Empowering Individuals with Down Syndrome and Their Families Since 1973

The National Down Syndrome Congress was founded in 1973 by a group of parents and professionals who pushed back against a system which routinely recommended that babies with Down syndrome be institutionalized. Rather, these parents decided to keep their children at home with them and raise them alongside their other children. Their vision? A world with equal rights and opportunities for people with Down syndrome.

Fifty years later, people with Down syndrome are living into their 40’s, 50’s, and even 60’s, and for the most part, they continue to live in the family home with their parents, adult siblings, or somewhat independently in the community with supports. We recognize that for many families, not just those affected by Down syndrome, conversations between parents and adult children on the topics of death, medical incapacitation, healthcare directives and wills, are difficult. They are often put off, and in worst cases, these conversations NEVER HAPPEN.

At the NDSC, we are committed to providing information, advocacy and support concerning all aspects of life for individuals with Down syndrome. We want to help families work through these issues and facilitate conversations that will lead to actions which will secure the future of their adult children with and without Down syndrome, bring peace of mind to all those involved, and result in the best possible continuum of care for the family member with Down syndrome.

Adult siblings, who want to be involved in their brother or sister’s life, but are not familiar with the details involved, can use this toolkit to have discussions with their parents, and learn how to be an effective advocate, friend and perhaps, caregiver for their sibling after their parents are no longer able.

NATIONAL
DOWN SYNDROME
CONGRESS

Adult Sibling Toolkit™ Purpose

The reality is this your parents are not getting any younger. They may be slowing down. What will happen when Mom and Dad are no longer able to care for your sibling with Down syndrome?

NDSC's Adult Sibling Toolkit provides families with an easy-to-use resource which will facilitate family conversations about their loved one with Down syndrome and lay the groundwork for making a plan for the future.

Use this notebook:

- As a guide in talking with your parents about uncomfortable topics
- To record contact information for doctors, specialists, support staff and friends of your sibling
- To track your sibling's daily routine and weekly activities
- To list current medical conditions and medications
- To provide basic information about the "system"
- To find local resources specific to your family situation

This is an overview of possible issues you may encounter as your family develops a plan for the future. It is not intended to be an exhaustive resource on any particular topic or to give professional legal, financial or medical advice. Laws vary from state to state; you should consult a professional in the state of your sibling's residence.

Post-Parental Care: Will Your Family Be Ready?

1. Sit down with your parents, your sibling with Down syndrome and other interested family members and friends.
2. Decide who should take your parents place as the **key** support person.
3. Determine the roles of the others present.
4. Go through this toolkit page-by-page with your parents and fill out the information to the best of your abilities.
5. Gather the important documents or at least identify where to find them.
6. Which documents are missing? For legal and financial documents make a plan for

> *"Vision without action is a daydream. Action without vision is a nightmare."*
>
> -Japanese Proverb

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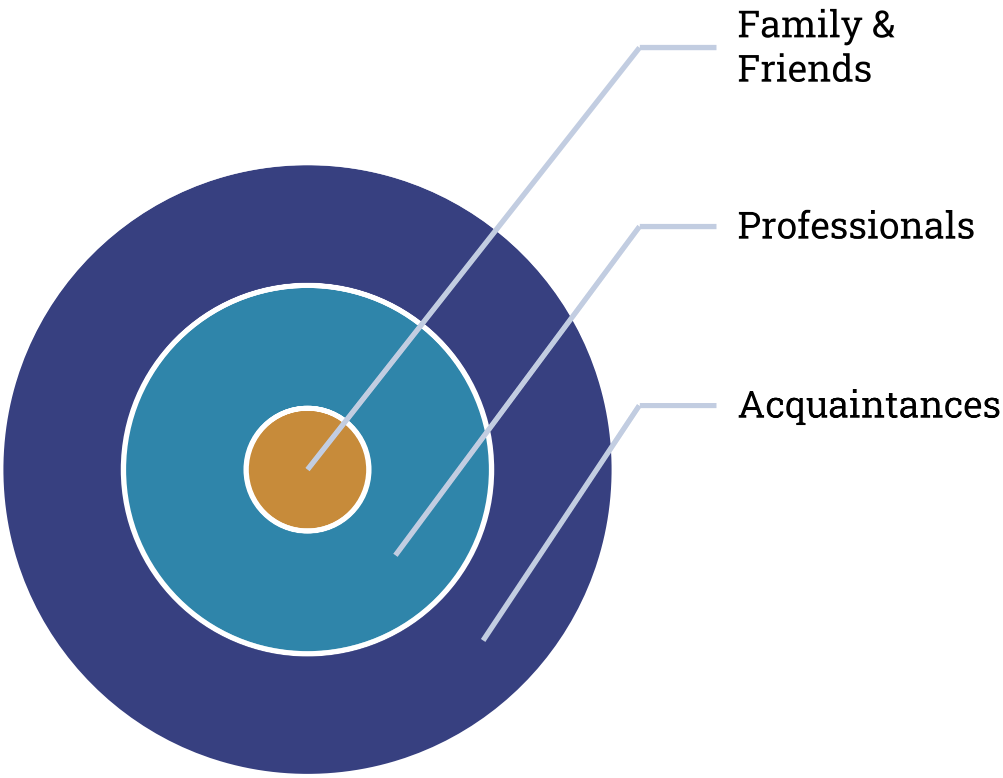
Who are the key people in your sibling's life?



Questions to consider

How does your sibling fill his days? Does he work five days a week? Volunteer? Belong to a drama group or book club?

How does your sibling get from home to work? Work to drama group? Do your parents drive him everywhere or does he use public transportation? Is any activity within walking distance?

Who are your sibling's friends? What do they like to do when they hang out together? If they go on an outing, how do they get there?

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Daily Schedule

	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
Early AM							
Mid-morning							
Lunch							
Mid-afternoon							
Evening							

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Friends

Name	Phone #	E-mail	Address	City, State & Zip	Activity

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Support Professionals (job coach, caseworker, etc.)

Name	Title	E-mail	Phone #	Responsibilities

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Activities

Place	Phone #	Contact	Address	City, State & Zip	Activity

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Completing the Health Section

Because the healthcare needs of older individuals with Down syndrome can be complex and sometimes misdiagnosed, it is important to understand the impact mental health and well-being has on physical health. Many families do not have access to physicians with a comprehensive understanding of the healthcare needs for adults with Down syndrome. GLOBAL Down Syndrome Foundation created the first of their kind, Adult Medical Care Guidelines that you can take to appointments with your physician to provide evidence-based medical recommendations to support clinicians in their care of adults with Down syndrome. You can find a copy of the family friendly guidelines and a guideline checklist in the "Resources" section of this toolkit.

The pocket folder provides a place to keep the most recent records of doctor visits, lab and test results, copies of insurance cards, etc. The worksheets in this section provide a place to record your sibling's medical history; the names of doctors and specialists your sibling sees; a place to list medications he/she is taking, and which condition the medication is treating; and information about self-talk, routines and "grooves" along with an hourly log. Completing these pages with your parents, giving as much detail as possible, is going to make any transition of primary care much easier. Please visit our website to download additional forms if necessary.

Keeping the information in one binder and taking it to every health care appointment will give the provider an important overview of your sibling's health. It can also help the physician make a more accurate diagnosis.

Dr. Brian Chicoine and Dr. Dennis McGuire, who founded the Adult Down Syndrome Center in Chicago, IL, have said it best, "Health is defined as being more than the absence of disease; it involves physical, mental, and spiritual well-being. Developing an understanding of how physical health problems contribute to mental health issues and evaluating patients for these connections are essential to providing quality health care." Their books, *Mental Wellness in Adults with Down Syndrome and The Guide to Good Health for Teens & Adults with Down Syndrome,* should be mandatory reading for everyone who loves someone with Down syndrome.

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Medical History

Does your sibling have any allergies to medications? YES NO
(If yes, list here)

Does your sibling have any food allergies? YES NO
(If yes, list here)

Does your sibling have any chronic health conditions? YES NO

(Please Circle All that Apply & Enter Treating Physician on Medical Professionals Page)

Diabetes
Asthma
Seizures
Heart Condition
G I Issues
Vision Impairment
Joint Problems

Celiac Disease
Sleep Apnea
Depression
Thyroid Disease
Hearing Impairment
Skin Conditions
Atlanto-axial instability

Any other Conditions? (Enter Treating Physician on Medical Professionals Page)

Diet & Exercise

Does your sibling struggle with being overweight? YES NO

Follows specific food guidelines? YES NO

Have a regular exercise program? YES NO

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Medical History

Has your sibling had surgery or been hospitalized in the past ten years?

