



DOWN SYNDROME GUILD
OF DALLAS

Resource Guide for Families of
Adults with Down Syndrome



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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:

“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.

Sincerely,

Kathi Hutchins, Committee Co-chair
Mom of Kelly

Sherri Munn, Committee Co-chair
Mom of Abby



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Resource Guide for Families of Adults with Down Syndrome

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 - ◆ Checklist for families
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Introduction



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

- ✓ Get connected to 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.
- ✓ Call the Social Security Administration to apply for Supplemental Insurance Income.
- ✓ 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.
- ✓ 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 HCS “interest list” – do it NOW – there is a 10 year wait.
- ✓ 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 child with Down syndrome is 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 - 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 Down Syndrome Clinic – A subcommittee is working to make the necessary connections that will, hopefully, result in the establishment of a clinic in Dallas to address the complex healthcare needs of adults with Down syndrome, similar to the model implemented at Down Syndrome Clinic at Children's Medical Center Dallas.

Advocacy & Self Determination



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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
- Rehabilitation Act
- Supreme Court ruling called, 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.capitol.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. Some great resources for more information about the many legislative issues of interest to families of adults with Down syndrome are:

- 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
- Arc of Texas- visit their website at www.thearcoftexas.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 they live. For more information, contact Jeff Garrison-Tate of Community Now! at communitynowfreedom@gamil.com.



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Important Legislation

Americans with Disabilities Act

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 – Equal Employment Opportunity Commission, Department of Justice, Department of Transportation, and 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, however. *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 legislature, 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 join together (within the corporate structure of a non-profit organization) to plan the support services required by one individual person with disabilities.

The Arc of Texas has introduced the microboard concept to Texas, in conjunction with its *Real Life* program – see www.thearcoftexas.org. The first microboard, a trademark term, was initiated in Canada by the Vela Microboard Association – see www.microboard.org.

The elements of a microboard are:

- Membership of 5-7 family, 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 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

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

Social Security Benefits



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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 \$635/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 at 1-800-772-1213. An application for SSI can be filed on the phone - the documents that must be filled out can be sent to your house - there is no need to go to a Social Security office.

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 have had a paying job for more than 2 years. To qualify for benefits, you must first have worked in jobs covered by Social Security, and then become disabled and unable to work.

Disabled Adult Child Benefit: An adult disabled before age 22 may be eligible for child's benefits if a parent is deceased or starts receiving retirement or disability benefits. The SSA considers this a "child's" benefit because it is paid on a parent's Social Security earnings record. Based on some of our parents' own experience with this program, if a child 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), often receives higher monthly SS benefits because benefits are based on a percentage of benefits earned by the parent and after 2 years 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 - 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.

For more information on Medicaid in Texas see this brochure from Texas Health & Human Services: <http://www.hhsc.state.tx.us/Help/ConsumerGuideEnglish.pdf>

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.

Funding Sources



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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:

- I. Private health insurance and Medicaid may provide funding for therapies for children and adults with Down syndrome
- II. Some agencies (i.e., Easter Seals, CHAI, etc.) offer “fee for service” therapies and support services for adults with Down syndrome
- III. MHMR- In Home Family (IHFS) services, etc...
- IV. Medicaid-waiver programs (a combination of federal and state dollars)

The following pages are 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 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 40,000 people with disabilities in Texas – some families have been waiting for ten years!

“The Waiting List” 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 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.



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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 5 years ago the Texas legislature combined several agencies – the new name is 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 at to get on the waiting lists.

Dallas County:

Dallas MetroCare
Eligibility Determination Unit (EDU)
1353 N. Westmorland, Cottage 4
Dallas, Texas 75211
214-333-7000
<http://www.metrocareservices.org>

Collin County:

LifePath
P.O. Box 828,
McKinney, TX. 75070
972-727-9133
<http://www.lifepathsystems.org>

Denton County:

Denton County MHMR Center
PO Box 2346
Denton, Texas 76202
940-381-5000
<http://www.dentonmhmr.org>

What types of Services may be available?

