



CENTRAL MISSISSIPPI DOWN SYNDROME SOCIETY

Transitioning to Adulthood Guide



Central MS Down Syndrome Society's Transitioning to Adulthood Guide

Welcome to the Central MS Down Syndrome Society's Transitioning to Adulthood Guide. If you are reading this Guide, you may have a young child with Down syndrome for whom you are making future plans. You may also have a child preparing to phase out of the school system and enter the world of adulthood! Whatever age your child is, as they grow and reach towards adulthood, parents and guardians must consider what will happen once their loved one with Down syndrome phases out of the school system.

Planning for life after high school can be challenging. Often times, during these younger years, the educational system is responsible for the majority of the services your child receives. As your young adult transitions out of the school system, you may be working with a variety of agencies and services. You will be moving from services your child has been entitled to, to services that require criteria and eligibility. Planning and forethought are crucial during this time.

Transition planning is a different kind of planning with an ultimate goal of moving uninterrupted into adulthood. This may include post-secondary education, employment or community engagement. It is vital that your child participates in the transition planning process. Each transition process is a personal journey and should be based on the individual's strengths and desires.

As teenagers with Down syndrome finish their high school years and enter into adulthood, they face the same questions as other young people. They need to figure out where to live, what to do for work, and how to create new social circles outside of school. It's exciting but stressful for any young adult and can be even harder for someone with Down syndrome. This makes it important to start planning as early as possible.

The Individualized Education Program (IEP) that children with Down syndrome have in public schools includes transition planning. The goal is to picture the future and think about the skills and services teens will need as they become adults. When you work closely with teachers, doctors, and therapists to make a solid plan, it can ease the stress of going out into the world.



How to plan your child's future:

For most of your child's life, you have made decisions on their behalf. You have been their advocate and voice through school, appointments, and therapies. Now that your child has reached middle school or beyond, they may be capable of advocating for themselves. It is important to teach your child to advocate so that as they mature and transition, they can voice their concerns and demonstrate their true abilities.

It is important to keep your child involved in the transition process and included in the decision-making. A starting point would be to have a conversation about what they want their future to look like. Ask them questions like "where do they see themselves in five or ten years?" Teach them to continue to voice those desires.

The transition process can be confusing and generate loads of paperwork. You'll save yourself time and frustration if you create a system for organizing both electronic and paper files. Some caregivers find it helpful to print out all electronic files and create binders or folders. Others prefer to scan all paper files to a computer for safe keeping. Whatever method you decide to use to document, keep it consistent as this will save you time and frustration.

Outline of Topics that are covered in this Guide:

- Legal
- Job assistance
- Housing / assisted living
- Day programs
- Finances and Planning
- Health and Hygiene
- Post-secondary education
- Community engagement: Service/Volunteerism/Leadership/Advocacy
- Healthcare
- Recreation

**If you read no further in this Guide,
please take a moment to review this checklist.**

Each item below is covered more in-depth in this Guide.

Checklist of Suggested Steps:

- Contact Hudspeth and ask for an evaluation for the ID/DD Waiver and the 1915i community support program
- Apply for SSI at age 18 (*if your child was previously ineligible due to financial assets)
- Contact Medicaid *If you are determined eligible for SSI, you will automatically be eligible for Medicaid
- Males – Register for Selective Service at age 18



TRANSITION SKILLS CHECKLIST

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VOCATIONAL SKILLS

Can your child:

- Get to and from work, on time
- Perform work satisfactorily
- Work cooperatively with others
- Take break or lunch appropriately
- Wear suitable clothing
- Use appropriate safety procedures
- Follow directions
- Accept supervision
- Community Skills

Can your child:

- Use public transportation
- Shop for groceries, clothing
- Make necessary appointments
- Use a phone
- Use bank accounts
- Be safe in traffic, among strangers
- Know how to seek help
- Handle money
- Use an ATM
- Use vending machines (laundry machines, fare cards, and so on)

DOMESTIC SKILLS

Can your child:

- Plan menus
- Make shopping list from menus
- Prepare breakfast, lunch, supper, snack, or pack a lunch
- Wash dishes, pots, and pans
- Clean up apartment (bathroom, living areas, kitchen, and so on)
- Clean own room
- Do laundry: use washer, dryer, and iron

SOCIAL & PERSONAL SKILLS

Can your child:

- Supply appropriate personal identification
- Greet people appropriately
- Use contemporary style of dress, hair, make-up
- Use good grooming, hygiene skills consistently
- "Talk" with friends and coworkers
- Be courteous
- Be responsible
- Be happy

RECREATION & LEISURE SKILLS

Can your child:

- Use free time for pleasure
- Choose reasonable activities
- Pick a hobby
- Perform required activities
- Use community resources
- Call friends to make plans with them

OTHER USEFUL SKILLS

Can your child:

- Use a cell phone
- Use a datebook
- Take prescriptions as directed
- Use over-the-counter medications appropriately
- Use sunscreen when needed
- Use insect repellent when needed

SAMPLE IEP TRANSITION GOALS

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Long-term postsecondary education goal: *The student will enroll in a teaching assistant certification program at community college.*

Possible short-term objectives:

Person/Agency Responsible

Visit or contact local colleges to learn about course/program offerings

Research entrance requirements and pre-requisites

Ensure student is enrolled in courses that will prepare him/her for college requirements

Long-term postsecondary education goal:

After graduation, student will have paid employment, but is not yet sure what kind of work he or she would like to do.

Possible short-term objectives Person/Agency Responsible

Enroll student in a career investigation course.

Locate volunteer opportunities in one or more area(s) of interest.

Or, find part-time employment that will give student a chance to develop general job skills Teacher-advisor, guidance department and student

Long-term housing goal:

Student wants to eventually live on his or her own and share an apartment with a roommate.

Possible short-term objectives Person/Agency Responsible

Enroll student in course that will help him or her develop independent-living skills. Student will take on new responsibilities/chores at home.

Things to keep in mind:

- Transition plan goals for postsecondary education, employment and housing often overlap.
- Short-term objectives can be general or very specific. However, it is important to set measurable goals.
- The IEP must include a target date for each short-term objective.

It is very important to make sure that all related factors be considered in planning for a goal. For example, a goal of working part-time must address the question of how the student will get to and from work. Similarly, a student's goal to live on his or her own must address how expenses such as rent, utility bills and groceries will be paid for.

