine, B. Mental Wellness in Adults with Down Syndrome. Bethesda, MD: Woodbine House (2005). http://www.woodbinehouse.com

Prasher, V. P. Alzheimer’s Disease and Dementia in Down Syndrome and Intellectual Disabilities. Radcliffe Publishing (2005). http://www.radcliffe-oxford.com

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DOWN SYNDROME GUILD
OF DALLAS

Basic Life Planning Steps

"Who will care when you are no longer there?" is an overwhelming concern people with disabilities and their families must address. A well thought out life plan is essential for long-term quality of life for your loved one with Down syndrome. Physical, social, financial and legal issues, among others must be considered. The life plan is evolving and ever-changing; it is a process, not an end result. It will require that different needs be addressed as your loved one ages. Below are some suggested steps to get started in the right direction:

Prepare a life plan. Decide what you want regarding residential needs, employment, education, social activities, medical and dental care, religion, and final arrangements.

Write a letter of intent. Put your hopes and desires in a written document. Include information regarding care providers and assistants, attending physicians, dentists, medicine, functioning abilities, types of activities enjoyed, daily living skills, and rights and values. Make a videotape during daily activities, such as bathing, dressing, eating, and recreation. A commentary accompanying the video is also useful.

Decide on a type of supervision. Guardianship and conservatorship are legal appointments requiring court-ordered mandates. Powers of Attorney are other, less restrictive options. Choose for today and tomorrow. Select capable individuals in the event you become unable to make decisions in the future.

Determine the cost. Make a list of current and anticipated monthly expenses. When you have established this amount, decide on a reasonable return on your investments, and calculate how much will be needed to provide enough funds to support his or her lifestyle. Don't forget to include disability income, Social Security, etc.

Find resources. Possible resources to fund your plan include government benefits, family assistance, inheritances, savings, life insurance, and investments.

Prepare legal documents. Choose a qualified attorney to assist in preparing wills, trusts, power of attorney, guardianship, living will, etc.

Consider a "Special Needs Trust." A Special Needs Trust holds assets for the benefit of people with disabilities and uses the income to provide for their supplemental needs. Appoint a trustee and successor trustees (individuals or corporate entities, such as banks).

Use a life plan binder. Place all documents in a single binder and notify caregivers/family where they can find it.

Hold a meeting. Give copies of relevant documents and instructions to family/caregivers. Review everyone's responsibilities.

Review your plan. At least once a year, review and update the plan. Modify legal documents as necessary.

DOWN SYNDROME GUILD
OF DALLAS

LETTER OF INTENT

One of the greatest illusions in the estate planning field today is that the average family can guarantee a bright future for the person with a disability simply by preparing a will and a special needs trust.

The purpose of a *letter of intent* is to provide vital personal information and guidance to others who may provide care, support or other assistance for the person with a disability. Times change and it is impossible to foresee the future, so a general outline of your expectations, hopes and wishes are preferred to rigid requirements.

A letter of intent can take a variety of forms and does not have to meet the special requirements of a will or other legal documents. It is not legally binding. However, it can be coordinated with your will so that it clearly communicates information to the appropriate people, such as a personal representative, trustee, guardian or service provider that would help them make important decisions on behalf of the individual.

When you write your letter of intent, use plain language rather than technical language. You may want to ask your attorney to review your letter to make sure that it does not contradict your will in any way, and to make sure that it is thorough and easy to understand.

Some choose to make the drafting of the letter a group effort, including the person with a disability for whom the planning is being done, close relatives and friends.

A letter of intent should provide information about the person in the past and the present, and explain your and the person with a disability's expectations and preferences regarding his/her future in a variety of areas:

- Home environment
- Learning and education
- Employment
- Relationships and affiliations
- Health and well-being
- Unique information about your family member (what works and doesn't work- important things to know)
- Abilities and needs regarding things like communication, daily living and personal care, money management and decision-making
- Personal beliefs (religious, spiritual)
- Financial information (government benefits, bank accounts, trust, life insurance)

You should periodically review and update your letter of intent when significant changes occur. Some people review their letter of intent around the time of the person's birthday each year. Make certain that important people in your life either have a copy of your letter or know where to locate it.