Traditional/usual resources and services to consider for placement on wait lists /interest lists. **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.**

- 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
- Day programs
- Special needs trust (financial protection)
- Case management and service coordination
- Vocational Evaluations



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General Revenue Services

General Revenue funded services were primarily intended to help people remain in their own or their family's homes. Unlike the Medicaid waiver programs, this funding is non-transferable; if you move out of the county you are in, the money will not follow you. There is often a long waiting list for services which fall under the following two categories:

Community Living Support

Services include:

- Day habilitation
- Transportation
- Respite
- Employment assistance
- Supported employment
- Vocational training

Professional and Technical Support

Services include:

- Nursing
- Behavioral supports
- Specialized therapies
- Counseling services
- Occupational therapy
- Physical therapy
- Speech and language therapy
- Audiology services
- Dietary services
- Day habilitation

To apply for services contact your local Mental Retardation Authority (MRA)



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In-Home and Family Support

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 and there is a substantial waiting list for services.*

This is considered 'funding of last resort' and is *not* a Medicaid Waiver program. Therefore, the money will not follow you if you move to another county. Some services that *may* be available are:

- Attendant care,
- Home health, home health aide, homemaker, or chore services
- Counseling and training programs
- Purchase or lease of special equipment or architectural modifications of a home
- Respite care
- Transportation services

To apply for services contact your local Mental Retardation Authority (MRA).



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What is a Medicaid Waiver?

A Medicaid waiver allows the state to be more flexible in how it spends money to provide some long-term services to 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.

A Medicaid Waiver 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
- **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 resources 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 the funding to help people get the supports they need in the community.



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Medicaid Waiver Descriptions

Home & Community-based Services Program-HCS

The HCS Program provides individualized services and supports to persons with mental retardation 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 mental retardation or a related condition that results in deficits in adaptive behavior and full scale IQ of 75 or below; be eligible for Medicaid. Spending limits dependent upon 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 mental retardation 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 mental retardation 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 die 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 \$ 10,000.

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- FAQ

What is the Consumer Directed Services (CDS) option?

Consumer Directed Services (CDS) allows DADS consumers to hire and manage the persons who provide their services. A CDS agency (CDSA), selected by you does your payroll and federal and state taxes. Not every service in every program is eligible for CDS (see list below for details). You also must currently be receiving services through a medical waiver program to use CDS.

What is the difference between the traditional agency option and CDS for delivery of services?

Agency option- Agency hires service providers, sets wages for service providers, and does payroll and taxes

CDS -You hire your own employees, set wages and benefits based on your service budget, and you hire a CDS agency to do payroll and taxes

How does CDS work?

You will select the CDSA that will process your payroll and act as your agent to pay 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.

What is support consultation?

It is an optional service you can purchase to train you to be an employer. Not all programs offer support consultation. Currently, support consultation is available in Home and Community-based Services (HCS) and Texas Home Living (TxHmL). Your case manager or service coordinator will include support consultation in your service plan. You pay for support consultation out of your CDS service budget.

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.

How will I find people to hire?

You will be trained by your CDSA or support advisor. You can also ask friends, neighbors, and family members to work for you, and in some cases, you can contract with your agency provider for back-up arrangements.

How would my employees be paid?

Your employees complete timesheets and your CDSA will do your payroll and taxes.

Who trains my employees?

You train your own employees. You will be given training materials from the CDSA or your support advisor to show employees how to complete employment and payroll forms.

How do I do the paperwork?

Your CDSA will train you to do your portion of any paperwork. You will also be shown what paperwork you need to maintain for your records.

What do I do if an employee doesn't work out?

As the employer, you can dismiss anyone who doesn't work out. Your CDSA or support advisor will train you to manage employees.

What happens if I choose the CDS option and later change my mind?

You can choose not to participate in the Consumer Directed Services option. Your case manager or service coordinator can help you change to the agency option, but you will be required to be off of the option for at least 90 days before participating in the CDS option again.

Who's responsible for ensuring that consumers receive their authorized services?

You, the employer, take responsibility for providing all program services under the CDS option. Employers will recruit, hire, and supervise their own employees and any back-up employees. The CDSA is not responsible for providing employees for you.

How is DADS billed for the services?

As the employer, you submit timesheets, receipts, and invoices related to services delivered to the CDSA. The CDSA pays allowable expenses on behalf of the employer. The CDSA bills DADS for the services provided or allowable costs incurred, and deposits required payroll deductions and withholdings with federal and state agencies.

Which services can be self-directed in which programs?

Community Based Alternatives (CBA) Personal Assistance Services, Respite (Starting late 2008- Professional Therapies, Nursing)

Community Living Assistance and Support Services (CLASS) Respite, Habilitation

Home and Community-Based Services (HCS) Respite, Supported Home Living and Support Consultation

Texas Home Living (TxHmL) All Services with the addition of Support Consultation, Integrated Care Management (ICM), Personal Assistance Services, Respite

Do I get more money in my service plan if I use the CDS option rather than having an agency provide my services?