KNOW YOUR RIGHTS:

Having a basic understanding of the laws that grant rights to individuals with different needs is helpful when seeking assistance and services. These laws include rights to a free and appropriate education and lack of discrimination in the workplace. Four laws that are critical to transition planning are:

1. Section 504 of the Rehabilitation Act of 1973
2. The Americans with Disabilities Act of 1990
3. The Individuals with Disabilities Education Improvement Act of 2004
4. The Carl D. Perkins Vocational and Technical Education Act of 2006



KNOW YOUR WAIVERS AND STATE PLANS:

Intellectual or Developmental Disabilities (IDD) Community Support Program (1915i)

Eligibility:

The first step is undergoing an evaluation at your local Regional IDD Program. If you are determined eligible, you will be assigned a Targeted Case Manager to assist you with access to available services.

To be eligible, you must:

- Be 18 years of age or older
- Have full Medicaid benefits
- Have completed education
- Meet eligibility requirements (determined using a need-based criterion)

Services available:

- Day Services Adult – Assists individuals in gaining the greatest level of independence, while supporting them in meaningful activities of their choice throughout the day.
- Prevocational Services – Teaches pre-employment skills and assists in exploring job opportunities in the community.
- Supported Employment – Provides a job coach to assist in finding a job and training to work independently.
- Supported Living – Provides persons who can live independently in their own home or apartment with limited support (max of 4 hours per day) to access their community, pay bills, shop for groceries, access medical care, and other personal assistance, as needed.

In Mississippi the waiting list is around 12 years. Apply while your child is young in preparation for the services you will eventually use.

Intellectual Disabilities/Developmental Disabilities (ID/DD) Home & Community Based Waiver Program

Provides individualized support (ISS) to people in living successfully at home and in the community.

ELIGIBILITY:

There are no age restrictions. You must require the same level of care as someone applying for admission to an intermediate care facility for those with an intellectual/developmental disability.

What services are provided:

Adult Day Services focus on enabling you to attain or maintain your maximum functional level. Services are provided in a non-residential setting and transportation is provided.

Prevocational services are designed to prepare you for paid employment.

Residential Habilitation provides individually tailored supports which assist you in the acquisition, retention and/or improvement in skills related to living in the community.

Job Discovery is a time limited service used to develop a participant's person-centered career profile and employment goals or career plan.

Support Coordination Services consists of working with you to: establish initial and ongoing eligibility for the ID/DD Waiver, develop an individualized plan of care, monitor the services provided to ensure your health and welfare needs are being met, and coordinate all services you receive whether they are provided through the ID/DD Waiver or another source.

Supported Employment are services that provide you with an ongoing support enabling you an opportunity to obtain and maintain competitive employment.

Crisis Intervention is an immediate therapeutic intervention service available twenty-four hours per day that is designed to stabilize you in crisis, prevent further deterioration, and restore you to the level of functioning before the crisis.

Crisis Support is a time limited service that is provided in an (ICF/IID) when a participant's behavior, or family/primary caregiver notification regarding behavior, warrants a need for immediate specialized services that exceeds the capacity of Crisis or Behavior Support Services.

Host Homes are personal care and supportive services through a family living arrangement in which the principal caregiver in the Host Home assumes the direct responsibility for the participant's physical, social and emotional well-being and growth in a family environment.

Supervised Living is designed to assist the participant with acquisition, retention, or improvement in skills related to living in the community.

Supported Living are services designed to assist the participant with acquisition, retention or improvement in skills related to living in the community. Skills include adaptive and developmental.

Transitional Assistance is a one-time set up expense for participants who transition from an institution to a less restrictive community living arrangement.

In Home Nursing Respite is provided for persons who require skilled nursing services, as prescribed by a physician or nurse practitioner, in the absence of the primary caregiver.

Community Respite are services provided in a Department of Mental Health certified community setting.

In Home Respite provides temporary, periodic relief to those persons normally providing care for the eligible person.

Shared Supported Living services are for persons age 18 and older and are provided in compact geographical areas (e.g. an apartment complex) in residences either owned or leased by themselves or a provider. Staff supervision is provided at the program site and in the community but does not include direct staff supervision at all times.

To apply for the ID/DD Waiver, you must first apply at a Department of Mental Health Regional Center.

North Mississippi Regional Center

Phone: 662-513-7728

Boswell Regional Center

Phone: 601-876-5196

Hudspeth Regional Center

Phone: 601-664-6130

South Mississippi Regional Center

Phone 228-867-1321

Ellisville State School

Phone: 601-477-6180

QUESTIONS?

For information about the ID/DD Waiver, contact:

Mississippi Access to Care Center
(MAC Center)
Toll-free: 844-822-4MAC (4622)
Website: mississippiaccesstocare.org

Mississippi Department of Mental Health
Toll-free: 877-210-8513
Local: 601-359-1288
Website: dmh.ms.gov

Mississippi Division of Medicaid
Toll-free: 800-421-2408
Local: 601-359-9545
Website: medicaid.ms.gov



IMPORTANT ITEMS TO CONSIDER:

Social Security Benefits

Supplemental Security Income (SSI) is a need-based federal assistance program that provides income to a person with a disability who has limited assets with which to support themselves.

When your child turns 18, he or she qualifies for Social Security Income (SSI) regardless of parent's income. To receive SSI, individuals need to have fewer than \$2000 in assets, so it is important to establish a special needs trust or an ABLA Account* for any gifts or inheritance.

Someone who receives Supplemental Security Income (SSI) is automatically eligible for Medicaid. SSI makes monthly payments to people who have low income and few resources that are either age 65 or over or blind or disabled. An application for SSI is filed with the Social Security Administration.

Identification Cards

Your child will need a government issued I.D. Be sure to obtain a state I.D. card or driver's license from the Bureau of Motor Vehicles.

Registering to Vote

Every qualified Mississippi elector is entitled to vote regardless of race, creed, color, or disability.

*See Finances and Planning section for more information



ADVOCACY/LEADERSHIP/VOLUNTEERISM

Involvement with meaningful community programs affords young adults with disabilities the opportunities to give back to their communities (volunteerism), provide insight and direction (leadership), and learn to speak up for themselves and others (advocacy). Involvement with programs outside of one's family environment allows for growth in independence which leads to believing in oneself and the ability to succeed.

Resources:

STEP UP Advisory Council is made up of youth and young adults with and without disabilities. Members serve as leaders within their schools, colleges, universities, and communities.

Living Independence for Everyone (Life of Mississippi) provides information and referral, peer support, skills training, community transition, advocacy.
1304 Vine Street, Jackson, MS 39202

Volunteer Mississippi works in tandem with many organizations to systematically address the most crucial needs in the community. It is through strong collaboration that Volunteer Mississippi brings service, leadership and quantifiable results to Mississippi.
3825 Ridgewood Road, Jackson, MS 39211 601.432.6779

AmeriCorps is a national network of hundreds of programs throughout the United States committed to using national service to address critical community needs in education, public safety, health, and the environment.