List the year & the cause

Does your sibling have any psychological/emotional difficulties? (Please Circle All that Apply & Enter Treating Physician on Medical Professionals Page)

Depression	Anxiety
Self-Talk	OCD
Behavioral Issues	PTSD
Agitation	Physical Aggression
Memory loss	Loss of skills

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Medical Professionals

Doctor	Specialty	Condition	Phone #	Address	City, State & Zip

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Medication Information

Medication name:
Medication purpose:
Dosage:
Prescribing doctor:
Comments:

Medication name:
Medication purpose:
Dosage:
Prescribing doctor:
Comments:

Medication name:
Medication purpose:
Dosage:
Prescribing doctor:
Comments:

Medication name:
Medication purpose:
Dosage:
Prescribing doctor:
Comments:

Medication Information

Medication name:

Medication purpose:

Dosage:

Prescribing doctor:

Comments:

Medication name:

Medication purpose:

Dosage:

Prescribing doctor:

Comments:

Medication name:

Medication purpose:

Dosage:

Prescribing doctor:

Comments:

Medication name:

Medication purpose:

Dosage:

Prescribing doctor:

Comments:

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Medication Schedule

	Medication name	Dosage	Condition for	Prescribed by	Special Instructions	Possible Side Effects
Early AM						
Mid-morning						
Lunch						
Mid-						
Evening						

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Include vitamins & supplements

Psychosocial/emotional issues common to people with Down syndrome

Your sibling may exhibit odd or repetitious behaviors that others find disturbing. These are referred to as "grooves" or "stereotypic behaviors". Grooves can be a strength, allowing people to organize their rooms and personal items, and present themselves to the world in a neat and dignified fashion. Grooves may also increase independence at home or work by following through reliably with self-care or workplace tasks, once these activities are part of a daily routine. However, a groove can also be a safety valve allowing people to have some outlet when they are under stress. In these instances people can get stuck in certain set patterns of behavior that may be unproductive. These become more problematic when the grooves interfere with essential life activities or unforeseen schedule changes (i.e. Friday night is pizza night *no matter what*). Often these behaviors increase when your sibling is stressed or very tired. Related to this are stereotypic behaviors, which may not appear to be under conscious control. This could include repetitious body movements: hand-flapping, rocking, rubbing, or unusual noises.

Does your sibling have any grooves or stereotypic behaviors?

What behaviors occur if the routine is changed?

Does your parent have any strategies to redirect these if inappropriate in a certain situation?

Suggestions for reducing behaviors that are worrisome:

- Establish a secret gesture with your sibling that reminds her in a positive fashion, such as finger to the lips for "quiet mouth" if noises are an issue.
- Keep hands busy and mind engaged. People are disengaged if they are not being included in the conversation or if the subject is beyond them or of no interest.

Sometimes grooves can be very beneficial, especially when combined with visuals like a checklist or calendar. You might establish a visual checklist for completing household chores, personal hygiene, or eating healthy foods.

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Self-Talk or Imaginary friends

Often this is misunderstood as a mental health problem. For the person with Down syndrome it could be thinking out loud, processing events of the day, or planning ahead for the week or month. For many, self-talk is easier to understand than their conversations.

Is self-talk frequent for your sibling?

Have your parents established any rules around self-talk, such as only doing it at home, or never at work?

When to be concerned

If there is a change in quality or an increase in the quantity of self-talk, it could indicate stress or depression.

Eavesdrop! If it becomes mean or belittling, has an angry tone, contains phrases like "you are stupid" or "leave me alone" your sibling could be processing an actual negative experience. This could have occurred recently or the distant past.

Look for other signs of depression:

- Loss of interest in things she used to love.
- Change in sleep patterns, loss of appetite, vitality.
- Increase in irritability, avoidance of situations, or being unwilling to leave the house.

Has your sibling ever been seen by a psychologist or social worker? Who would your parents recommend?

Use the Daily Routine page to record your sibling's typical day. Does he need visual cues or picture cards to remind him?

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Is it Alzheimer's Disease?

Alzheimer's disease is a progressive neurological condition. It is a type of dementia. Alzheimer's disease is characterized by microscopic changes in the brain that are described as plaques (clumps of a protein called beta-amyloid) and tangles (twisted strands of a protein called tau).

There is not one specific test that definitively diagnoses Alzheimer's disease. Researchers continue to work on developing diagnostic tools. Some of the efforts include developing tests of blood or spinal fluid samples that measure levels of beta-amyloid or other biomarkers of Alzheimer's disease. In addition, brain scans called positron emission tomography (PET) scans are being used to detect plaques. These tests are primarily used in research settings.

Outside of research settings, a diagnosis of Alzheimer's disease is made by assessing for and finding a pattern of decline that is consistent with Alzheimer's disease and ruling out other possible causes of a decline. A pattern of decline consistent with Alzheimer's disease may include:

- Memory deterioration
- Loss of previously mastered skills
- Incontinence
- Unsteady gait
- Dysphagia (difficulty swallowing)
- Seizures
- Weight loss
- Psychological changes

While the life expectancy for persons with Down syndrome has risen over the last decade and many are living well into their 50s and 60s, it is still shorter than in persons without Down syndrome. In addition, adults with Down syndrome do seem to develop some health conditions at a younger age. When adults with Down syndrome develop Alzheimer's disease, it occurs on average 20 years earlier than in others. One way to look at it would be that the rate of Alzheimer's disease in patients with Down syndrome in their forties is similar to those without Down syndrome in their sixties.

As there may be some people who fall outside the typical age range, if a person with Down syndrome declines at a younger age (e.g. age 20) it is more likely that there is an alternative explanation. Whether a decline comes early or later, since there are many conditions that can cause dementia, it is vital to thoroughly evaluate and rule out other health issues when a decline in skills is first noted. Careful assessment, support, observation over time, and treatment of any potentially reversible conditions will often help make the diagnosis more clear and lead to improvement in those individuals who don't have Alzheimer's disease.

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Psychosocial/emotional issues common to people with Down syndrome

Neuropsychological testing is typically part of the evaluation for Alzheimer's disease for people who do not have an intellectual disability. This testing may include questions and tasks to assess memory and cognition. It is usually more difficult in people with Down syndrome and other intellectual disabilities. There are a few tests that are more specific for people with Down syndrome, such as the Down Syndrome Mental Status Examination and the Dementia Scale for Down Syndrome. These tests seem to be most beneficial when done sequentially over time. Clinically, we find that, by the time a cognitive decline is evident on the testing, the decline and diagnosis are often clear from the person's symptoms.

If there is a pattern of decline, it is important to rule out other factors that may be causing or contributing to the decline. Many of the other causes have treatments that can improve or eliminate symptoms. They include (but are not limited to):

- Depression and other psychological concerns
- Sleep apnea
- Thyroid disease
- Vitamin B-12 deficiency
- Metabolic diseases such as kidney disease, diabetes, or calcium abnormalities
- Celiac disease
- Loss of hearing or vision
- Atlantoaxial instability or other cervical (neck) problems
- Heart disease
- Seizure disorder
- Normal pressure hydrocephalus
- Cataracts
- Medication side effects

Shared with permission from the Adult Down Syndrome Center in Park Ridge, IL

Daily Routine

Time	Typical Day
7:00am	
7:30am	
8:00am	
8:30am	
9:00am	
9:30am	
10:00am	
10:30am	
11:00am	
11:30am	
12:00pm	
12:30pm	
1:00pm	
1:30pm	
2:00pm	
2:30pm	
3:00pm	
3:30pm	
4:00pm	
4:30pm	
5:00pm	
5:30pm	
6:00pm	
6:30pm	
7:00pm	
7:30pm	
8:00pm	
8:30pm	
9:00pm	
9:30pm	
10:00pm	

Routines or Grooves
Work support
Additional information
Special activities or TV shows

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A Place to Call Home



Today, adults with Down syndrome live in a variety of settings and the options available can vary widely from state to state. Some of the most important things to consider when determining where your sibling will live are: What are his preferences? What are her independent living skills? What are her support needs? What funding is available?

As with all decisions concerning your sibling, your sibling needs to be part of the conversation and given the opportunity to express her preferences and desires. Living arrangements must be developed through a "person centered planning" process that addresses health and long-term services and support needs in a manner that reflects individual preferences and goals. It would be helpful to connect your sibling with other disabled adults in various housing models so that they can hear about their experiences firsthand and see if they would be a good fit. Make sure that all communications relating to housing choice are done in language and on a level that your sibling can understand so that they can meaningfully participate in the decision.

Most individuals with Down syndrome need support to live independently – from family, friends, and/or paid support people. However, the type and intensity of these supports may vary greatly. Some examples of support needs are help with cleaning and maintaining their home, grocery shopping and meal preparation, budgeting, managing medications, personal care, and transportation, Some people may need a support person 24 hours a day for 7 days/week, while others may just need a check-in for several hours a day or once or twice a week. These long-term support services can be costly and many rely on public funding (i.e. Medicaid waivers) to pay for those services.

Housing itself is very expensive, and there are very few families who can self-fund housing. Hopefully financial planning has already been done, and your sibling has assets in savings mechanisms that won't jeopardize their benefits such as an Achieving a Better Life Experience (ABLE) account or a special needs trust.

There are government-subsidized public housing and rental assistance benefits available through your local Public Housing Agency. Many people with disabilities will qualify for these public housing benefits, though they have limitations and there may be waitlists. If your sibling is contemplating living independently, connecting with your local Public

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Housing Agency as soon as possible would be advisable so that you learn about the options for housing assistance and can get his name on a waitlist.

There are many different types of living arrangements available for people with disabilities, all with varying levels of independence, supports needed, and the extent of community inclusion.

Independent Living is the most independent model, where the disabled person lives mostly independently in the community (e.g., a house or apartment) and signs their own lease. Under this model, it is common to have drop-in supports based on need, such as help with transportation, grocery shopping and household chores, but the person basically lives on his or her own or with roommates in a typical living situation.

Congregate Living is a more restrictive model, where the disabled person lives in a home with other disabled people and they have more intensive support needs, often requiring assistance 24 hours/day. The disabled person has less choice under this model, often not even being able to choose their roommates or set their own schedule. The support personnel and resources needed for congregate living arrangements are typically provided by service provider agencies. Some examples of congregate living situations would be group homes, gated communities, and farmsteads, all of which have different levels of community inclusion. Congregate living arrangements are now highly regulated (as a precaution so as not to create more institutions), with up to 4 disabled individuals living together.