For a detailed template and guide to writing your letter of intent, contact the Down Syndrome Guild office and request a copy of "The Life Planning Approach."

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Guardianship and Alternatives

Many people assume that because their child has a disability they are automatically the child's legal guardian. However, ***every person over the age of eighteen is presumed to have the legal rights of an adult no matter what their abilities.*** In order to become someone's guardian a parent or sibling must go to court and petition to become responsible for that person. They must demonstrate to the court that the disabled person is incapacitated---that they are unable to act responsibly on their own behalf.

Just like making educational decisions (inclusion vs. self-contained classes), each family has to weigh the options (from least restrictive to most restrictive), and make the decision that is best for them and for their child.

Guardianship is a legal process designed to protect vulnerable persons from abuse, neglect (including self-neglect) and exploitation. There are several types of guardianship. If you are contemplating establishing a guardianship you need to discuss the specific details of your situation with your attorney to determine what form of guardianship is most appropriate. It is also important to understand guardianship-and its consequences, some of which may not be desirable for the individuals or families:

- In the legal system, guardianship declares a person *incapacitate***,** and *removes rights and privileges* from a person with a disability. These rights may vary, but could include entering into contracts, end of life and medical decisions among others.
- Obtaining guardianship involves the court system and, typically, attorney fees. This can create an unnecessary financial hardship on families.
- For many people, it is applying a legal solution to personal issues that can be handled through less intrusive means.
- The Arc and many other advocacy groups feel strongly that there are alternatives to guardianship that respect the person's rights and privileges yet can define the needed supports for a person with a disability to be safe.

The following alternatives can help individuals with disabilities and their advocates handle decision-making in a way that enables the person the dignity and freedom to live the lives they choose, while also protecting them:

- **Power of Attorney (POA)**: Executed by an adult, called the principal, authorizing another person to act as his or her agent. The power to the agent may be either specific or general.

- **Durable Power of Attorney:** A power of attorney that remains in effect if the principal becomes incapacitated. If a power of attorney is not specifically made durable, it automatically expires if the principal becomes incapacitated

- **Durable Power of Attorney for Health Care (also called Medical Power of Attorney):** an instrument executed by an adult giving another person the authority to make health care decisions for him or her.

- **Social Security's Representative Payment Program:** Provides fiduciary assistance for Social Security beneficiaries who are incapable of managing or directing someone else to manage their Social Security or SSI payments. Generally, family or friends are asked to serve in this capacity. For more information, see the Social Security Administration website: http://www.socialsecurity.gov/payee/faqrep.html

- **Trustee:** Because owning even a small amount of money can jeopardize government benefits, a trust may be needed to hold assets to provide for an individual's supplementary needs and desires. The trustee is someone responsible for the management and distribution of such funds. For more information see ***Special Needs Trusts Frequently Asked Questions***.

- **Release of information form:** In this age of privacy and the Health Insurance Portability and Accountability Act (HIPAA), some agencies might have you believe that because your child is their own guardian, you may not have access to pertinent information regarding their personal issues- **NOT TRUE!** Simply have the person with a disability sign a "release" form granting you permission to have access to their personal information.

For more information about guardianship, check out this publication from Advocacy Inc. *www.advocacyinc.org/CS5.cfm*

Also check out: www.texasguardianship.org

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Special Needs Trusts: Frequently Asked Questions

Adapted with permission from National Special Needs Network, Inc., and/or Jeffrey H. Minde Attorney and Counselor At Law P,A. These questions and answers are meant to be suggestive only; please contact your personal attorney regarding any legal matters.

WHAT IS A SPECIAL NEED TRUST & WHY USE IT? **To Preserve Governmental Benefits And Protect Assets.** A Special Needs Trust is a specialized legal document designed to benefit an individual who has a disability. A Special Needs Trust is most often a stand alone document, but it can form part of a Last Will and Testament. Special Needs Trusts have been in use for many years and were given an official legal status by the United States Congress in 1993.

A Special Needs Trust enables a person with a physical or mental disability, to have, held in Trust for his or her benefit, an unlimited amount of assets. In a properly-drafted Special Needs Trust, those assets are not considered countable assets for purposes of qualification for certain governmental benefits. Such benefits may include Supplemental Security Income (SSI), Medicaid, vocational rehabilitation, subsidized housing, and other benefits based upon need.