No. Use of the CDS option must be cost neutral. The money in your service plan will be the same regardless of whether or not you use CDS.

For more info on CDS see these DADS brochures:

<http://www.dads.state.tx.us/providers/CDS/publications.html>

Choosing an HCS Provider That Meets Your Needs

The first step in choosing a provider is identifying your individual needs and 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.

A list of providers can often be obtained upon request from the 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 a person with a disability obtain and the position 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 YOU! As you begin to interview support providers, you may think of additional questions. This is okay- 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.

To see survey results on a comparison of several HCS providers in the Dallas area go to: http://www.arcdallas.org/hcs_survey.htm or contact the DSG to network with other families regarding their experiences with HCS providers.

Employment



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OF DALLAS

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 (or 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 (*see “What is DARS?” and the DARS brochure for more information*)



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Employment and Social Security

How do we pay for employment services?

The state agency which 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. For assistance or more information, please contact Becky Slakman at 214-267-1374 or dsgED@sbcglobal.net. See also-DARS brochure.

Can my child with Down syndrome work and not lose 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, at 972-668-2628.



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What is *DARS*?

DARS – Texas Department of Assistive and Rehabilitative Services

DARS is the new name (as of January 2005) 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” *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

972-485-6005

Margo.Rye@dars.state.tx.us



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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 which 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 972-668-2628.



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*

Day Activities



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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 adult day care centers, day habilitation centers, sheltered workshops, and recreation centers. Below are some suggestions:
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
www.achievementcenteroftexas.com

Coventry- Wylie
(214) 498-7298
<http://www.coventryreserve.org/>

Easter Seals of North Texas- Carrollton
(817) 759-7911
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.*

Adult Day Care

Christian Adult Day Care Center - Dallas
(214) 391-2178

Christian Heights- Dallas
(214)371-4285

Circle of Friends Adult Daycare - Dallas
(972) 235-5688

Cliff Haven Adult Day Care, Inc.- Dallas
(214) 339-4920

Developmentally Delayed Young Adults- Garland
(972) 272-8343

Everybody's House- Mesquite
(972) 270-1772

Mesquite Adult Day Health Services-Mesquite
(972) 226-2131

Scenario Adult Restorative Nursing & Day Care-Dallas
(214) 351-1212

Town Hall Adult Day and Health Care Centers (Two locations)
Dallas or Grand Prairie
(214) 948-8892 (972)-237-1905

Young At Heart Adult Daycare- Plano
(972) 424-7294

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 recreational and leisure opportunities see the ARC of Dallas Resource Directory at www.arcofdallas.org or call (214) 634-9810**

Post Secondary Education



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 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!

The following are highlights of some local 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.

Richland College- 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 will include an internship following completion of classes. Please contact Melinda Weaver- Director of Continuing Education @ 972-238-3750 or MWeaver@dccd.edu

EL Centro College- 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

Northlake College- a new program called CAPS- Career Action Pathways to Success currently offers one, 4 week class through Disability Services that address employability skills. This class fluctuates each semester and may not always be offered. For more information contact Tony Miller, Disability Services Coordinator at (972) 273-3166.

Tarrant County Community College-currently offers 2 different programs: The Transitional Skills program on the Northeast campus (*for more information call- (817)515-6657*) and The First Choice Program on the Southeast campus (*call (817) 515-3020*).

Vocat- The program is 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) 479-4084 or see: <http://www.taicenter.com/vocat1.html>

College Living Experience (CLE) - Located in Austin, Texas (they also have several other locations throughout the US), 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, call: Shelly Underwood at (512) 850-7445.

Houston Community College- The VAST Program 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 VAST program through their website: http://learning.cc.hccs.edu/Courses/vast/index_html or call 713-718-6000.

Eastern New Mexico University Roswell- 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 http://www.roswell.enmu.edu/special_services/occupational_training_program.php

The National Down Syndrome Society is working to expand post-secondary education opportunities for individuals with Down syndrome by developing a model program in New Jersey that can then be replicated in various parts of the country. To find out more about this program see: **The Mercer County DREAM Project** at http://www.mccc.edu/student_services_needs_dream.shtml#1 or **The College of New Jersey Career and Community Studies Program** at: <http://www.tcnj.edu/~ccs/index.html>

For more helpful information also see: <http://www.thinkcollege.net/index.php>

Residential Options



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’s *Options for Adults* Committee advocates for “inclusive” community living.