TRIAD AmeriCorps is part of the University of Southern Mississippi Institute for Disability Studies. The program focuses on providing health-related education to improve the lifestyle changes for youth with disabilities. As an all-inclusive AmeriCorps program, members also receive professional development training covering resume building, interview skills, computer literacy skills, and leadership skills.



EMPLOYMENT

The road to employment often begins in high school. Students with disabilities are able to participate in Pre-ETS (pre-employment training services) through the Mississippi Department of Rehabilitation Services (MDRS). These programs are implemented through several agencies. The University of Southern Mississippi Institute for Disability Studies offers several opportunities for young people to participate in such groups. The student should have a referral from MDRS, which can take several months. After they have a referral, they are then eligible to participate, either through their school or privately.

Resources:

Mississippi Department of Employment Security contains a wealth of information concerning training and employment assistance for those with disabilities.

Ability Works is a network of community rehabilitation programs that provide vocational assessment, job training, and actual work experience for individuals with disabilities.

MS Job Corps Center provides job assistance to youth ages 16-24. The age limit can be extended for people with disabilities.

Mississippi Community College Board partners with MDRS in its Community-Based Services Work Experience Program to employ Mississippians with disabilities. People interested in this program should contact MDRS at 1-800-443-1000.

ToTAL (Transition of Teens to Adult Life) is a Pre-ETS program administered through USM Institute for Disability Studies for children 14 years and older. Contact person is Danielle Parks, LMSW, Transition Specialist 601.266.5962

TRIAD AmeriCorps is a program at USM Institute for Disability Studies that is all-inclusive. It provides professional development training, volunteer experiences in the community and stipends. Contact person is Scott Mullins, Transition Specialist, at scott.mullins@usm.edu

Living Independence for Everyone (LIFE of Mississippi) provides information and referral, peer support, skills training, community transition and advocacy. 1304 Vine Street, Jackson, MS 39402

National Technical Assistance Center on Transition (NTACT) provides information and resources for transition/post-secondary

DS Works is the National Down Syndrome Society employment initiative whose goal is to encourage corporations and businesses to invest in hiring people with Down syndrome, and increase the number of opportunities for individuals with Down syndrome to work in meaningful and competitive employment settings.

Pearl River Community College The Workforce Team at PRCC has several regularly occurring non-credit courses called “Pinebelt Works” that are basic manufacturing skills courses to teach soft skills, job safety, and industry specific skill sets.

Project Search is a business-led, nine-month employment preparation program that takes place entirely at the workplace. Students with disabilities experience total workplace immersion, classroom instruction, career exploration, and hands-on training through three different work-site rotations. The goal for each participant is competitive employment. To reach that goal, the program provides real-life work experience combined with training in employability and independent-living skills to help young people with significant disabilities make successful transitions to productive adult life. Project SEARCH Mississippi is administered by the Mississippi Department of Rehabilitation Services and is a joint partnership between MDRS, a business and a school district.

Project Search Current Sites/Participating Schools

University Medical Center in Jackson
Rankin County School District
Pearl School District

Baptist Hospital in Jackson
Clinton Public School District
Jackson Public School District
Germantown High School

Forrest General–Hattiesburg
Hattiesburg, Petal and Lamar County School District

North Mississippi Medical Center–Tupelo
Tupelo School District
Lee County School District

South Central Regional Medical Center–Laurel
Jones County School District / Laurel County Schools

Merit Health River
Region-Vicksburg / Vicksburg–Warren School District

Baptist Medical Center
Attala-Kosciusko / Kosciusko–Attala School District

Viking/Alluvian–Greenwood Leflore Christian School

King Daughters Hospital–Brookhaven
Brookhaven School District / Lincoln County School District

Singing River Hospital–Ocean Springs
Ocean Springs School District / Jackson County School District

Neshoba General Hospital–Philadelphia Neshoba County School District
Baptist Memorial Hospital–Oxford Lafayette High School / Oxford School District

Baptist Memorial Hospital–DeSoto
DeSoto County School District



Parent Focus . . . What is Pre-ETS?

Transition to Adulthood

What are Pre-ETS? Pre-Employment Transition Services (Pre-ETS) are activities that provide an early start at job exploration for students with disabilities ages 14-21 to assist with transitioning from school to postsecondary education or employment.

What is Pre-ETS?

- Specific services funded by Vocational Rehabilitation for students with a disability still enrolled in school
- Take place at the school or in the community
- May occur during or after school hours
- Free for the students and school
- Meet in groups with individualized activities

Who can receive Pre-ETS?

Students

- Between ages of 14 & 21
- Enrolled in high school or college
- With an IEP, 504 Plan, or documented disability

Pre-ETS is based on five core sections!

Job Exploration- Explore career opportunities that fit a student's interest, skills and abilities

Counseling in Post-Secondary Education- Explore opportunities for enrolling in higher education

Workplace Readiness Training- Develop independent living and work readiness skills

Instruction in Self-Advocacy- Learn about self-advocacy and develop related skills

Work-Based Learning- Experience hands-on work-related experiences after school or outside traditional setting

How to Apply?

- Call Ms. Department Rehabilitation Services at 800.443.1000
- School staff, families, and/or students apply by contacting their vocational rehab counselor
- Call Institute for Disability Studies staff (see contact information to the right)



Transition of Teens to Adult Life

Danielle Parks, LMSW
Transition Specialist
Phone: 601.266.5962
Email: alyssa.parks@usm.edu
www.usm.edu/ids



INSTITUTE FOR DISABILITY STUDIES
THE UNIVERSITY OF SOUTHERN MISSISSIPPI

MS DIPLOMA OPTIONS

1. Traditional Diploma (option for all students)

Requirements:

- 24 credits
- Pass all MAAP required state tests

2. Alternate Diploma (option for students with a Significant Cognitive Disability.)

Requirements:

- 24 credits
 - Pass all required MAAP-A State Tests
- *Alternate diploma is not equivalent to a traditional diploma and is not recognized by postsecondary entities

3. Certificate of Completion

Requirements:

- An acknowledgement of the student's participation in and completion of his/her individualized education program.



POST SECONDARY EDUCATION

Post-Secondary Education is becoming more of a reality for people with disabilities. Many possibilities exist including traditional and non-traditional degrees. Other options include non-credit courses and work-study courses. Many on-line certification programs exist which do not require in person attendance.

Mississippi Department of Rehabilitation Services (MDRS) MDRS is the “umbrella” agency for so many services available to people with disabilities. These services can only be accessed through the referral of a MDRS counselor. The process may take several months.

Mississippi Community College Board partners with MDRS in its Community-Based Services Work Experience Program to employ Mississippians with disabilities. Community colleges also offer educational opportunities to this population. Contact MDRS at 1.800.443.1000

ThinkCollege.net is a search engine for universities that offer post-secondary programs for students with intellectual disabilities.