A Special Needs Trust provides for supplemental and extra care over and above that which the government provides. Each Special Needs Trust is its own "entity" with its own Federal Identification Number (Employer Identification Number) issued by the Internal Revenue Service. The Trust is not registered under either the Grantor's or the Beneficiary's Social Security Numbers.

MY FAMILY IS WEALTHY AND WE'RE NOT TOO CONCERNED ABOUT GOVERNMENTAL BENEFITS. WHY BOTHER CREATING A SPECIAL NEEDS TRUST? **To Protect Your Disabled Family Member.** Other types of Spendthrift or Family Trusts aren't appropriate for people with disabilities because they don't address the specific needs of the disabled beneficiary or his future lifestyle. Even in situations where a family may have significant resources to help a disabled family member a Special Needs Trust should be established to address these issues.

Monies placed in the Trust remain non-countable assets and allow the beneficiary to qualify for available benefits and programs. Why sacrifice services that might be available to your relative now and in the future? Just as importantly, Trust funds are not subject to creditors or seizure. Therefore, if the disabled beneficiary should ever be sued in a personal injury or other type of lawsuit, the beneficiary is not a "deep pocket" because monies placed in the Trust are not subject to a judgment.

IF HAVING MONEY CAUSES PROBLEMS FOR MY DISABLED DAUGHTER, WHY CAN'T I JUST LEAVE THAT MONEY TO HER BROTHER SO THAT HE CAN LOOK AFTER HER? **Leaving Money To Others Can Create Serious Problems.** "Disinheritance" was commonly used before the use of Special Needs Trusts was officially recognized by Congress. Disinheritance as a means of providing for a disabled or ill person puts the assets at risk.

Assets held by a non-disabled sibling for the benefit for of a disabled sibling could be subject to such liabilities such as judgments from automobile accidents, a bankruptcy, or a divorce. In such circumstances, the assets meant to benefit the person with the disability could go to pay the judgment creditors or the estranged spouse of the non-disabled sibling. Using a Special Needs Trust guarantees that the funds will be held only for the benefit of the person with the disability, and not for any other purpose whatsoever.

WHEN SHOULD I CREATE A SPECIAL NEEDS TRUST? **A Special Needs Trust Is A Valuable Estate Planning Tool.** A Special Needs Trust can be established at any time before the beneficiary's 65th birthday. It is very common to create a Special Needs Trust early in a child's life as a long term means for holding assets to benefit the disabled family member. As a part of Estate Planning, the costs of the creation of the Trust may be tax deductible.

Additionally, the special needs trust is the best receptacle for funds from third party sources, such as a personal injury settlement or a bequest from relatives or friends, Social Security back payments, insurance proceeds, or the like.

WHAT KIND OF ASSETS CAN BE USED TO FUND A SPECIAL NEEDS TRUST? **Almost Any Kind Of Asset Can Be Used To Fund The Trust.** Virtually any kind of asset can be used to fund a Special Needs Trust, including insurance proceeds, inheritances, lump-sum payments from Social Security Disability or Supplemental Security Income, settlements in legal matters, or just "piggy bank" money.

Many people neglect to set up a trust when they receive assets, particularly lump sums of governmental benefits. However, it is important to realize that monies received as "back pay" for SSI or SSDI claims become income to the beneficiary when received. Ironically, this sudden influx of income can disqualify a person from the benefits they were just approved for.

For SSI, the rule is straightforward: A recipient cannot have more than $2,000 in assets. SSDI employment, income, and asset limits are more complex and confusing and need to be anticipated. In order to maintain benefits qualification, a trust is a necessity as a "safe harbor" for any assets belonging to the disabled beneficiary.

CAN ANY LAWYER CREATE A SUPPLEMENTAL NEEDS TRUST? **Just As Most Podiatrists Aren't Neurosurgeons…** A family or person that wishes to benefit an individual with a disability will be well advised to utilize the services of an attorney that specializes in Special Needs issues. A poorly written trust can cause a loss of benefits, a loss of savings, or other financial and legal hardships for the beneficiary or the trustee, some quite severe, including civil litigation or criminal prosecution in certain extraordinary circumstances. Using a law firm that specializes in special needs issues assures you that the attorney is familiar with the benefits systems, the proper creation of the trust, and ultimately the defense of the trust in the event that it should be challenged by a court, the Social Security Administration, Medicaid, or the like.