Shared Living is when a disabled adult lives with a paid (often unrelated) caregiver in the caregiver's own home so the caregiver can provide services. This model has been analogized to adult foster care. The hosting caregiver and their family are provided with extensive training by an accredited agency so they can meet the needs of the disabled individual. The disabled individuals under this model typically need more intensive one-on-one supports so can't live independently.

Intermediate Care Facilities (ICFs) are institutional settings that house people with intellectual and developmental with the highest support needs who often have mental illness, behavior problems, visual or hearing impairments, seizure disorders and are non-ambulatory. These facilities are funded through Medicaid and are the most restrictive housing situations, segregated from the broader community and where residents have little to no choices in their daily lives.

Living in the Family Home is when a disabled adult stays in the family home with his or her parents or other family members. Since there are massive affordable housing shortages, this often becomes the default option when people with IDD can't find or afford alternatives.

This list is not comprehensive, as new and innovative housing models for people with IDD are cropping up around the country with frequency to address the scarcity of available and affordable housing options. One such model is **Integrated Community Living**, where people with and without disabilities live together in a truly integrated environment, like an apartment building with shared common areas or when parents hire a college student to live with their disabled son or daughter and provide some supports.

If your sibling's goal is independent or semi-independent living in the community, it is important to ascertain how proficient they are in independent living skills, and how they are learning and practicing skills such as:

- Hygiene and grooming
- Cooking, grocery shopping, meal prep and clean up
- Laundry, making the bed, light cleaning
- Awareness of personal safety at home, such as locking the door behind you and making sure the stove is turned off
- Travel training, particularly if public transportation is an option
- Building technology proficiency is another critical skill, so they can use things such as a GPS app on their phone and calendar/scheduling software.

It is never too early to start practicing these skills, which will improve independence and quality of life even if your sibling chooses to live in a congregate setting or stay in the family home.

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A Place to Call Home

Talk with your sibling:

Where does he want to live?

Is it possible for her to continue living in the family home with supports in place?

Does he want to live with a roommate or alone? ?

Will it be necessary for him to move to another state?

How will that affect his benefits?

Is there a key person in his community willing to provide a foster home?

Think about partial transitions…trial weekends or a vacation from Mom & Dad

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Employment

People with Down syndrome have the skills to pursue meaningful careers and play an important role in their own economic success and overall happiness. It is important to know your sibling's strengths, weaknesses, level of support needed, dreams and goals when setting out to find an employment opportunity. Often, volunteering is a way to not only gain job training, but also to help your brother or sister feel competent and comfortable in the workplace setting. Employers who hire individuals with disabilities benefit from above average employee retention, attendance, and productivity.

What are the different types of employment?

Competitive Employment is full-time or part-time work for a business in the community where the disabled worker is paid at or above minimum wage and works with co-workers who may or may not also have disabilities. All employees have access to the same opportunities for advancement and the same benefits. The disabled employee may receive initial coaching and supports, but they ultimately become somewhat independent at their job with little supports.

Supported Employment is an employment model that provides people with severe disabilities the appropriate, ongoing support that is necessary for success in a competitive work environment. A common example of support is a job coach, who would work at the job site to help the employee learn job tasks, identify modifications that might be necessary, and collaborate with the employer to solve social or behavioral problems. Under the supported employment model, most individuals receive services from a community-based service provider, which helps them to figure out their strengths and preferences, locate or develop jobs, and provide job skills training.

Customized Employment is an employment model that uses an individualized approach to find a match between your strengths, interests and needs and the employer's needs. It is a process that involves a negotiation with an employer when the disabled person can perform many of the job requirements, but not all of them. It can involve reassigning tasks to other employees, having two people share a job, or carving out part of a job for the disabled employee.

Self-Employment is when the disabled person starts their own business. This model has become very popular in that it offers much flexibility and built-in customization, but it takes a lot of resources (typically from parents) to get started and keep it going. Examples of businesses started and run by disabled individuals are paper shredding, coffee, popcorn, soaps, humorous T-shirts and jewelry; it really depends upon the interests of the disabled individual and the feasibility of running a particular business.

Group Employment is when a work group of a handful of individuals with disabilities, with a supervisor and/or support person, is driven to varied work locations (for example, to do landscaping or janitorial work). The group moves as a unit and is typically comprised of only workers with disabilities who may or may not be paid minimum wage, but they usually earn less than comparable employees without disabilities. The group remains under the supervision of a job coach and often receives on-site training with the tasks.

Sheltered Employment is facility-based work that occurs in a sheltered workshop where workers with disabilities do piecemeal work in a segregated setting away from the community. In sheltered employment, the disabled employees typically earn less than minimum wage, sometimes even pennies on the dollar (this is still legal due to an archaic law, Section 14(c) of the Fair Labor Standards Act). This employment model is outdated and many advocates on the federal and state levels are working to phase it out. Sheltered workshops are viewed as isolating, with disabled employees often getting “stuck” there for many years or decades without being given the choice to work in the community. Additionally, the payment of “subminimum wages” in these sheltered workshops is now considered to be a civil rights violation by the U.S. Civil Rights Commission. At least twelve states have eliminated the sheltered workshop model, and the federal government is also moving in that direction.

WHAT PUBLIC BENEFITS CAN AFFECT EMPLOYMENT?

Public benefits programs are offered through local, state and federal governments and provide money and services to low-income people and people with disabilities. Some of the benefits programs can help people with disabilities to obtain and retain jobs. Most public benefits are means-tested programs, so people with disabilities and their families need to be wary that earning too much income could reduce or terminate benefits.

Medicaid: Medicaid is a jointly funded, federal-state health insurance program for low-income, elderly and disabled people and provides essential medical care and a broad range of health services, including doctors’ visits, hospital care, and medical equipment. Medicaid is a means-tested program and is often tied to eligibility for Supplemental Security Income (SSI), so qualifying for one will automatically qualify the person for the other. For people with disabilities, Medicaid is much more than a health care program – it also provides vital supports for people with disabilities to live self-determined lives and to keep them in their communities.

- **Medicaid Home and Community Based Services (HCBS):** Through Medicaid, people with disabilities can receive services and supports in the community instead of institutional settings. HCBS can include supports such as employment training, supported employment and job coaching. Services available through “HCBS waivers” vary by state, and unfortunately many states have long waiting lists for these services.

- **Medicaid Buy-In Programs:** Some states have adopted Medicaid “Buy-In” programs to allow people with disabilities who are earning money to maintain their Medicaid health care and HCBS coverage by paying a small premium until they reach a specific income above the poverty level.

Supplemental Security Income (SSI): SSI is a means-tested program for people with disabilities who have little or no income and few resources. SSI recipients receive monthly income checks as part of this program, but these checks will be reduced or suspended if the recipient earns too much income in a month or has too many resources. The Social Security Administration has developed some work incentives programs such as Ticket to Work and Plan to Achieve Self-Support (PASS). These programs allow people to be employed and keep their SSI benefits, but there are very strict rules and timelines involved.

Social Security Disability Insurance (SSDI): Social Security Disability Insurance (SSDI) is a payroll tax-funded federal insurance program of the federal government which is designed to provide monthly benefits to people who have a medically-determinable disability that restricts their ability to work. The SSDI program pays benefits to employees who have worked and paid Social Security taxes on their earnings, and can also provide benefits to dependent family members of these employees. People who receive SSDI are eligible for Medicare after a certain time period. Some people with disabilities receive both SSI and SSDI benefits and can be dually enrolled in Medicaid and Medicare. While SSDI is not means-tested to qualify for benefits, people who earn too much money through work may see their benefits reduced or suspended. It is important to follow the rules of these programs.

- **Vocational Rehabilitation:** Vocational Rehabilitation (VR) is administered at the state level by a state agency, and the programs vary by state. VR assists people in finding jobs, and provides other employment-related services such as vocational assessments, training, counseling and guidance. You can find information about your state's VR agency here: https://rsa.ed.gov/about/states

How will working affect Social Security disability benefits?

If your sibling receives SSI or SSDI benefits and starts working or returns to work, he/she must report any income earned to the Social Security Administration (SSA). However, this does not mean that the amount of their benefits will be affected or that they will stop receiving disability benefits. Visit www.ssa.gov to learn about trial work periods and more.

Discrimination in the workplace

The Americans with Disabilities Act (ADA) makes it unlawful to discriminate against a qualified individual with a disability with regards to employment procedures and practices, hiring, firing, job training and advancement. If you believe that your sibling has been discriminated against at work because of race, color, religion, sex (including pregnancy), national origin, age (40 or older), disability or genetic information, you can file a Charge of Discrimination. Just remember there is a time limit (180 days) in which to file the claim. Call 1-800-669-4000 or visit http://www.eeoc.gov/employees/howtofile.cfm .

Additional employment resources

The US Department of Labor's Office of Disability Employment Policy (ODEP) develops and influences policies and practices that increase the number and quality of employment opportunities for people with disabilities. http://www.dol.gov/odep/

The Job Accommodation Network (JAN) is the leading source of free, expert, and confidential guidance on workplace accommodations and disability employment issues as a service of ODEP. www.askjan.org

Employment History

Current Employer____

Supervisor____

Phone__________________ Email _______________________________________

Job Coach____________________________ Supported through waiver? Y N

Phone __________________ Email ______________________________________

Transportation___________________________________ Phone _______________

Work days/hours____

Responsibilities:

What does he/she love about the job?