ACCESS Admission Criteria

Those eligible to apply for admission to ACCESS must have a mild intellectual, developmental, or other disability that significantly interferes with their academic performance, social development and independent living skills.

Desired applicants display the following:

- a. Must have a diagnosed intellectual or developmental disability
- b. Preferably between 18 and 26 years of age upon admission to the program
- c. Strong desire to live and work independently
- d. Functional reading and math skills (e.g. demonstrate comprehension of basic text, ability to apply basic math applications such as addition and subtraction, identification and basic understanding of money, etc.)
- e. Adequate communication skills to interact with others
- f. Understanding of technology and electronic communications (e.g. text messaging, emailing, etc.)
- g. Demonstrates independence, motivation, and stability with minor assistance
- h. Handles changes in routine; flexible in fluctuating circumstances
- i. Follows direction and guidance of those in authority
- j. Prior employment or volunteer experience preferable
- k. Independence in handling specialized dietary requirements, medical needs, medication, and hygiene (ACCESS staff will not manage, supervise, or administer medications)
- l. Unified commitment from family to support goals of ACCESS
- m. Navigate a daily routine (concept of time, independent transition throughout day, etc.)
- n. Ability to self-manage when left unsupervised for an extended period of time
- o. Non-degree seeking student

Preparing Students with IDD for the Transition to College

Freshman and Sophomore Years of High School

Parents and Teachers:

- Begin researching post-secondary institutions that align with the needs of your student
 - Areas of Focus Offered (E.g. Sports Management, Retail Management, Early Education, Culinary Arts)
 - CTP Status (Comprehensive Transition Program for Post-Secondary Education)
 - Duration of Program – 2 or 4 Years
 - Residential Requirements – On or Off Campus
 - Location – In-State or Out-of-State
- Develop a financial plan for college: for tuition, spending money, room and board
- Partner with teachers to create IEP goals that focus on program requirements and expectations
- Begin incorporating employment and independent living skills into daily life
- Allow for more decision-making and scheduling of free-time by student
- Develop plan to independently improve hygiene skills
- Provide socialization opportunities
- Teach student strategies about how to advocate for him/herself and allow him/her to practice this skill
- Provide opportunities to teach money management skills

Students:

- Begin volunteering or working a part-time job in the community
- Practice improving hygiene skills
- Practice new housekeeping skills
- Find opportunities to be more social
- Practice money management skills

Junior and Senior Years of High School

Parents and Teachers:

- Attend Open Houses for colleges
- Research the application processes and deadlines for colleges of interest
- Prepare service partnerships in advance
 - E.g.: College: counselors, mentors, student services, disability services
 - E.g.: Community: Voc. Rehab., Social Services
- Senior Year: Apply for financial aid at www.FAFSA.gov (MSU priority deadline is April 1st)
- Practice communication via text messaging and emails
- Allow for greater decision-making and independence
- Establish a budgeting routine and a checking/savings account
- Attend events at the college of choice to familiarize student and family with campus and community
- Allow student to advocate, when possible
- Ensure confidence
- Practice navigation skills

Students:

- Continue volunteering or working a part-time job in the community
- Begin mastering hygiene skills
- Learn new housekeeping skills and continue to practice current skills
- Implement budgeting plan
- Advocate for yourself
- Learn new recipes and practice preparing meals



Specific Skills to Practice

Independent Living Skills

Personal Hygiene:

- Bathing/Showering
- Brushing, Flossing, Rinsing Teeth Twice Daily
- Cutting Finger/Toenails
- Shaving
- Applying Deodorant
- Brushing and Styling Hair

Daily Routines:

- Setting Alarm Clock and Understanding Concept of Time
- Preparing Appropriate Outfits
- Taking Medications Independently
- Getting Adequate Amount of Sleep (7-8 hours)
- Outlining and Implementing Morning and Evening Procedures

Housekeeping Skills:

- Laundry: Washing, Drying, Folding, Putting Away Clothes
- Washing and Putting Away Dishes
- Sweeping/Vacuuming
- Cleaning Bedroom and Bathroom (using proper cleaning supplies)
- Maintaining a Healthy Refrigerator

Additional Skills:

- Budgeting, Saving, and Counting Money
- Telling Time and Understanding Concept of Time
- Cooking Skills: Microwave, Toaster, Toaster Oven
- Navigating via Cell Phone and Maps
- Following Safety Strategies:
 - Differentiate between strangers and friends
 - Understand what information should be shared and with whom
 - Practice safety procedures for new places
 - Teach appropriate boundaries in a variety of settings and people

Socialization Skills

- Attending School and Community Events
- Using Appropriate Conversational Skills (e.g. topics to discuss with people)
- Practicing Self-Advocacy:
 - Guide student in making decisions and encourage problem solving
 - Teach appropriate ways to ask for help
 - Teach student to be proactive
 - Model appropriate self-advocacy behavior
 - Ensure supports are in place to continue the learning process

Employment Skills

- Being Routinely Punctual and Present for Work
- Dressing Professionally/Appropriate for Job
- Practice Problem-Solving and Decision-Making Skills
- Practicing Interview Skills
- Appropriately Communicating with Employers and Co-Workers

Academic Skills

- Performing at a 3rd Grade Reading and Math Level
- Following a Schedule
- Practice Writing and Note-Taking Skills
- Practicing Computer Skills: keyboarding, emailing, attaching documents





HOUSING

Finding safe and affordable housing for those with disabilities can be quite difficult. As this population ages, the need for more resources is crucial. For some of the resources available, a documented significant intellectual or/and developmental delay is required. Those with less severe disabilities often have fewer government options. One option gaining acceptance in several other states is the “roommate” scenario. In exchange for room and boarding, a responsible person aids with the daily needs of the person with a disability. The assistance is determined beforehand through the input of the person with a disability, his or her family, and others.

RESIDENTIAL AND ASSISTED LIVING

Baddour Center
PO Box 97
3297 Hwy 51 South
Senatobia, MS 38668
662-366-6928 csmith@baddour.org

Mustard Seed
(Private Pay only)
www.mustardseedinc.org
1085 Luckney Road
Brandon, MS 39047
601-992-3556

Oxford Options
3828 I-55 North
Jackson, MS 39211
Number: 601- 982-7311 Fax: 601-981-2586

Son Valley
461 Goodloe Road Canton, MS 39046
601-859-2100
wfm@sonvalley.net
shs@sonvalley.net

Willowood Developmental Center
1635 Boling Street Jackson, MS 39047
601-366-0123

Other Resources

BrandiShope offers home and community supports for those participating in the Medicaid ID/DD Waiver program, as well.

MS Regional Housing Authority VI serves the Jackson area by helping to find housing for people with disabilities.

Assisted Living Research Institute an organization dedicated to helping educate families and individuals on elder care and assisted living facilities.