MY SISTER IS DISABLED. CAN I SET UP A TRUST FOR HER? **Yes, But…** The United States Code section that authorizes Special Needs Trusts states that "a parent, grandparent or guardian" is authorized to establish a Special Needs Trust. Siblings, caregivers or friends are not mentioned at all. However, the law does not forbid siblings and others to set up a Special Needs Trusts. A well-written Special Needs Trust established by someone other than a parent, grandparent or legal guardian should include a citation to this law for the sake of clarity. Benefits providers and agencies often create "red herring" difficulties around this issue. Be cautious, and make sure you work with a lawyer familiar with this problem and that the Trust is properly drafted.

I HAVE TWINS WITH DOWN SYNDROME. CAN I USE ONE TRUST FOR BOTH OF THEM? **Just As Your Children Are Exceptional So Are Their Trust.** Each disabled individual must have his or her own trust document. The law requires that each Special Needs Trust contain specific examples of what constitutes supplemental care for the beneficiary. No one's needs, not even twins, are absolutely identical. This is particularly the case as people get older and their abilities change.

I'M VERY CONFUSED. I HEARD A LAWYER SAY SOMETHING ABOUT HAVING TWO SEPARATE TRUSTS. **It Really Isn't Necessary.** This confusion stems from the Social Security Regulations, which make a distinction between "First Party" (or self-funded) Special Needs Trusts that contain the beneficiary's own money and "Third Party" funded Trusts that contain money from other sources. "First Party" money is usually subject to the Medicaid repayment requirements. Therefore, many lawyers insist on creating separate Trusts. ***This costs more and is often confusing to the Trustee.*** A well-drafted Special Needs Trust should be able to hold money from both "First Party" and "Third Party" sources. Funds from the different sources can be held and managed in the Trust in separate accounts.

WHY NOT JUST USE A POOLED TRUST? **Pooled Trusts Aren't For Everybody.** "Pooled" or Cooperative Master Trusts are a special form of Special Needs Trust that can be established by not-for-profit organizations or groups on behalf of their membership (for example, a group home may create one for its residents). While it is true that Cooperative Master Trusts are exempt from the Medicaid repayment rules, the money that is placed in a Cooperative Master Trust is used generally to address the needs of all the members of the group, not just the specific needs of your disabled family member.

Once you place your money in the pool it usually cannot be withdrawn or returned to you. You cannot direct where the Trust avails will go if your family member leaves the group for any reason. Your money remains in the pool to assist future members. You do not have control over how the money is spent. As a result, your family member may not get all the services he or she needs or might want.

Cooperative Master Trusts can work well if you find one that suits your circumstances. It provides a way for a family of more modest means to obtain professional expertise and trust services that would be unavailable to them on an individual basis. If this is an option for you, you are well advised to seek out a group that you know well and trust, can serve your special needs, and which has an established track record of successful trust management.

I'M MY SON'S TRUSTEE. THAT MAKES ME HIS GUARDIAN, RIGHT? **Not Right.** Merely setting up a trust, becoming a trustee, becoming a Power of Attorney, or being someone's Representative Payee for Social Security purposes does not make you a guardian even if you may have effective control of the disabled person's finances and provide for all their needs.

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Can You Trust Your Financial Planner?

Reprinted in part from MSN Money-By Liz Pulliam Weston

Knowing your planner's exact job title may help you tell whether he or she is a 'fiduciary' -- a professional who's 100% committed to putting your financial interests first.

It's a $10 word, but not knowing it could cost you a fortune. The word is "fiduciary," and in the world of money it means someone who's committed to putting your financial interests ahead of his or her own. The word is important because true fiduciaries are harder to find than you might think. Most of the people who want to give you advice about your money aren't held to that high standard. At best, they're held to a "suitability" standard, which means they're supposed to reasonably believe that the investment and insurance products they want you to buy are appropriate for your situation. Just "appropriate" -- not "the best choice" or "in your best interests."