What you should look for:

- Safe location in the community where the person with a developmental disability grew up and has a network of people who know him/her
- Appropriate level of supervision to ensure safety but allow for the person with a developmental disability to grow and become more independent
- Ability for a person with a developmental disability 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 a developmental disability – not the “disabled only” rec center, Special Ed Sunday school class, day-hab 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 a developmental disability
- Permanency provided by a system of supervision so that a person with a developmental disability can maintain the same life style even when his/her parents are not involved due to death or disability
- Flexibility to change living arrangements as the person with a developmental disability ages
- Resources (special needs trust and/or government program) that will not be depleted before the death of the person with a developmental disability



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Residential Services for People with Developmental Disabilities

Individuals with Down syndrome and their families often explore possible changes in living arrangements as part of the transition to adulthood and the move towards 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 student 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 developmental disabilities live together. The property is usually owned and maintained by a provider agency. “Shift staff” provides 24-hour/day supervision. Group homes can be private pay, state or federal government supported. The federal government term used for this setting is ICFMR – Intermediate Care Facility for the Mentally Retarded – and the funding comes from Medicaid. **No new funding is available for ICFMR slots and the few remaining facilities funded with 100% state dollars are being phased out. Currently HCS is the only residential funding option for people with Down syndrome.**

Home and Community-based Services 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 developmental disabilities can live together.
 2. **Supervised living** – no more than three people with developmental disabilities can live together – none of whom require awake staff at night.
- **Supported Home Living** – a person with a developmental 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 developmental disability lives with a companion in the companion's home or the home of the person with a developmental disability. The Foster/Companion Care provider may be a family member. No more than 3 people with developmental 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 developmental 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 seven to 200+ people with developmental 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.



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Residential Options in Texas

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

***Association for Independent Living (Dallas) 214-351-0798 www.afildallas.org.**
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. Residents *must* be competitively employed.

***Breckenridge Village (Tyler) 903-596-8100 www.breckenridgevillage.com**
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 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 inter-faith 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
Calab offers ICFMR group homes in Mesquite & Grand Prairie and HCS homes in Arlington & Grand Prairie. Services also include HCS and Texas Home Living, and a sheltered workshop.

Community Homes for Adults, Inc. (CHAI) (Dallas) 214-373-8600 www.chaidallas.org
A private, non-profit, non-sectarian organization operated under Jewish auspices. Provides supervised group homes and other residential options. Programming includes: vocational training, skill development, job opportunities. Provided are physical and mental health services, leisure time, recreation activities, personal care, daily living training & counseling for families and clients.

Community Options (Dallas) 972-503-3901 www.comop.org
Community Options, Inc. provides residential and employment support services to individuals with disabilities living in (16) counties in the Northern Texas. Other services include: In home support, HCS and ICFMR residential, foster/companion care, OT, PT, and speech, case management, day habilitation, respite

***Cornerstone (McKinney)** **214-223-9387** **www.cornerstonegrouphomes.com**
Gated 42 acre segregated ranch. Christian based with mandatory daily bible study (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. Volunteer staff- founded and run by individual couple. This facility is currently unlicensed.

Dallas MetroCare Services (Dallas County) **214-333-7000** **www.dallasmetrocare.com**
Offers variety residential services ranging from small group homes for teenagers and adults to adults residing in their own apartments with staff supervision, or individuals living in their natural homes or foster homes.

Daybreak (Dallas & Tarrant Counties) **1-800-299-5161** **www.daybreak-hcs.com**
Offers HCS and other residential programs serving adults. Homes are located in Lancaster/Desoto/Duncanville area and offer vocational, personal/social and recreational services via individualized programs and designed to meet the needs of each resident.

Disability Resources, Inc. (Abilene) **325-677-6815** **www.DRIAbilene.org**
Provides residential care, training and sheltered employment. DRI is financed by private donations, residential fees, vocational enterprises and some State funds. At the present time, DRI operates four residential facilities.

Down Home Ranch (Elgin) **512-856-0128** **www.downhomeranch.org**
Working ranch in a segregated environment. Residents live and work on the ranch with staff, but may be employed outside of the ranch if they desire.

EduCare Community Living (Dallas & Tarrant Counties) **972-929-5000** **www.rescare.com**
Provides community based residential programs, in-home and family support services and supervised semi-independent living arrangements.

Evergreen Presbyterian Ministries (Dallas) **972-386-4834** **www.epmi.org**
Louisiana based nonprofit organization. The North Central Texas Division offers ICF/MR group homes; a vocational workshop; Respite Care; and a supportive work program.