What does he/she have challenges with?

Any co-workers that are friends too?

Any co-workers that are unfriendly?

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Employment History

Previous Employer____

Supervisor________________________________ Phone ____________________

Responsibilities:

Any other Employers in the past three years?

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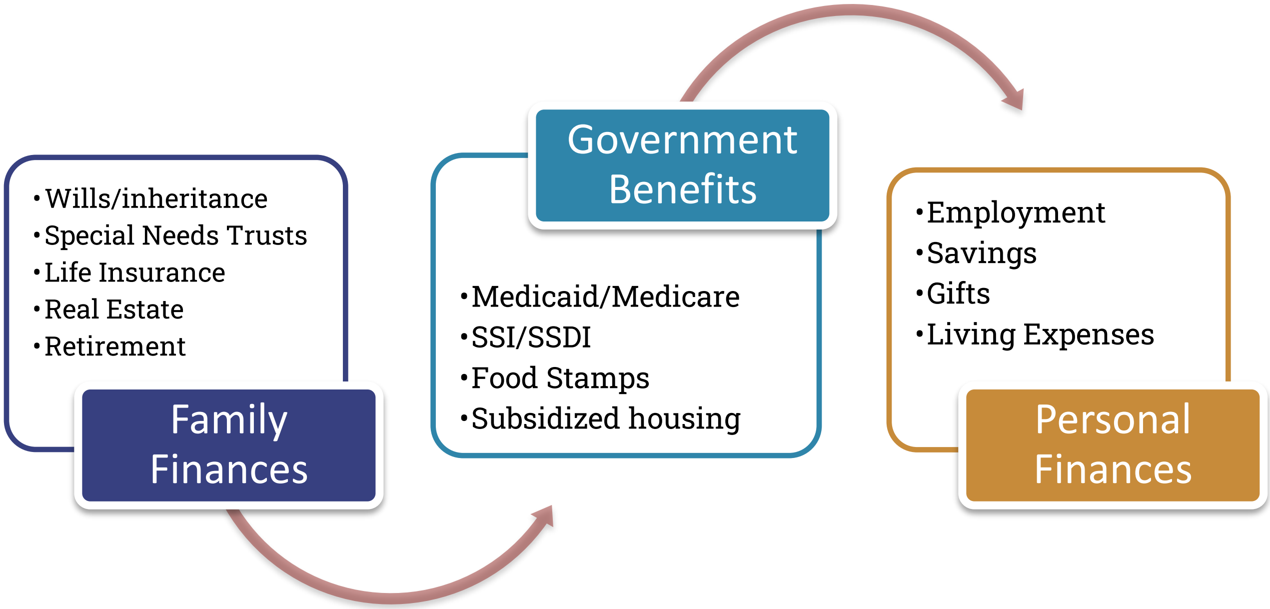

Family Finances

- Wills/inheritance
- Special Needs Trusts
- Life Insurance
- Real Estate
- Retirement

Government Benefits

- Medicaid/Medicare
- SSI/SSDI
- Food Stamps
- Subsidized housing

Personal Finances

- Employment
- Savings
- Gifts
- Living Expenses

It's Complicated!

What's even worse? Each state has its' own rules!

Is it possible that your sibling would move from their current state to another? How will this affect his benefits?

Do Mom & Dad have a will? Where is it?

Do they have a special needs trust set up for my sibling?

Where can I find all these documents?

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Annual Review

An annual review of the financial and caregiving plan is necessary

A great many things can affect your strategy, including:

- a new job, the loss of a job, or a significant bonus;
- a marriage, divorce, death, or birth;
- children growing up, attending college, getting married, and sometimes moving back home;
- a person you've named as a future guardian or someone you thought could provide future care is no longer able—or capable—to handle the responsibility;
- someone once thought to be irresponsible is now up to the task and eager to help;
- a change in estate tax laws, giving you more, or fewer, opportunities to stretch your discretionary income; and
- new financial or insurance products becoming available to put your money to work in different ways than your strategy currently uses.

What to check during a review?

Beneficiary designations can sometimes cause trouble. Check your contracted instruments, such as life insurance policies, pension plans, wills, and other instruments where you've named someone to receive benefits. Sometimes these go overlooked, especially if it's something you've received as an employee benefit many years ago. Ensure that you still want the person(s) you've named to receive those benefits. Additionally, if any beneficiary you've named is a person with special needs, consult with your professional team to confirm you have the correct beneficiary designation to meet your strategy goals. *Otherwise, the money received may make that person ineligible to receive government benefits.* Look at current and future health care requirements and expenses, and what they might incorporate into their strategy to support those needs. Meet with your attorney to review wills and trusts, and an accountant to determine if any tax law changes may affect you. Of course, a general review of the strategy itself should be done to help ensure it's still in line with the goals you've set for yourself and your family.

Embrace the process

Creating and reviewing a financial strategy can seem overwhelming at first, but it's only scary if you don't actively engage in the process. The more involved you become, the easier it will seem. And when you begin to see the results, when you feel less stressed and more secure about caring for your family's finances, you'll be glad you made the effort.

Guardianship and Alternatives

What is Guardianship?

Guardianship is a legal relationship granted by a court between two people: a guardian and a ward. The intent of guardianship (called a "conservatorship" in some states) is to protect the ward from exploitation in matters of finance, property ownership, services and to receive guidance for medical decisions. However, guardianship, in some states removes certain rights from an individual (i.e. the right to marry or vote); *so it should be considered only after all available alternatives have been explored*. A guardian does not have to be a family member but should be someone who will look out for the best interest of your sibling.

What are the responsibilities of being a guardian?

The powers and duties of a guardian will depend on individual circumstances. Personal care might involve deciding where the ward will live, and arranging for meals, transportation, clothing, personal care, recreation, and health care. Financial care might involve making a budget, paying bills, investing money, collecting income, and protecting assets. Some adult children may be able to take care of their personal needs, but have difficulty managing money. Or they might need help making medical decisions. Letters of Guardianship will explain what the guardian has the authority to do.

Guardianship is a big responsibility, so it's important to choose a person who's willing and able. A special-needs child may have a loving brother or sister, but if that person is far away, or overburdened with other responsibilities, he or she may not be a good choice. It's never wise to pressure anyone into undertaking such an important position as guardianship or conservatorship.

Sometimes, the responsibilities may be shared by two people. One person may be appointed to take care of the personal needs, and another person, the finances. If a friend or relative is willing to serve, but is uncertain about having the financial expertise to do so, he or she may be appointed jointly with a bank or other institution. If no friend or relative can be found, a private professional guardian or a public agency may be appointed.

What Are Some Issues to Consider?

A guardianship will necessarily mean a lot of involvement with the legal system. The guardian may have to account to the court periodically about the status of the special-needs individual and the management of the assets. Every time the guardianship is questioned or changed, it must be done through the courts. The guardian is required, in most states, to complete a report for the court on at least an annual basis. In the case of a conservator, an initial inventory and annual accountings must be filed.

A big drawback to guardianship is that it strips the disabled individual of some or all rights. People under guardianship cannot make their own choices about where they live, where they work, what kind of medical care they get, what they eat, who they get to spend time with, and whether they will get married. In some states, people under guardianship cannot vote and cannot sign contracts (for example, an apartment lease). Guardianship is a permanent arrangement that is difficult to reverse or change. Guardianship also comes with a stigma – it is like a public declaration of incompetency. It is costly, with regular paperwork to file and regular interactions with the court.

Should the Guardian Be a Sibling?

A sibling is often the best choice of guardian for many reasons. A sibling knows the challenges and joys the relationship can bring. Also, siblings are usually close in age. A younger guardian means there's a better chance for a long relationship because the guardian's age-related health issues, as well as lifestyle adjustments at retirement, are less likely to be factors. In addition to age and finances, the family's goals regarding the quality of life of the child with special needs should be discussed. Even if the guardian will be a sibling, creating a letter of intent, which outlines medical, financial, social, and personal facts about the person to be cared for, is recommended. It helps to eliminate questions or doubts that might arise when a new guardian steps in.

Conversations about choosing a guardian should be open and ongoing. When parents (or siblings, or aunts, or whoever the guardian may be) are trying to choose a successor guardian, they shouldn't assume they know who would want, or *not* want, the responsibility. Ask. And be aware of how the passing of time might make the perfect choice of guardian not so perfect anymore. Keep revisiting your decisions. Always be prepared for the changes life brings by having a successor guardian lined up and an alternate in mind.

LESS RESTRICTIVE OPTIONS TO GUARDIANSHIP

There is a national trend away from guardianship. Before seeking guardianship over an individual, families should examine less restrictive options that can best help the individual with decision making. Many families pursue one or more of the following options:

- ***Supported Decision Making*** – a model where the disabled individual retains all rights and decision-making authority but has a circle of close advisors helping them every step of the way.
- ***Person Centered Planning*** – this is an ongoing problem-solving process that can help disabled people plan and make decisions.
- ***Advance Directives*** – these are legal documents that address narrow and specific issues. For example, a health care power of attorney allows the person to designate

someone to make health care decisions, and a living will specifies which life-saving medical interventions the disabled person wants and does not want should a life-threatening situation arise.