The high cost of being too trusting

Let's say you have $10,000 a year to save for retirement. Your financial adviser could recommend you invest the money in a low-cost index fund that might net you a return of 8% a year. After 30 years, you'd have over $1.1 million. But let's say the adviser could earn a fat commission for recommending a higher-cost investment being promoted by his financial-services firm. So instead of netting 8% a year, you might net 6%. After 30 years, your nest egg would grow to just under $800,000, a difference of more than $300,000. The high-cost investment might be perfectly "suitable," since it meets your financial objective of saving for retirement, even if it could leave you significantly poorer than had you invested in the index fund.

Scrutinize the job titles

Figuring out who's a fiduciary isn't always easy. In the financial-services world, there are three job titles that automatically connote a fiduciary standard:

- Attorney
- Certified public accountant (CPA)
- Registered investment advisor (RIA)

There are several other job titles that indicate the opposite. People who are stock brokers (also known as "registered representatives") or insurance agents are allowed to put their own interests, or those of their firm, ahead of yours.

But other titles, including "financial adviser" or "financial planner," can be used to imply you're getting good advice without any requirement that said advice be in your best interests.

Fiduciary or not?

Professional title	Is he a fiduciary?
Attorney	Yes
Certified financial planner (CFP)	Maybe
Certified public accountant (CPA)	Yes
Financial planner	Maybe
Insurance agent	No
Registered investment adviser (RIA)	Yes
Registered representative	No
Stock broker	No

Salespeople masquerading as professionals
It's a situation that's being exploited by many of today's brokerage and insurance companies, said Bob Veres, editor of Inside Information, a newsletter for financial planners. These financial-service companies have figured out their customers want objective advice, but the companies aren't ready to abandon their commission-based sales model or commit wholeheartedly to the fiduciary standard. So instead of calling their employees "brokers" or "agents," they call them "advisers," "asset gatherers" or "fee-based consultants," Veres said, to give them that whiff of "we're in your corner" respectability without necessarily having to adhere to a fiduciary standard.

The Securities and Exchange Commission, which regulates brokerages and financial planners, has muddled the situation still further. In 2005, the regulatory agency made permanent a rule that allowed brokers to avoid registering as investment advisers -- which would require them to uphold fiduciary standards -- as long as the advice they gave was "incidental" to their primary business of selling investments. Then, in a staff letter, the SEC said an adviser could play more than one role with a client. An adviser could agree to a fiduciary duty in order to create a financial plan, and then switch back to the non-fiduciary role of broker when actually buying investments to execute the plan. The SEC decision allows advisers "to walk away from their fiduciary duty right at the point when the greatest risk to the client exists," Roper said. "How are people supposed to understand that the person who was their trusted adviser has now turned into a salesperson that no longer has to have their best interests at heart? There's no way you can disclose away that confusion."

Ask the tough questions
If you want to know where you stand, you'll need to be proactive and ask the following questions of anyone giving you financial advice:

- **Are you legally obligated to act in my best interests at all times? If so, are you willing to put that in writing?** Anyone who purports to uphold a fiduciary standard should be willing to stand behind that claim.
- **Will you disclose all potential conflicts of interest?** A fiduciary should be willing to disclose any relationship, compensation, incentive or other factor that *potentially* could interfere with his or her ability to act in your best interests. Even if you're not interested in a fiduciary relationship, though, you should press your adviser to tell you about any potential conflicts so you can better evaluate his or her advice.
- **In what ways are you compensated?** Ask if the adviser receives commissions, referral fees or other financial incentives. Some advisers tout themselves as "fee-based," but also accept other payments that could influence their recommendations.

You may well find that your adviser isn't a fiduciary but decide to work with him or her anyway. If your stockbroker has done well by you so far, for example, you may be perfectly comfortable continuing to follow his or her tips. But you need to keep in mind that your adviser, like a car salesperson, isn't working for you. "It's all right to work with somebody who hasn't agreed to live up to the fiduciary standard," Veres said, "but make sure you're on your guard at all times, so you don't get sold the financial equivalent of a lemon." Of course, even if you have an adviser who agrees to a full-time fiduciary standard, you're not home free. An unethical or incompetent adviser can still violate your trust -- in fact, "breach of fiduciary duty" is constantly the most commonly cited beef in arbitrations conducted by the National Association of Securities Dealers.