**Independent Living Postsecondary Goal
IEP Team Decision Assistance Form**

This form is designed to help the IEP team decide if a student needs a postsecondary goal in the area of independent living. *Independent living includes the skills and knowledge an individual needs to direct his or her life at home and in the community.* Transition assessment information should be taken into account when completing this form and additional assessment may be necessary to adequately identify goal(s).

Review each statement, and consider whether the student possesses the identified skills.

Yes – performs independently and consistently

No – performs inconsistently or not at all; consider an independent living goal

NA – not an area of independence being considered at this time

Home Living	Yes	No	NA
Follows daily living routine (e.g., personal hygiene, dressing, selecting clothes)	___	___	___
Purchases, prepares and stores food; maintains healthy diet	___	___	___
Performs light household maintenance (e.g., cleaning, unclogging drains or toilets)	___	___	___
Appropriately makes and receives telephone calls	___	___	___
Follows disaster safety routines for fire and natural disasters	___	___	___
Household & Money Management	Yes	No	NA
Creates and maintains checking & savings accounts	___	___	___
Manages money (e.g., counts money, makes change, budgets, pays taxes, and monthly bills)	___	___	___
Evaluates cost of services (e.g., banking, telephone, leasing, credit cards, loans)	___	___	___
Locates & acquires place to live (e.g., finds housing, understands rental agreements)	___	___	___
Sets up living setting (e.g., organizes furniture, arranges for utilities and services)	___	___	___
Understands the importance of a good credit rating, how to view and interpret a credit report, and methods to improve credit rating	___	___	___
Transportation	Yes	No	NA
Selects appropriate method of transportation	___	___	___
Possesses required transportation documentation (e.g., driver’s license, bus pass)	___	___	___
Organizes transportation (e.g., carpool partners, door-to-door bus or cab service)	___	___	___
Navigates throughout community using preferred mode of transportation	___	___	___
If driving, knows of automotive maintenance schedules and routines	___	___	___
Law & Politics	Yes	No	NA
Knows how to participate in voting and political decision-making	___	___	___
Understands basic local, state, and national laws	___	___	___
Understands rights as a person with a disability	___	___	___
Community Involvement	Yes	No	NA
Locates & participates in leisure, recreation, and community activities	___	___	___
Locates and uses community services (e.g., stores, banks, medical facilities, recreation facilities, health department, police department, social services)	___	___	___
Completes paperwork for medical treatment, community services, insurance, etc.	___	___	___
Plans and acquires wardrobe (e.g., select appropriate clothes, compare prices)	___	___	___
Responds appropriately to environmental cues (e.g., signs, sirens)	___	___	___

Personal Safety and Interpersonal Relationships	Yes	No	NA
Performs basic first aid and seeks medical assistance when appropriate	___	___	___
Practices community safety routines (e.g., when to talk to strangers, avoiding unsafe locations, locking doors, asking for directions)	___	___	___
Understands when it is appropriate to call 911	___	___	___
Knows CPR and when it is necessary	___	___	___
Maintains relationships with family and friends; establishes new friendships	___	___	___
Understands the concepts of sexuality (e.g., physical self, reproductive process, dating, relationship, marriage).	___	___	___
Makes informed choices regarding sexual behavior	___	___	___
Understands basic parenting skills	___	___	___

Self-Advocacy	Yes	No	NA
Expresses strengths and needs; asks for accommodations when needed	___	___	___
Expresses preferences appropriately, identifies long- and short-range goals, and takes steps to reach goals	___	___	___
Assertively advocates for self in situations outside of school	___	___	___
Responds appropriately to typical exchanges with others (e.g., saying hello, being bumped or brushed against, making small talk, sarcastic remarks, etc.)	___	___	___
Resolves conflicts through discussion, reasoning, & compromise	___	___	___

Additional Independent Living Skills	Yes	No	NA
_____	___	___	___
_____	___	___	___
_____	___	___	___
_____	___	___	___
_____	___	___	___

If “No” was answered for any of the skills identified above, a postsecondary goal should be considered for the area of independent living. The discussion questions below help further identify an appropriate goal.

Independent living goal(s) needed at this time? ___ Yes ___ No

Is additional assessment information needed in the area of independent living? Why?

What are the 3 most important independent living skills to be addressed in IEP?

- 1.
- 2.
- 3.

How can we work on these particular skills throughout this coming year (i.e., instruction, related services, post-school living objectives, daily living skills, and/or functional vocational evaluation)?

What annual IEP goal(s) will enable the student to meet the postsecondary independent living goal?

DAY PROGRAMS

Day programs for individuals with disabilities offer the opportunity to be active in the community, socialize with their peers, and engage in productive activities while maintaining access to health and personal care services. The goal of day programs is to assist individuals in attaining the greatest level of independence within a supportive and encouraging environment.

Involving your loved one with a disability in a day program also allows caregivers time to work outside of the home, tend to personal needs, and engage in activities that are often unavailable. Utilizing the available chances for community involvement also provides these individuals with additional social opportunities and much needed support groups for caregivers.

There are two main types of day programs: Medicaid funded and unfunded. Medicaid funded programs are covered by the HCBS Waiver and/or the State Plan 1915i. The 1915i program generally has no wait list and currently covers Day Services, Supported Employment, Pre-Voc and the Supported Living residential program that unfortunately only allows staff for a maximum of 4 hours a day. The waiver has a very long waiting list but offers all the same Day Services plus HCS and Supervised Living.

Some day programs offer work opportunities. These jobs are generally through Supported Employment which allows a Job Coach to transport and remain with the individual while working, some programs offer transportation and management of the job without a Job Coach present and some programs offer on-site work all of which at least pay minimum wage.

Day programs often offer a variety of activities to engage in such as:

1. Exercise programs
2. Cultural and education programs (continuing education)
3. Recreational activities (arts and crafts, games, day trips, etc.)
4. Volunteer activities (community garden, recycling programs)
5. Medical rehabilitation (physical therapy, occupational therapy, audiology and speech therapy)
6. Health services (counseling, medical evaluations, etc.)

Checklist:

- Brainstorm a working concept of the services your loved one needs, the activities they enjoy, and personal values that are important to the care of your child.
- Visit and tour different facilities within your area to see which is a best fit for your loved one's needs and interests.
- Be sure to ask about available transportation and food services.
- Register to be placed on a waitlist- if there is one.
- Fill out all necessary applications.
- Inquire about financial assistance opportunities for the chosen day program.

Finances & Planning

Proper estate planning is important for any family, but even more so for a family with a child with special needs. Good quality health care and longer life spans for children with disabilities means that plans must be made to preserve public benefits like SSI and Medicaid and to provide a quality of life for many years to come.