LifePath Systems **972-727-9133** **www.lifepathsystems.org**
Offers variety residential services ranging from small group homes for teenagers and adults to adults residing in their own apartments with staff supervision, or individuals living in their natural homes or foster homes.

***Marbridge Ranch (Austin)** **512-282-1144** **www.marbridge.org**
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 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
HCS provider of semi-independent living apartments along with day programming, and vocational services.

Mosaic (Dallas) 972-866-9989 www.mosaicinfo.org
Five ICF-MR group home; three homes are in Carrollton and two homes are located in Richardson. The HCS program has one residence for three people. Additionally within the HCS program, they provide Supported Home Living supports and Foster Care supports.

New Danville (Willis) 936-522-7279 www.newdanville.org
New community in rural setting partnering with Lone Star HCS to provide job training and other education opportunities, recreation and transportation, independent living support and HCS group homes in self-sustaining master-planned community. Construction is to begin in October of 2008 with residential homes becoming available in the spring of 2009.

***New Beginnings (Dallas) 972-740-4373** sobriens8@yahoo.com
Parents have purchased a 6 bedroom home in North Dallas for young adults with cognitive disabilities, including their son Luke. There will be 24 hour shift staff managed by a private company.

***N. TX Special Needs Assistance Partners (SNAP)(Tarrant County) 817-481-6522** ntxsnap.org
SNAP rents the condominiums to people with disabilities at a subsidized rate. A longer range project would include housing for those needing a greater level of supervision or care

Sequoia, Inc. (Dallas & Tarrant Counties) 214-634-3431 sequoiainc.org
Sequoia's Residential program currently consists of four group homes; two homes in Dallas (HCS and ICF/MR) and two in Burleson (HCS).

United Cerebral Palsy of Metro Dallas (Dallas) 214-351-2500 ucpdallas.org
UCP of North Texas currently operates four group homes in the North Texas area; two in Dallas, one in Garland, and one in Richardson. Both HCS and ICFMR

Volunteers of America (VOA) (Dallas, Collin, & Tarrant Counties) 817-529-7300 voatx.org
Provide residential services including ICFMR group homes, supported home living, in home support services, and case management.

*** Private Pay ONLY**

Health



DOWN SYNDROME GUILD
OF DALLAS

Health Resources

Local Resource:

The Down Syndrome Guild of Dallas has developed a relationship with a local physician, who has agreed to see adults with Down syndrome.

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. He sees patients at the Family Practice Clinic, located at 6263 Harry Hines Blvd., Bldg #1, Dallas 75390. To make an appointment, call 214-645-3900 - tell the receptionist that the patient has Down syndrome and request to see Dr. Shakil. Because this clinic is associated with the medical school, Dr. Shakil will always be assisted by interns and residents.

Book Review: Mental Wellness

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 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.

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
- Ophthalmologic 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
- 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
- Monitor for behavior/emotional/mental health. Psych referral (as needed)
- Continue speech and language therapy (as indicated).

* [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.

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.

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, your 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.

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NATIONAL DOWN SYNDROME SOCIETY

alzheimer's disease

and down syndrome

CLINICAL

INFORMATION SERIES

ALZHEIMER'S DISEASE AND DOWN SYNDROME

—by Ira Lott, M.D., Professor of Pediatrics and
Neurology, University of California at Irvine

Alzheimer's Disease is a degenerative neurological disorder characterized by progressive memory loss, personality deterioration and loss of functional motor capabilities. It is far more common in individuals with Down syndrome than in 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.

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

ANSWER: 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 ten 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.

QUESTION: What are the symptoms of Alzheimer's disease?

ANSWER: 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.

QUESTION: How is a final diagnosis made?

ANSWER: 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, depressive illness by psychiatric criteria, 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.

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

ANSWER: 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.

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

ANSWER: Current research is 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 individuals with Down syndrome that appear to benefit people with Alzheimer's disease in the general population.

QUESTION: How can research into Alzheimer's disease and Down syndrome be advanced?