Inform yourself to protect yourself
That's why it's important to do your due diligence before following any adviser's financial advice. Among other things, you should:

- **Understand what titles and credentials mean.** The AARP has a brief list of common designations; NASD has an exhaustive drop-down list. Consider contacting the organization that issued the adviser's credential to make sure he or she did, in fact, earn the mark and still holds it in good standing.
- **Check his or her background.** NASD's BrokerCheck allows you to review a broker's work and disciplinary history. You should check with state regulators as well; the North American Securities Administrators Association has links. The National Association of Insurance Commissioners has links to insurance regulators.
- **Read Form ADV.** Registered investment advisers are required to file this disclosure form with the SEC. You'll find the first part, which includes any public disciplinary actions or legal proceedings, at the SEC's Web site. Ask for the second part, which discloses compensation and conflicts of interest, from the adviser.

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Assistance with Wills, Trusts and Guardianship

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

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

Chris Mims
3102 Maple Ave. # 625
Dallas, TX 75201
214-855-5160

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

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

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

Legal Aid of Northwest Texas
(Serving Dallas & Ellis Counties)
214-748-1234

Legal Aid of Northwest Texas (McKinney office)
(Serving Collin, Grayson, Kaufman & Rockwall Counties)
972-542-9405

Lawyer Referral Service
Dallas Bar Association
214-220-7444

Legal Clinic
SMU School of Law
214-768-2562

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.

For financial planning information, The Down Syndrome Guild suggests that families visit: www.cfp.net.

Down Syndrome Guild
OF DALLAS

Website Links for More Information

Local Agencies:

Down Syndrome Guild of Dallas
www.downsyndromedallas.org

The Arc of Dallas-resource for local organizations
http://www.arcdallas.org

Texas Department of Aging and Disability Services (DADS) FAQ and fact sheets
http://www.dads.state.tx.us/services/faqs-fact/index.html

Department of Rehabilitative Services (DARS)
http://www.dars.state.tx.us/index.shtml

Dallas Metrocare (Dallas County MRA)
http://www.metrocareservices.org/

LifePath (Collin County MRA)
http://www.lifepathsystems.org/

Medicaid:

Health & Human Services Medicaid home page
http://www.hhsc.state.tx.us/medicaid/

Social Security:

Information about SSI
http://www.ssa.gov/pgm/links_ssi.htm

Information about the PASS program
http://www.ssa.gov/disabilityresearch/wi/pass.htm

More information about PASS program
http://www.ilr.cornell.edu/edi/pass/default.html

Health:

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

Down Syndrome Health Issues by Dr. Len Leshin
http://www.ds-health.com/

Denver Adult Down Syndrome Clinic
http://www.denverdsclinic.org/patientsHealthIssues.htm

Down Syndrome Research & Treatment Foundation
http://www.DSRTF.org

Advocacy:

The Arc of Texas
http://www.thearcoftexas.org/

Disability Policy Consortium
http://www.dpctexas.org

Advocacy Inc.
http://www.advocacyinc.org/index.cfm

Post-Secondary Education:

Think College
http://www.thinkcollege.net/index.php

Texas Council for Developmental Disabilities College Guide
http://www.txddc.state.tx.us/resources/publications/collegehtml.asp

General Information/ Literature and Publications - these sites provide more links and/or publications and literature for a wide range of disability topics:

National Down Syndrome Congress
http://www.ndsccenter.org/

Down Syndrome Association of the UK- great resource for literature
http://www.downs-syndrome.org.uk/

Institute for Community Inclusion
http://www.communityinclusion.org/

Texas Council for Developmental Disabilities
http://www.txddc.state.tx.us/index.asp

National Down Syndrome Society
http://www.ndss.org/

National Association for Down Syndrome
http://www.nads.org/

The Beach Center on Disability
http://www.beachcenter.org

Recommended Down syndrome sites on all topics prepared by Dr. Len Leshin
http://www.ds-health.com/ds_sites.htm

The Directory of Community Resources (DCR)- allows users to search, contribute, and update disability resources throughout the state of Texas
http://disabilityresources.tamu.edu/