Failure to plan leads to a lack of choices. If the family of a person with special needs does not develop a financial plan for the future, state bureaucratic solutions may be imposed on individuals with developmental disabilities. The consequences may not be what the family would choose for their son or daughter with a disability.

It is extremely important to seek legal advice from an attorney who has experience in estate planning for special needs children. There are numerous Mississippi and federal benefit programs that may serve the child's needs, including SSI to provide a monthly income payment and Medicaid for medical insurance coverage. The laws and regulations of these programs vary greatly, and a special needs planning attorney can help you navigate and understand their requirements and benefits.

While CMDSS cannot offer specific legal advice or recommendations, the following are some planning steps that experts recommend:

The parents of a child with Down syndrome should establish a Will ("last will and testament") as soon as possible. A Will directs how and to whom your assets will be distributed at your death. You may also name a guardian who would care for your child in the event of your death. Without expressing your instructions about these matters, state law will dictate the share of assets your child will receive, and there may be a conflict between family members over who will have custody of your child.

Many public benefit programs limit their benefits to persons with few assets, and you should be careful in your Will NOT to leave money or property directly to your child with Down syndrome. Instead, a Special Needs Trust should be established for that child, and the trust can be named as the recipient of the child's share of assets. The trust can also be designated as the beneficiary of a life insurance policy or an IRA or other retirement account. (Warning: The IRS has specific rules that allow a trust to be named beneficiary of a retirement account, and you must have a knowledgeable attorney review the trust to make sure it qualifies.) When properly drafted and administered, the assets in the trust will not be counted as the child's assets, and he or she can keep SSI and Medicaid benefits in addition to the funds in the trust for future needs. It is essential to name, as trustee over the trust, a person or bank who will be devoted to the best interest of your child (the trust "beneficiary") and is willing to seek professional guidance about investments and public benefit rules in making payments from the trust

A Special Needs Trust may be established in your Will, in which case the trust will not exist until your death. Or, you may create a "living" Special Needs Trust that will be in effect now, so that other family or community members can contribute to the trust for your child now if they desire. It is important that other relatives or friends NOT name your child as beneficiary; they should instead leave those assets to the trust. If your child receives an inheritance directly, he or she could be disqualified for SSI or Medicaid benefits and for other services that may require Medicaid eligibility.

The parents of a child with Down syndrome must also plan for their own incapacity or death. A “durable power of attorney” is the legal document that allows you to name the person(s) who will manage your financial affairs – including providing for the financial care of your child – if you later become incapacitated from an illness or injury. The power of attorney must contain certain specific wording to be effective, and it should state any rules or requirements you want your agent to follow in managing your affairs. An adult with Down syndrome may have sufficient legal capacity to do their own power of attorney, thereby expressing their own wishes about who will be able to handle their affairs and how.

Similar to the durable power of attorney, the “advance health care directive” document can name the person(s) who would make medical treatment or health care decisions for you if you become unable to do so. A person age 18 or older with a disability can sign a health care directive if they understand what they are signing.

When a child with a disability becomes an adult, some medical or educational programs may be unwilling to let the parents continue to make decisions for the child. In such cases, it may be necessary to get appointed as guardian for the child. This is a court proceeding that is handled by an attorney who should be able to advise you about the ongoing requirements of law on the guardian.

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

What is an ABLE Account?

An ABLE account is a savings account for people diagnosed with a disability before the age of 26. It’s a great place for parents to save for their child with a disability’s future expenses—and to receive gifts from people who want to show their support for the child without risking the child’s government benefits. All earnings are tax-free.

In late 2014, the Achieving a Better Life Experience Act, or ABLE Act, created a tax-advantaged savings option for people who were diagnosed with their disability before the age of 26 and can meet certain other requirements. ABLE accounts are ideal for parents saving for their child with a disability’s future expenses, for the individuals themselves if they are employed and for people who want to give or bequest funds to someone with a disability without jeopardizing their government benefits. With the ABLE Act, Congress’ intent was to offer individuals with disabilities flexible savings tools similar to college savings accounts, health savings accounts and individual retirement accounts. ABLE accounts are often used alongside a special needs trust.

An ABLE account is funded with after-tax money, and all earnings are tax-free, as are distributions when used for qualified expenses. Contributions to an ABLE account are limited to \$15,000 for a single tax year, as of 2021, unless the ABLE beneficiary works and earns income while not participating in his or her employer’s retirement plan. In that case, an additional \$12,760 can be contributed. Lifetime maximum contributions vary by state but can go as high as \$500,000.



Up to \$100,000 in ABLÉ accounts will not be counted as assets for means-tested benefits, such as SSI. If an ABLÉ account balance exceeds \$100,000, SSI payments will be suspended but the eligibility of the person with a disability remains. Medicaid benefits continue even if the ABLÉ account balance exceeds \$100,000, although states may ask for reimbursement from the estate containing the ABLÉ account after the beneficiary dies.

You can establish an ABLÉ account in Mississippi. The Mississippi ABLÉ Act was signed into law in 2017.



Financial Planning Checklist:

- Created a broad, far-reaching Life Care Plan that covers long-term care for your family member.
- Written a “Letter of Intent” or “Letter of Instruction” concerning your family member’s needs, both now and in the future.
- Had a family meeting to make sure everyone knows about—and where to find—the Life Care Plan and Letter of Intent.
- Identified all the ways you can create the future you and your family member envision, such as government benefits, employer benefits, insurance, and personal assets.
- Reviewed all medical health plan options and coverages, including what it takes to qualify for Medicaid and Medicare and the Children’s Health Insurance Program as well as the details of your plan at work.
- Looked at available resources for managing care, including online.
- Researched all the benefits available to you at work, especially insurance policies (both basic and supplemental coverages) and how they can help you manage your tasks and supplement your special needs plan.
- Chosen a guardian, trustee, and successors to oversee the care and resources of your family member should you be unable to.
- Used a wide variety of legal tools, for example, wills, trusts, durable powers of attorney and living wills/advanced directives to devise your estate plan.
- Studied all beneficiary designations, titling or ownership to make sure any inheritances won’t impede your family member’s government benefits.
- Talked to an attorney who specializes in first party, third party, and pooled special needs trusts to determine which is the proper fit for you and the family member.
- Considered starting an ABLE account to save for and manage disability-related spending.
- Carefully thought through the following considerations before your family member turns 18.
 - Will the family member with a disability need help taking care of themselves and/or their finances?
 - Did you get on the ID/IDD Waiting list?
 - Do they have any particular social and/or recreational interests?
 - Do they plan to work?
 - Will they need any specific transportation and/or housing accommodations or anything else that improves quality of life?