- ***Durable Power of Attorney*** – this allows an individual to be given legal authority over another in limited circumstances. For example, a financial power of attorney allows someone else to make financial decisions.
- ***Representative Payee*** – this is a person or organization designated through the Social Security Administration to handle Social Security benefits. It involves special paperwork and procedures.
- ***Personal Money Managers and Advisors*** – these are individuals or organizations that can help with financial services such as paying bills.
- ***Limited Bank Accounts*** – these can be set up with a parent as co-signer, withdrawal limits, etc. to minimize the chance that the disabled person could be taken advantage of financially. (Note that, unless the account is an ABLE account, the assets in this account must be kept under $2000 or public benefits could be jeopardized).

A KEY ALTERNATIVE TO GUARDIANSHIP: SUPPORTED DECISION MAKING

Supported decision making (SDM) is an alternative model that is gaining popularity around the country as a less restrictive alternative to guardianship that honors the disabled person's right to self-determination. SDM is a way for the disabled adult to keep their decision-making rights by choosing others to help them make their own decisions and choices. Normally, a person with a disability using SDM relies upon a parent, family member, friends, professionals, and others to help them with decision making, but the decisions ultimately lie with the disabled individual.

The process of SDM looks different for each person, depending upon their needs. It may involve tools such as developing plain-language materials or information in audio or visual form, extra time to discuss choices, pros and cons lists, role-playing activities, and bringing a supporter into important appointments to take notes and help the person remember and discuss their options.

A major benefit of SDM is that the individual still has rights to make decisions impacting their well-being and life, but they rely upon other individuals (often called a circle of support) to help them make good decisions. They can also choose their own support team and substitute people out whenever they would like (whereas changing a guardian is a very expensive legal process). This support team helps the disabled individual to make his or her own decisions, whereas under guardianship, the guardian gets to make all decisions.

SDM does not preclude a parent from assuming partial legal responsibility over certain issues such as finances and health care decisions. This can be done relatively easily and a lawyer and the courts do not need to get involved. Power of attorney forms also vary by state but can be found online free of charge.

Many who pursue SDM will tell you that this is a very good option since it helps the individual make decisions based upon the support others give to him or her and therefore allows a learning process for the individual to practice making good decisions. Many people, with or without a disability, rely upon others to advise them: a person investing funds in the stock market relies upon an investment advisor; a person buying a house relies upon a realtor, etc. SDM is often a way to protect the person from making bad decisions while teaching them and empowering them.

Because the law varies from state to state it will be necessary to involve an attorney knowledgeable in this area.

Selecting a Special Needs Attorney

What Should You Consider When Selecting a Special Needs Attorney?

Planning for the future of your loved one with Down syndrome is a complex process. Given the cost of supporting a person with a disability for his or her lifespan, careful planning must take place. Medicaid/Medicare, SSI/SSDI, waivers and other federal programs are the primary sources of revenue for supporting persons with disabilities. What medical care will be needed? Where will he or she live? Work? Go to school?

In order to find answers to all of these questions, you may need to reach out to many people, experts in various fields such as health care, social work, education, disability advocacy, financial services and law. You will need to have frank discussions with family and close friends. You may need to look for other families struggling with the same issues you are dealing with, to give you advice and support. Together these individuals help form your special needs team. A key leader of your team, because of the critical nature of his legal expertise, is the special needs attorney. It's therefore essential that you choose your attorney well.

A good special needs attorney should have the following qualities:

- The lawyer should be an expert in federal social security programs for individuals with disabilities and their families, including application processes, eligibility requirements, and continuing qualification standards for such programs as Medicare, Medicaid, Medicaid Waiver Programs, and Supplemental Security Income (SSI)
- The attorney should be an expert in the design and drafting of special needs trusts (SNTs), which allow you to leave an inheritance to your family member without needing to disqualify him for government benefits, or disinherit her, or leave his or her share to another person and hope that person will provide proper oversight and care.
- The lawyer should be an expert in the use, purpose, and preparation of legal documents essential to the implementation of the special needs strategy, including living and testamentary wills, trusts, and health care directives and proxies, letters of intent, general and special durable and non-durable powers of attorney, guardianships and conservatorships.
- The lawyer should be an expert in federal, state and local laws and regulations governing the eligibility and admission of individuals with disabilities to long-term care facilities and the standards such facilities are required to meet, elder

abuse and exploitation laws (Older Americans Act—Vulnerable Elder Rights Protection under Title VII).

- The lawyer should be an expert in income, estate, and gift tax laws as they pertain to lifetime and testamentary gifts and transfers, as well as the Americans with Disabilities Act (ADA) and related state anti-discrimination laws.

- The lawyer should be aware of ABLE accounts and willing to incorporate an ABLE account into the financial plan.

- **Experience.** The lawyer's practice should be focused on special needs, not merely a small part of it. The lawyer should be able to provide you with references from a number of satisfied clients. A good way to locate an experienced professional is to ask other members of your team: your financial advisor, for example, or a family dealing with the same issues that you are, who has found an attorney they like and trust.

- **Good Communication Skills.** It doesn't matter how brilliant attorneys are if you can't get a speedy response from them when you need it. Effective professionals have well-run offices with courteous, organized staff to take and relay messages. They get back to you when they say they will, and work well with other members of your team. If your attorney, financial professional, and accountant have worked together in the past, you're in luck. So once you've picked one of these experts for your special needs team, consider asking that individual for recommendations to fill the other positions. If they've worked well together in the past, they will very likely work well together as your team.

- **Resourcefulness.** Everyone's situation is unique, and the special needs attorney needs to be able to respond to your particular set of circumstances. When money is short, when the future is unclear, when medical crises arise, or when other less-than-ideal circumstances present themselves, you'll want an expert with creativity and imagination to manage your long-term special needs strategy.

The goal of the special needs team is to ensure the best possible quality of life for the individual with Down syndrome while safeguarding the assets of the family. When your team is headed up by a special needs attorney possessing these qualities, you're well on your way to reaching that goal.

Legal Documents Checklist

1. IMPORTANT PAPERS

☐ Life insurance policies for parents and sibling with DS
☐ Health insurance policies & ID cards for parents and sibling with DS
☐ Real estate holdings/deeds
☐ Power of Attorney (parents)
☐ Social Security cards and benefits records
☐ Birth certificates for parents and sibling with DS

2. GUARDIANSHIP

☐ Guardianship papers
☐ Power of Attorney - financial (sibling)
☐ Power of Attorney - medical (sibling)
☐ Letter of Intent (from parents)
☐ Advance Directives (sibling)

3. FINANCIAL

☐ Special needs trust/Attorney contact information
☐ Bank records/Personal banker contact
☐ Federal, State & Local Tax Returns/Accountant & financial planner contact information
☐ Car insurance/title

4. SIBLING'S DOCUMENTS

☐ Medicaid, Medicare and other Health insurance cards, plus waiver information if any
☐ Bank account information
☐ Copy of last Individual Service Plan (ISP)
☐ Copy of medical records and psychological evaluation

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FINANCIAL SAVINGS

People with Down syndrome (and all disabilities) often incur extra expenses such as frequent doctors visits and medications, special dietary needs, adaptive equipment, paid support at their job and extracurricular activities, transportation, and more. Hopefully your parents have already engaged a special needs attorney and/or financial planner and have developed a savings plan to help pay for these additional expenses. If not, we encourage you to hire one as soon as possible. These are complicated issues and the consequences of setting up a financial plan in the wrong way can be detrimental to your sibling's future.

A Note about Balancing Financial Savings with Asset and Income Limits

For most people with Down syndrome, government assistance programs such as Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) will be needed throughout their lives. These programs are designed for, respectively, low-income people and people who are unable to work. When saving money for your loved one with a disability, you need to take care not to disqualify them from government benefits by putting too much money in their name or by them earning too much income.

What qualifies as "too much"? For SSI, the asset limit is currently $2000 while the income limit varies based on where the recipient lives (but is generally tied to the federal benefit rate, which is $794/month for an individual). SSDI does not have an asset limit but the income limitation in 2021 is $1,310/month for an individual. Saving money for your sibling with Down syndrome needs to be done very carefully and according to the rules of government assistance programs or they may become ineligible for these benefits.

WHAT ARE THE OPTIONS FOR FINANCIAL SAVINGS TO HELP YOUR SIBLING?

Regular Savings and Investments: For some families, they are able to help meet current costs of supporting the needs of a loved one with Down syndrome by setting aside a set amount of money per month to meet costs as well as increasing savings through a Special Needs Trust (described below), ABLE Account (described below) and/or other financial instruments. However, most families rely upon government supports to supplement these savings.

Government Support: The primary support (beyond family) to help a person with a disability comes from government entities, particularly the Social Security Administration.

- **Supplemental Security Income (SSI)** is the most used support for disabled adults, provided they are able to qualify for the support. Among other rules such as income limitations, the individual applying must not have more than $2000 in assets (which includes savings in that person's name, a car, etc). After age 18, the government does not include any of the family income in determining their assets but they may count certain types of support (such as if you allow your sibling to live with you rent free). SSI currently provides an individual with $771/month (some states have a higher payment) as well as Medicaid.

- **Social Security Disability Insurance (SSDI)** is a payroll tax-funded federal insurance program designed to provide monthly benefits to people who have a medically-determinable disability that restricts their ability to be employed. SSDI benefits can be based on the disabled person's own work history or the work history of their parents. Like with SSI, there are very detailed rules for initial and continuing eligibility for this benefits program. Please check with your local Social Security office on SSDI eligibility and amounts paid. For SSI, you should also contact your local Social Security Office and/or state or county agency that can be identified by calling your county or state office providing community services.