ANSWER: As is true for Alzheimer's disease in the general population, a full understanding of the disorder involves post-mortem examination of brain tissue. Contributions to a brain tissue repository for purposes of extending knowledge about the relationship between Down syndrome and Alzheimer's disease will help to advance research in this area. For information for families and physicians considering such a donation, please contact the National Down Syndrome Society at 800-221-4602.

summary

- Individuals with Down syndrome are three to five times more likely than the general population to develop Alzheimer's disease. Onset of Alzheimer's may begin as early as age 30 in the Down syndrome population as compared to age 50 in the general population.
- Symptoms of a variety of other diseases and conditions mimic the symptoms of Alzheimer's disease: personality change, decline in daily living skills, memory loss, changes in coordination and gait and other changes. Diseases and conditions such as depression, thyroid disorders, brain tumor, recurrent brain strokes, metabolic imbalances and various neurological conditions must be ruled out prior to a diagnosis of Alzheimer's disease.
- It is recommended that individuals with Down syndrome take a baseline test of cognitive function at age 30, and that this test be repeated annually to determine any deterioration in this function. Some Alzheimer's disease symptoms can be treated, although there is no current means of curing or arresting the disease.
- Current research suggests a causative link between the extra "gene dosage" from the third chromosome 21 of Down syndrome and Alzheimer's disease. To advance research, donations of brain tissue from individuals with Down syndrome and Alzheimer's disease are being sought.

For additional information and a resource list on Alzheimer's disease and Down syndrome, visit our Web site at www.ndss.org or contact the NDSS information and referral center at 800-221-4602 or info@ndss.org.

NDSS thanks Dr. Ira Lott for the preparation of this brochure.

about ndss

Our Mission:

The National Down Syndrome Society works through education, research and advocacy, to ensure that all people with Down syndrome have the opportunity to achieve their full potential.

Our Constituents:

Today, there are 350,000 people in the United States living with Down syndrome. Each of these individuals touches the lives of family members, educators, employers, health care professionals, peers and others. This network of people who are affected by Down syndrome numbers in the millions.

Our Programs:

Education. Through our model programs, Web site, Information and Referral Center, and more, NDSS provides targeted, in-depth information that meets the diverse needs of our constituents. **Research.** The Society hosts international research conferences and funds research both independently and through a partnership with the NIH. NDSS is the largest private funder of Down syndrome research in the U.S.

Advocacy. In cooperation with our more than 200 affiliate groups, NDSS has influenced important local and federal legislation, established October as National Down Syndrome Awareness Month, organizes the Buddy Walk, and much more.



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Guardianship & Trusts

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.

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 who 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 past, the present, and explain yours 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".



DOWN SYNDROME GUILD
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Guardianship- A Personal Choice

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 most restrictive to least 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 *incapacitated*, and *removes rights and privileges from a person with a disability*
- ◆ Obtaining guardianship involves the court system and, typically, attorney fees. This can create an unnecessary financial hardship on families.
- ◆ For many people, it is a 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, 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.htm>

- ♦ **Trustee:** If a substantial amount of money comes into the individual's life, there are trust documents that can be drafted that can protect the governmental benefits and still use the funds to provide an enhanced life for the individual. A trustee or co-trustees can be designated to distribute the funds and see that the individual's needs and desires are met.

- ♦ **Release of information form:** In this age of privacy and “HIPPA”, 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.
<http://www.advocacyinc.org/CS5.cfm>*

Also check out: www.texasguardianship.org.

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 under 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.

A non-disabled sibling holding assets for the benefit 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 under 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 And Investment 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 are tax deductible.

Additionally, the individual with the disability may at some time during his or her lifetime come into 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 \$2,000.00 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 under 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 Trusts... 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 which 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 is properly supervised and if you are willing to relinquish control of your assets to others. If this is an option that appeals to 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.



DOWN SYNDROME GUILD
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Assistance with Wills, Trusts and Guardianship

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

Karen C. Caton

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

Richard O'Connor

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

Chris Mims

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

John C. Wray

200A North Rogers Street
Waxahachie, TX 75165
972-938-1850

J. Mitchell Miller

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

Legal 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.

Resource Links



DOWN SYNDROME GUILD
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Website Links for More Information

Local Agencies:

Texas Department of Aging and Disability Services (DADS) FAQ and fact sheets
http://www.dads.state.tx.us/news_info/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:

For more information on Medicaid in Texas see this brochure
<http://www.hhsc.state.tx.us/Help/ConsumerGuideEnglish.pdf>

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

Health:

Adult Down syndrome Center at the Advocate Lutheran General Hospital
<http://www.advocatehealth.com/luth/services/other/adsc/publications.html>

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

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

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.passonline.org/default.html>

Advocacy:

Disability policy consortium
<http://www.dpctexas.org/>

Advocacy Inc.
www.advocacyinc.org

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:

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

Down Syndrome Association of the UK- great resource for literature
http://www.dsa-uk.com/DSA_1stLiterature.aspx

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://www1.ndss.org/index.php>

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

The Beach Center on Disability
www.beachcenter.org

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