Resources:

Each family must choose a qualified attorney with whom they are comfortable working. A good place to get started would be contacting an attorney:

Professionals Specializing in Special Needs Trusts/Wills:

Richard Courtney, CELA
Frascoigna Courtney, PLLC
7708 Old Canton Road, Suite B Madison, MS 39110
(601) 987-3000
1-866-ELDERLAW www.frascourtlaw.com/courtney.php
rcourtney@frascourtlaw.com

Financial Consultants
Bill Stone
EFP
1501 Lakeland Dr., Suite 250 Jackson, MS 39216 601-206-0006
601-540-3031 bstone@wostoneadvisors.com

Linda Bounds Keng
Jones Walker
190 E. Capital St., Suite 800 Jackson, MS 39201
(601) 949-4960 lkeng@joneswalker.com



Personal Issues: Nutrition, Hygiene, Puberty and Safety

Nutrition

Good nutrition is crucial to one's health and well-being. Individuals with Down syndrome can face dietary challenges as they age, making the need for nutrition education even more important. People with Down syndrome are at higher risk for obesity, Celiac disease, diabetes, constipation, hyper/hypo-thyroidism, and GERD (More information on these under Healthcare). A healthy diet may minimize risks for these complications. Parents and caregivers should assist with grocery shopping while teaching their loved one how to make healthy food choices and what to avoid.

Safety

According to the CDC, people with disabilities can be at higher risk for injuries and abuse. Your child should know that everyone has a right to say what happens to their body and has a right to feel safe. All people, with or without an IDD, should learn what behaviors are appropriate and how to assertively say "no" to unwanted behavior.

Relationships

As your child goes through puberty, they will develop feelings that are just the same as in all other teenagers. They may wish to form relationships and be able to manage all aspects of their relationships. However, they may also need some extra support e.g. talking about pregnancy and contraception. Throughout their school life, your child will be involved in lessons about friendships and relationships. It is often helpful to know what they are learning so that discussions can continue at home. These lessons usually include sex, sexual health, family matters and relationships, as well as personal and social skills. Some parents are worried that their child will be vulnerable. Teaching children about what part of their body is private and how to stay safe are very important in helping them to stay safe, as is making sure they know who they can talk to at home or at school if they are feeling sad or worried about something.

Puberty & Hygiene

These adolescents will go through pubescent changes like any other child. It is important for caretakers and parents to take the time to discuss sexuality and puberty, regardless of their developmental delays or needs. Education is a vital part in your child's awareness of their body, developing positive hygiene habits and understanding privacy and personal boundaries. Below are tips to having an open conversation about difficult topics with your child.

- Discuss sexuality with your child using facts and anatomically correct labels.
- People with disabilities can be at higher risk for injuries and abuse. Your child should know that everyone has a right to say what happens to their body and has a right to feel safe. All people, with or without an IDD should learn what behaviors are appropriate and how to assertively say "no" to unwanted behavior.
- Address what appropriate behaviors are and what privacy means.
- Discuss age-appropriate topics like masturbation, birth control, pregnancy, and relationships when the time is right.
- Explain social rules and reinforce topics like private and public behavior.
- Help your child set a daily routine to take care of hygiene needs. Teach him or her to shower or bathe and use deodorant.

Personal Issues: Nutrition, Hygiene, Puberty and Safety

Sexuality & Down Syndrome

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Human sexuality encompasses an individual's self-esteem, interpersonal relationships and social experiences relating to dating, marriage and the physical aspects of sex. Sex education, appropriate for the developmental level and intellectual attainment of individuals with Down syndrome, adds to life quality by developing healthy sexuality, reducing the risk of sexual abuse, avoiding sexual misunderstandings, preventing disease transmission, preventing unwanted pregnancy and alleviating other problems related to sexual function.

Do Individuals with Down Syndrome Have Sexual Feelings?

In the past, sexuality was not considered an issue for any people with Down syndrome because of the inaccurate belief that intellectual disability produced permanent childhood. In fact, all people with Down syndrome have sexual feelings and intimacy needs. It is important that expression of these feelings in socially acceptable, age appropriate ways be recognized by families and caregivers.

Sexuality education is the way to plan for this aspect of adulthood as it applies to independence in educational, social, residential and vocational settings.

Do Children with Down Syndrome Develop Physically the Same Way as Their Peers in the General Population?

Children with Down syndrome experience the same sequence of physical and hormonal changes associated with puberty as other children their age. However, there is often a lag in the development of social maturity, emotional self-control, social communication, abstract thinking and problem-solving abilities.

Do Children with Down Syndrome Experience the Emotional Upheavals Characteristic of Adolescence?

The emotional changes characteristic of adolescence are also present in pre-teens and teens with Down syndrome, and may be intensified by social factors. Any adolescent who lives in the community, attends school and is exposed to media inevitably develops an awareness of sexuality. Teenagers and young adults with Down syndrome often express interest in dating, marriage and parenthood. They can be expected to experience typical adolescent changes in mood and outlook.

Personal Issues: Nutrition, Hygiene, Puberty and Safety

What Kind of Sex Education is Appropriate for Individuals with Down Syndrome?

To be effective, education must be individualized and understandable, focusing not only on the physical reproductive aspects, but with strong attention to decision-making, cultural norms, peer pressures, relationships, social skills and opportunities. Positioning sexuality within the context of community life requires the development of personal values and adult responsibilities. An ideal curriculum will ensure that individuals with Down syndrome understand their bodies, their emotions, their behaviors and their relationships within their social and cultural environment. Information about sexual intercourse, as well as other expressions of adult sexuality, including parenting, should be factual, realistic and stress the importance of personal responsibility and community standards for adult behavior.

How Can Healthy Sexuality be Encouraged for Individuals with Down Syndrome?

Creating an environment conducive to healthy sexual expression must be considered in designing educational, vocational, social, recreational and residential programs. Positive sexual awareness can only develop through personal empowerment, self-esteem, understanding of social relationships and personal interaction/communication skills. All these factors influence how intimacy needs are met.

Are There Any Special Needs for Individuals with Down syndrome in Regard to Disease Prevention?

Men and women with Down syndrome have the same susceptibility to sexually transmitted infections (STIs) as the rest of the population. Use of condoms during sexual intercourse is the best known form of protection against AIDS, herpes and other sexually transmitted infections. Sexual education should include information on sexually transmitted diseases and how to reduce the risk of transmitting them.

How Can a Person with Down Syndrome Be Protected Against Sexual Abuse?

It is highly recommended that age-appropriate education in protective behaviors begin in childhood and be reinforced throughout the life of the person with Down syndrome. Individuals with Down syndrome must be taught the boundaries of normal physical interactions in the social sphere, as well as the self-assertion skills to enlist help if necessary. Practicing assertive behaviors and designating trusted individuals in settings that are frequented with whom to discuss or report questionable activities are important aspects of abuse prevention training.

Personal Issues: Nutrition, Hygiene, Puberty and Safety

Are Males with Down Syndrome Fertile?