- **Other Government Supports:** There are many other federal, state and local government assistance programs that can help people with disabilities with daily life. These programs include housing assistance, job training, health care, nutrition/food stamps and more.

ABLE Account: An Achieving a Better Life Experience (ABLE) Account is a tax-advantaged savings account for individuals with disabilities and their families. The beneficiary of the ABLE Account will not be taxed on income earned from the account. Contributions to an ABLE Account can be made by any person or Trust and such contributions must be made via post tax dollars. Some states are even allowing tax deductions for contributions made to an ABLE Account. Most importantly, assets in ABLE accounts do not count toward the SSI asset limit up to $100,000 (once assets in the ABLE account exceed $100,000, SSI payments may be suspended but Medicaid will still not be impacted). ABLE account funds also do not count as "assets" for most other federal, state and local government assistance programs such as food stamps, housing vouchers and Medicaid. Funds in the ABLE account can be used for any "qualified disability expense", which is defined very broadly to include things such as housing, food, health care expenses, employment training, transportation, support services, and more.

There are limits on how much money can be put in an ABLE Account per year, and each disabled individual can only have one ABLE account total. Under current law, the maximum amount allowed per year is $16,000 (please note that if the individual is employed, they may be able to contribute more per year) There are maximum amounts that can be in an ABLE Account over time and those amounts are determined by your state of residency. Please note that if your sibling is on SSI, once the ABLE Account exceeds $100,000, SSI cash payments will likely be suspended. Note that employment income can also be put into an ABLE account but the SSI and SSDI income limitations will still apply (ABLE accounts help with government benefits' asset limitations but not the income limitations).

ABLE accounts are very easy to set up and, in most cases, you do not need a lawyer or financial planner to do this for you. Since each person can only open one single ABLE account, you will need to decide which state's ABLE program is right for your family (most ABLE programs are open nationwide and not limited to the residents of their state). For more information, please see the ABLE National Resource Center at www.ablenrc.org

Special Needs Trusts: A Special Needs Trust (sometimes referred to as a supplemental needs trust) is a trust that allows your sibling to benefit from funds in the trust without loss of SSI and/or other government supported services or benefits your sibling is receiving. A Special Needs Trust is an irrevocable trust and is run by a trustee who has a legal obligation to safeguard the funds. There are two types of Special Needs Trusts (SNTs) – first-party SNTs and third-party SNTs. A first-party SNT is when the beneficiary (person with a disability) funds the trust himself. In a third-party SNT, someone else (like the parents) has established and funded the trust, which is often triggered upon their death (and transfer of assets). A third-party Special Needs Trust is a viable option for parents to leave money to their disabled son or daughter so that government supports will not be jeopardized.

Special Needs Trusts are not mutually exclusive from ABLE accounts, and many people may utilize both savings mechanisms. They vary greatly in terms of who manages them, contribution limits, how the funds may be used, setup costs, whether the income is taxable, and whether the beneficiary may need to "pay back" the state Medicaid program at some point. These issues should be discussed with a special needs attorney when developing a financial savings plan.

Wills: Hopefully your parents have a will and, if not, please encourage them to get one as soon as possible. As you transition to the primary caretaker role, it is important that you also have a will. Your will, like your parents, will need to be written in a way that designates funds for your sibling to go directly to a Special Needs Trust or ABLE Account so you don't jeopardize their eligibility for government supports.

Additional Resources:

- Information clearinghouse on all ABLE programs and the details about ABLE accounts in general: ABLE National Resource Center: www.ablenrc.org
- Federal government website that lists different types of benefits available for people with disabilities and caregivers: https://www.usa.gov/disability-services
- Check with your state's Developmental Disabilities agency to see what government benefits might be available: https://www.nasddds.org/state-agencies/

PUBLIC BENEFITS

Having a disability brings with it many extra expenses, and most people with disabilities rely upon some type of government assistance. These benefits, such as cash assistance, health coverage, and community living supports, are vital to promoting independence and quality of life. There are many different types of public benefits available at the federal, state, and local levels. Most of them are "means-tested" programs, which means that they are designed for low-income individuals and eligibility could be jeopardized if the disabled person earns too much money or saves too many assets in accounts other than an ABLE account or a special needs trust. All government programs have specific rules to maintain benefits such as reporting income or filing reports.

It can be very time-consuming and frustrating keeping up with all of the paperwork and following all of the rules of each program. Your parents have likely been doing this for a long time – please have them explain to you how it all works to get your sibling the public assistance they need and keep their eligibility intact.

Government benefits may be available in the following areas:

HEALTH COVERAGE

- **Medicaid -** Medicaid is health coverage offered to low-income, disabled, and elderly people which is funded by the federal government in partnership with the states and is administered by the states. Its official name varies by state – some examples are KanCare, Medi-Cal, MassHealth, DenaliCare, Diamond State Health, HealthChoice, HoosierHealth, Passport Health Plan, Healthy Connections and more. The pathway to Medicaid eligibility is through Supplemental Security Income (SSI) (discussed below). Medicaid provides health coverage to children and adults, as well as long term services and supports (LTSS) through the state's Medicaid "waiver" program. There are no waitlists for Medicaid health coverage, but there may be long waitlists for LTSS.

- **Medicare -** Medicare is health insurance for people age 65 and older and younger people receiving Social Security disability benefits. Medicare health plans are administered by private companies that have contracted with the government to provide certain health benefits. Each state offers many different Medicare plans with varying benefits and costs. A person can become eligible for Medicare after being on SSDI for two years. Some people are dually eligible for both Medicare and Medicaid.

- **Affordable Care Act Marketplace -** Health insurance marketplaces (also called health exchanges) are organizations in each state through which people can purchase subsidized health insurance that complies with the Affordable Care Act (also called Obamacare). These state-based exchanges vary in name, such as Get Covered NJ, Maryland Health Connection, and Washington Healthplanfinder. See www.healthcare.gov for more information].

BENEFITS THROUGH SOCIAL SECURITY ADMINISTRATION

- **Supplemental Security Income (SSI) -** SSI is a means-tested government program that provides monthly checks to disabled children, adults and individuals aged 65 and older to meet their basic needs such as food, clothing, and shelter. See Supplemental Security Income (ssa.gov) for more information.

- **Social Security Disability Insurance (SSDI) -** SSDI is a payroll-funded federal insurance program managed by the Social Security Administration that provides monthly benefits to people who have a medically determinable disability that restricts their ability to be employed. Some people with Down syndrome may be eligible for benefits from their own employment history, while others may be eligible for benefits based on the work experience of a parent (known as Disabled Adult Child benefits). See Disability Benefits | SSA for more information]

People sometimes confuse SSI and SSDI because both programs are run by the Social Security Administration (SSA). Adding to the confusion, there are some people who are eligible for and receive checks from both SSI and SSDI. However, these programs are very different, and the pathways to obtain their benefits differ. Here is a chart explaining the differences:

San Francisco Region IX
AIAN
Nov 2009

Fact Sheet

Social Security and Supplemental Security Income (SSI): What's the difference?

* * *

There is often confusion about Social Security and Supplemental Security Income (SSI) because you apply for both programs with the Social Security Administration. **But, the programs are different.** The Social Security benefit programs are "entitlement" programs. This means that workers, employers and the self-employed pay for the benefits with their Social Security taxes. The taxes that are collected are put into special trust funds. You qualify for these benefits based on your work history (or your spouse or parent). The amount of the benefit is based on these earnings.

SSI is a needs-based program for people with limited income and resources. Resources are assets or things that you own. The program is paid for by general tax revenues -- not from the Social Security trust funds. The benefit amount is based on Federal and State laws which take into account where you live, who lives with you and what income you receive.

Look at the chart below to help you understand the difference between the two programs.

Social Security	SSI
• **Benefits based on earnings**	• **Benefits based on need**
• **Financed by employer and wage contributions**	• **Financed by General Revenues**
• **No income limit**	• **Limited income**
• **No resource limit**	• **Limited resources**
• **Must have enough work credits**	• **No work credits are required**
• **Medicare**	• **Medicaid (Medi-Cal in California)**
• **Benefit Types:** - **Retirement (age 62 & older)** - **Survivor** - **Disability (includes blindness)**	• **Benefit Types:** - **Aged (age 65 and older)** - **Disability (any age, includes children)** - **Blindness (any age, includes children)**
• **Provides benefits to eligible family members**	• **No family benefits**
• **Benefit amount based on average lifetime earnings**	• **Benefit amount based on Federal and State laws**
• **Other income does NOT affect benefits** *(Except wages may affect benefits under full retirement age or disability benefits)*	• **Other income MAY affect benefits – report any income you receive**
• **Where you live or who lives with you does NOT affect benefits**	• **Where you live or who lives with you MAY affect benefits – report all changes**

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Checklist for Online Adult Disability Application

The information below will help you gather the information you may need to create a *my* Social Security account and complete the online Disability application. We recommend you print this page to use while gathering your information.

Create a *my* Social Security Account

You are required to login to your existing *my* Social Security account, or attempt to create one. To create an account, we will ask you a series of identity questions for verification. You may want to have certain items on hand to be prepared for additional security questions, such as, but not limited to: **mobile phone (for the purpose of receiving texts and emails), credit card, W-2, and tax forms.**

File for Benefits Online – The Information You Need

Date and Place of Birth — If you were born outside the United States or its territories:

- Name of your birth country at the time of your birth (it may have a different name now)
- Permanent Resident Card number (if you are not a U.S. citizen)

Marriage and Divorce

- Name of current spouse, name of prior spouse (if the marriage lasted more than 10 years or ended in death)
- Spouse(s) date of birth and Social Security number (optional)
- Beginning and ending dates of marriage(s), place of marriage(s) (city, state or country, if married outside the U.S.)

Names and Dates of Birth of Children Who:

- Became disabled prior to age 22, or
- Are under age 18 and are unmarried, or
- Are aged 18 to 19 and still attending secondary school full time

U.S. Military Service

- Type of duty and branch, service period dates

Employer Details for Current Year and Prior 2 Years (not self-employment)

- View your *Social Security Statement* online at ***www.ssa.gov/myaccount***
- Employer name, employment start and end dates, total earnings (wages, tips, etc.)

Self-Employment Details for Current Year and Prior 2 Years

- View your *Social Security Statement* online at ***www.ssa.gov/myaccount***
- Business type and total net income

Direct Deposit — Domestic bank (USA)

- Account type and number
- Bank routing number

Direct Deposit — International bank (non-USA)

- International Direct Deposit (IDD) bank country
- Bank name, bank code, and currency
- Account type and number, branch/transit number

Alternate Contact

- Name, address, and phone number of someone we can contact who knows about your medical condition(s) and can help you with your claim

List of your Medical Conditions

Information About Doctors, Healthcare Professionals, Hospitals, and Clinics

- Names, addresses, phone numbers, patient ID numbers, and dates of examinations and treatments
- Names and dates of medical tests you have had and who sent you for them
- Names of medications (prescriptions and non-prescriptions), reason for medication, and who prescribed them

Information About Other Medical Records

- Vocational rehabilitation services, workers compensation, public welfare, prison/jail, an attorney, or another place

Job History

- Date your medical condition began to affect your ability to work
- Type of jobs (up to 5) that you had in the 15 years before you became unable to work because of your condition
- Type of duties you did on the longest job you had

Education and Training

- Highest grade in school completed (date), and any special education (school name, city, and state)
- Name of special job training, trade school, or vocational school and date completed

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HOUSING BENEFITS

Some people with disabilities and their families may live in a public, low-income housing project or obtain a reduced rent with designated rental properties. There are housing benefits available at the federal, state, and local level such as public housing **programs, rental assistance, or subsidized housing through your local public housing authority. Your local Public Housing Authority should have information about all of these potential benefits.** Find your local Public Housing Authority here: PHA Contact Information - HUD | HUD.gov / U.S. Department of Housing and Urban Development (HUD)]]

Some people with disabilities obtain a Housing Choice (Section 8) voucher to pay for all or part of the rent through the U.S. Department of Housing & Urban Development's Section 8 Housing Choice Voucher Program. For more information, see Housing Choice Voucher Program Section 8 | HUD.gov / U.S. Department of Housing and Urban Development (HUD)]

EMPLOYMENT BENEFITS

Many states offer job coaching and other training for employment and independent community living through their various Medicaid waiver programs to fund Long Term Services & Supports. These waivers have different names in each state and often have long wait lists for services. There are also vocational rehabilitation benefits through the state Vocational Rehabilitation Agency. Find your state VR program here: State Vocational Rehabilitation Services Program | Rehabilitation Services Administration (ed.gov)]

The Social Security Administration has created some SSI-based employment benefit programs such as Ticket to Work and Plan to Achieve Self-Support (PASS). Find more information at Choose Work! - Ticket to Work - Social Security (ssa.gov).

Finally, anyone who has worked for a certain amount of time may be eligible for unemployment benefits through the U.S. Department of Labor or the state unemployment office.

FOOD ASSISTANCE

Many people with disabilities and their families live at or below the poverty line. The Supplemental Nutrition Assistance Program (SNAP), formerly Food Stamp Program, is a federal program that provides food-purchasing assistance for low and no-income people. For more information, see Supplemental Nutrition Assistance Program (SNAP) | Food and

Nutrition Service (usda.gov)] There may be other meal programs available through state and local authorities such as free or reduced lunch and meals on wheels.

<u>OTHER BENEFITS AVAILABLE</u>

Other public benefits may be available such as:

- Temporary Assistance for Needy Families (TANF) (Welfare), which provides temporary cash assistance to low income families.
- Education assistance through Head Start and Federal Pell Grant programs
- Transportation assistance through Medicaid Waiver Funds or other local or state-based subsidies for transportation
- Respite care programs for caregivers
- Tribal and Veterans' benefits

Government Benefits

Type of Benefit	Agency Providing the Benefit	Contact Information for Agency	Do Benefits Expire (Y/N)	Other Notes

Organization Acronyms

AAIDD – American Association on Intellectual and Developmental Disabilities - *promotes progressive policies, sound research, effective practices, and universal human rights for people with intellectual and developmental disabilities.* – www.aaidd.org

ACL - Administration for Community Living - *created around the fundamental principle that older adults and people of all ages with disabilities should be able to live where they choose, with the people they choose, and with the ability to participate fully in their communities.* - www.acl.gov

APSE - Association of People Supporting EmploymentFirst - *the only national membership organization focused exclusively on Employment First to facilitate the full inclusion of people with disabilities in the workplace and community.* - www.apse.org

The Arc - (formerly Association for Retarded Citizens) - *promotes and protects the human rights of people with intellectual and developmental disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes. Their website offers resources for health, financial planning, residential options and more.* - www.thearc.org

AUCD - Association of University Centers on Disabilities - *a network of interdisciplinary centers advancing policy and practice for and with individuals with developmental and other disabilities, their families, and communities.* – www.aucd.org

CDC – Centers for Disease Control - *the nation's leading science-based, data-driven, service organization that protects the public's health.* – www.cdc.gov

DD Council - Developmental Disabilities Council (each state has one) - *develops and sustains inclusive communities and self-directed services and support for individuals with developmental disabilities.* (to search for your state office) – www.nacdd.org

DSAIA – Down Syndrome Affiliates in Action – *trade organization that supports and advances the growth and capacity of local and regional Down syndrome associations.* – www.dsaia.org

DSDN – Down Syndrome Diagnosis Network - *supports new and expectant parents with a Down syndrome diagnosis, and the medical professionals who serve them - from the time of diagnosis through age 3 while fostering the opportunity for lifelong connections.* – www.dsdiagnosisnetwork.org

EEOC - Equal Employment Opportunity Commission - *responsible for enforcing federal laws that make it illegal to discriminate against a job applicant or an employee because of the person's race, color, religion, sex (including pregnancy), national origin, age (40 or older), disability or genetic information. It is also illegal to discriminate against a person because the person complained about discrimination, filed a charge of discrimination, or participated in an employment discrimination investigation or lawsuit.* - www.eeoc.gov

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Organization Acronyms

GIGI'S – GiGi's Playhouse - *network of Down Syndrome Achievement Centers, providing free, therapeutic, educational, and career training programs for individuals of all ages.* – www.gigisplayhouse.org

GLOBAL – Global Down Syndrome Foundation -*dedicated to significantly improving the lives of people with Down syndrome through Research, Medical Care, Education and Advocacy.* – www.globaldownsyndrome.org

IMDSA – International Mosaic Down Syndrome Association - *supports any family or individual whose life has been affected by Mosaic Down syndrome by continuously pursuing research opportunities and increasing awareness in the medical, educational and public communities throughout the world* - www.imdsa.org

NDRN – National Disability Rights Network - *the nonprofit membership organization for the federally mandated Protection and Advocacy (P&A) Systems and Client Assistance Programs (CAP). Collectively, the P&A/CAP network is the largest provider of legally based advocacy services to people with disabilities in the United States.* – www.ndrn.org

NDSC - National Down Syndrome Congress - *provides accurate and up-to-date information, advocacy and support, concerning all aspects of life for individuals with Down syndrome, their families, and the professionals who serve them.* **– www.ndsccenter.org**

NDSS - National Down Syndrome Society - *advocates for the value, acceptance and inclusion of people with Down syndrome.* - www.ndss.org

NIH – National Institute of Health - *the largest source of funding for medical research in the world. NIH is made up of 27 centers and institutes, including the NICHD which conducts and supports laboratory research, clinical trials, and epidemiological studies that explore health processes; examines the impact of disabilities, diseases, and variations on the lives of individuals; and sponsors training programs for scientists, health care providers, and researchers.* - www.nih.gov

ODEP – Office of Disability Employment Policy - *develops and influences policies and practices that increase the number and quality of employment opportunities for people with disabilities.* - www.dol.gov/odep

SLN – Sibling Leadership Network - *provides siblings of individuals with disabilities the information, support, and tools to advocate with their brothers and sisters and to promote the issues important to them and their entire families.* – www.siblingleadership.org

SSA - Social Security Administration – *pays disability benefits under two programs, SSI and SSDI* – www.ssa.gov

TASH - *an international advocacy association of people with disabilities, their family members, other advocates, and people who work in the disability field.* – www.tash.org

Organization Acronyms

USAging – (formerly AAA - Area Agency on Aging) – *the national association representing and supporting the network of Area Agencies on Aging and advocating for the Title VI Native American Aging Programs. Our members help older adults and people with disabilities throughout the United States live with optimal health, well-being, independence and dignity in their homes and communities.* www.usaging.org

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Common Disability Acronyms

ABLE act - Achieving a Better Life Experience

AD - Alzheimer's Disease

ADA - Americans with Disabilities Act

ASD – Autism Spectrum Disorder

AT - Assistive Technology

BD - Behavior Disorder

CBI - Community Based Instruction

CM - Case Manager

DD - Developmental Disabilities

DME - Durable Medical Equipment

DS - Down syndrome

DS-ASD – Co-occurring Down syndrome and Autism Spectrum Disorder

FERPA - Family Education Rights and Privacy Act of 1974

HCBS – Home and Community Based Services

HHA - Home Health Agency

HSA - Home Service Agency

I/DD – Intellectual/Developmental Disabilities

ICF - Intermediate Care Facility

IDEA - Individuals with Disabilities Education Act

IFSP - Individualized Family Service Plan

IHP - Individual Habilitation Plan

IL - Independent Living

ILC - Independent Living Center

ILP - Integrated Living Plan

IRWE - Impairment-Related Work Expenses

ISP - Individual Service Plan

LOC - Level of Care

OT - Occupational Therapy/Therapist

PT - Physical Therapy/Therapist

PWD/PWDs - People with Disabilities

RT - Recreation Therapist

Sib – Sibling

SILP - Semi-Independent Living Program

SLP - Speech Language Pathologist

SLT - Speech Language Therapist

SMI - Supplementary Medical Insurance

SNT – Special Needs Trust

SSDI - Social Security Disability Insurance

SSI - Supplemental Security Income

TANF - Temporary Assistance to Needy Families

VR - Vocational Rehabilitation

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GLOBAL MEDICAL CARE GUIDELINES

for Adults with Down Syndrome Checklist

GLOBAL
DOWN SYNDROME FOUNDATION®

This checklist is intended to support the health of adults with Down syndrome directly or through their caregivers. We encourage this checklist to be shared with your medical professionals. Statements in blue represent our recommended, periodic health screenings/assessments that should begin at a specific age. Below each blue screening/assessment recommendation, there are blank boxes. Caregivers or individuals with Down syndrome can check off, date, or initial each blank box when the screening/assessment is completed. For screening/assessment recommendations with a time range (e.g. 1-2 years), the box size represents the longer possible time frame, such as 2 years versus 1. Statements in gray represent advisory recommendations that individuals with Down syndrome and caregivers should follow throughout adulthood.

🟦 Screening/Assessment
⬛ Advisory
☐ Checkbox
▨ No Recommendations

<table>
<tr><th></th><th>21-29 Years</th><th>30-39 Years</th><th>40-49 Years</th><th>50-59 Years</th><th>60+ Years</th></tr>
<tr><td rowspan="4">Behavior</td><td colspan="5">A review of behavioral, functional, adaptive, and psychosocial factors should be performed as part of an annual history that clinicians obtain from all adults with Down syndrome, their families, and caregivers. <i>(Boxes below represent 1 year increments)</i></td></tr>
<tr><td>☐☐☐☐☐☐☐☐☐</td><td>☐☐☐☐☐☐☐☐☐☐</td><td>☐☐☐☐☐☐☐☐☐☐</td><td>☐☐☐☐☐☐☐☐☐☐</td><td>☐☐☐☐☐☐☐☐☐☐</td></tr>
<tr><td colspan="5">When concern for a mental health disorder in adults with Down syndrome is present medical professionals should: a) Evaluate for medical conditions that may present with psychiatric and behavioral symptoms and b) Refer to a clinician knowledgeable about the medical, mental health disorders, and common behavioral characteristics of adults with Down syndrome.</td></tr>
<tr><td colspan="5">When concern for a mental health disorder in adults with Down syndrome is present, medical professionals should follow guidelines for diagnosis in the Diagnostic and Statistical Manual of Mental Disorders (DSM 5). The Diagnostic Manual-Intellectual Disability 2 (DM-ID-2) also may be used to adapt diagnostic criteria from the DSM-5.</td></tr>
<tr><td rowspan="2">Dementia</td><td colspan="2" rowspan="2">Caution is needed when diagnosing age-related, Alzheimer's Type Dementia in adults with Down syndrome less than age 40.</td><td colspan="3">Medical professionals should assess adults with Down syndrome and interview their primary caregivers about changes from baseline function annually beginning at age 40. Decline in the six domains as per the National Task Group – Early Detection Screen for Dementia (NTG-EDSD) should be used to identify early-stage age-related Alzheimer’s-type dementia and/or a potentially reversible medical condition. <i>(Boxes below represent 1 year increments)</i></td></tr>
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<tr><td rowspan="4">Diabetes</td><td rowspan="2">▨</td><td colspan="4">For asymptomatic adults with Down syndrome, screening for type 2 diabetes using HbA1c or fasting plasma glucose should be performed every 3 years beginning at age 30. <i>(Boxes below represent 3 year increments)</i></td></tr>
<tr><td>☐☐☐</td><td>☐☐☐</td><td>☐☐☐</td><td>☐☐☐</td></tr>
<tr><td colspan="5">For any adult with Down syndrome and comorbid obesity, screening for type 2 diabetes using HbA1c or fasting plasma glucose should be performed every 2-3 years beginning at age 21. <i>(Boxes below represent 3 year increments)</i></td></tr>
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<tr><td rowspan="4">Cardiac</td><td colspan="2" rowspan="2">▨</td><td colspan="3">For adults with Down syndrome without a history of atherosclerotic cardiovascular disease, the appropriateness of statin therapy should be assessed every 5 years starting at age 40 and using a 10-year risk calculator as recommended for adults without Down syndrome by the U.S. Preventive Services Task Force. <i>(Boxes below represent 5 year increments)</i></td></tr>
<tr><td>☐☐</td><td>☐☐</td><td>☐☐</td></tr>
<tr><td colspan="5">For adults with Down syndrome, risk factors for stroke should be managed as specified by the American Heart Association/American Stroke Association’s Guidelines for the Primary Prevention of Stroke.</td></tr>
<tr><td colspan="5">In adults with Down syndrome with a history of congenital heart disease, given the elevated risk of cardioembolic stroke, a periodic cardiac evaluation and a corresponding monitoring plan should be reviewed by a cardiologist.</td></tr>
<tr><td rowspan="3">Obesity</td><td colspan="5">Healthy diet, regular exercise, and calorie management should be followed by all adults with Down syndrome as part of a comprehensive approach to weight management, appetite control, and enhancement of quality of life .</td></tr>
<tr><td colspan="5">Monitoring for weight change and obesity should be performed annually by calculating Body Mass Index in adults with Down syndrome. The U.S. Preventive Services Task Force Behavioral Weight Loss Interventions to Prevent Obesity-Related Morbidity and Mortality in Adults should be followed. <i>(Boxes below represent 1 year increments)</i></td></tr>
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<tr><td rowspan="3">Atlantoaxial Instability</td><td colspan="5">In adults with Down syndrome, routine cervical spine x-rays should not be used to screen for risk of spinal cord injury in asymptomatic individuals.</td></tr>
<tr><td colspan="5">Annual screening for adults with Down syndrome should be based on a review of signs and symptoms of cervical myelopathy using targeted history and physical exam. <i>(Boxes below represent 1 year increments)</i></td></tr>
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<tr><td rowspan="2">Osteoporosis</td><td colspan="5">For primary prevention of osteoporotic fractures in adults with Down syndrome, there is insufficient evidence to recommend for or against applying established osteoporosis screening guidelines, including fracture risk estimation; thus, good clinical practice would support a shared decision-making approach to this issue would support a shared decision-making approach to this issue.</td></tr>
<tr><td colspan="5">All adults with Down syndrome who sustain a fragility fracture should be evaluated for secondary causes of osteoporosis, including screening for hyperthyroidism, celiac disease, vitamin D deficiency, hyperparathyroidism and medications associated with adverse effects on bone health.</td></tr>
<tr><td rowspan="2">Thyroid</td><td colspan="5">Screening adults with Down syndrome for hypothyroidism should be performed every 1-2 years using a serum thyroid-stimulating hormone (TSH) test beginning at age 21. <i>(Boxes below represent 2 year increments)</i></td></tr>
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<tr><td rowspan="2">Celiac Disease</td><td colspan="5">Adults with Down syndrome should receive an annual assessment for gastrointestinal and non-gastrointestinal signs and symptoms of celiac disease using targeted history, physical examination and clinical judgement of good practice. <i>(Boxes below represent 1 year increments)</i></td></tr>
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This checklist is not intended to be diagnostic. Presentation of medical and mental health conditions for people with Down syndrome may be atypical. Similar signs and symptoms may be a consequence of multiple reasons, including different disease processes. Thus, the patient evaluation should include considerations of additional causes for any detected sign or symptom. The development of new and/or changes in signs or symptoms should prompt a comprehensive evaluation with your clinician.

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We would especially like to acknowledge Dr. George Capone, who provided guidance and direction in creating this toolkit; Dr. Brian Chicoine and Dr. Dennis McGuire, whose work and writings provided a significant source of information and understanding of the issues facing families of adults with Down syndrome; and Dr. Kishore Vellody, who not only serves on NDSC's Board of Directors, but is a sibling himself, and has supported the development of this toolkit wholeheartedly.

We are grateful for the generous contributions from GLOBAL Down Syndrome Foundation to support NDSC's adult sibling resources and provide their Adult Medical Care Guidelines.

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