Scientific information about the fertility of men with Down syndrome is limited. There have been at least three documented cases where the paternity of a man with Down syndrome was confirmed. It is likely that additional cases will be recognized – especially since more men with Down syndrome have an increased life expectancy, have the opportunity to live in the community, receive treatment for physical and sensory impairments, receive optimum nutrition, and develop intimate relationships. It is not known if the offspring of men with Down syndrome are more likely to have Down syndrome.

It does seem clear that, in general, men with Down syndrome have a significantly lower overall fertility rate than that of other men of comparable ages. An individual's status can be partially assessed by having a semen analysis (sperm count) done, but this may not be definitive. Contraception should always be used, unless a couple has decided upon parenthood.

Do Boys with Down Syndrome Mature Later Than Their Peer Group in the General Population?

The onset of puberty in boys may be slightly delayed, but this is not a major factor. Genital anatomy is comparable to that of boys who do not have Down syndrome.



HEALTHCARE

Quality healthcare for everyone is essential to individual well-being. This is especially the case for individuals with disabilities as they often experience health disparities and limited access to appropriate healthcare. Common health issues among individuals with Down Syndrome include immune disorders, sleep apnea, loss of vision, stomach problems, and thyroid dysfunction. Taking care of a loved one with a disability will require greater involvement of healthcare services, which makes access to a functional healthcare plan imperative. Due to the complex nature of the United States healthcare system, there are times where high restrictions are placed on program eligibility and access to necessary benefits is limited.

The American Academy of Pediatrics provides a comprehensive list of medical issues common for individuals with Down Syndrome. (See chart below) Given that people change over time, lists are divided by age from the Prenatal Period to 21 years and older. Be sure to stay in consistent communication with your child's physician to ensure that no complications go undetected and their optimal health is maintained.

As your child reaches adulthood, caregivers will play a vital role in preparing them to transition to managing their own health. Before your child turns 18, consider asking your doctor the following questions:

- 1) When should my child meet alone for part of the visit to become more independent in their healthcare?
- 2) Do you have a checklist of self-care skills for my child to learn?
- 3) Can we work together to prepare a health summary and emergency care plan?
- 4) Before my child turns 18, what do I need to learn about privacy and consent?
- 5) Where can I get information about helping my child make health decisions?
- 6) Do you have a recommendation for an adult doctor for my child to transfer to?

Applying for Disabled Child Living at Home through the Division of Medicaid is one opportunity to supplement insurance or payment plans you may already have. Your child may be eligible to apply for the Intellectual Disabilities/Development Disabilities Medicaid Waiver if they do qualify for Medicaid for Disabled Child Living at Home program. The ID/DD Waiver services provides support and referrals for services such as Occupational Therapy, Physical Therapy, Speech Therapy, Day Services, Supervised Living, Community Respite, and so much more. The waitlist for this waiver can be very long, so you want to apply as soon as possible.

HEALTHCARE

What you need for applying for Disability Benefits:

1. Birth and Citizenship information
2. Marriage status information
3. Names and birth dates of children in household
4. Employer details for the past two years / Job history
5. Banking information
6. Information about healthcare professionals, hospitals, and clinics
7. Documentation of a history/physical exam completed within the past year
8. Medical records from health care providers



Resources:

Mississippi Division of Medicaid

<https://medicaid.ms.gov/>

Disabled Child Living at Home

<https://medicaid.ms.gov/medicaid-coverage/who-qualifies-for-coverage/disabled-child-living-at-home/>

Mississippi Health Advocacy Program

www.mhap.org

Mississippi Department of Mental Health

<http://www.dmh.ms.gov/>

Child Access to Mental Health and Psychiatry

Consultation and educational service for pediatric primary care providers in Mississippi.

champms.org

Mississippi Department of Rehabilitation Services

State Attendant Care <https://www.mdrs.ms.gov/SpecialPrograms/Pages/State-Attendant-Care.aspx>

Southern Physical Therapy Clinic

<https://southernptclinic.com/landing-page/>

Pine Belt Mental Health Resources

Intellectual/Developmental Disability Resources <http://www.pbmhr.org/developmentalservices/>

Weems Community Mental Health Center

<http://www.weemsmh.com/default/>

Common Medical Conditions

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This section focuses on medical issues that are commonly encountered in individuals with Down syndrome throughout adulthood and into older age. These are issues to watch for over time and to ensure are being monitored by a doctor or other health care provider.

Sensory Loss

Eyes: Adults with Down syndrome are at risk of early cataracts and keratoconus. Cataracts cause a clouding of the lens of the eye, producing blurry and impaired vision. Keratoconus causes the round cornea to become cone shaped, which can lead to a distortion of vision. Both of these conditions can be screened for by an eye doctor and should be assessed regularly.

Ears: Adults with Down syndrome are at high risk for conductive hearing loss. In addition, they tend to have small ear canals and frequently can have ear wax impactions that can impair hearing. Routine ear examinations can assess wax impactions, and periodic screening with an audiologist can formally assess hearing loss.

Undiagnosed sensory impairments (vision or hearing) are frequently mistaken as stubbornness, confusion or disorientation in adults with Down syndrome. These conditions are quite common and, when properly identified, can be greatly improved with glasses, hearing aids, ear cleanings and environmental adaptations.

Screen for vision and hearing impairment and get regular exams to assess overall eye and ear health.

Hypothyroidism

The thyroid gland is involved in various metabolic processes controlling how quickly the body uses energy, makes proteins and regulates hormones. Thyroid dysfunction is common in adults with Down syndrome and can lead to symptoms of fatigue, mental sluggishness, weight fluctuations and irritability. Thyroid dysfunction is easily detected via a screening blood test that can be performed by a primary care doctor, and treatment will usually involve taking thyroid medication that regulates abnormal hormone levels.

Discuss screening with the primary care doctor and consider checking for thyroid dysfunction if new symptoms of sleepiness, confusion or mood changes occur.

Common Medical Conditions

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Obstructive Sleep Apnea

Adults with Down syndrome are at increased risk for sleep apnea, a sleep disorder that leads to poor quality, non-restorative sleep. Signs of possible sleep apnea include snoring, gasping noises, daytime sleepiness, morning fatigue (difficulty getting out of bed), excessive napping and fragmented sleep. Undiagnosed or untreated sleep apnea leads to symptoms of irritability, poor concentration, behavior changes and impaired attention. It also can put a strain on the heart and lungs and cause high blood pressure. Sleep apnea can be detected via a sleep study performed at a sleep lab. In some cases, sleep testing can be arranged in the home.

Osteoarthritis

People with Down syndrome are typically hyperflexible. Over the years they can put increased wear-and-tear on their large joints (hips, knees, etc.). This leads to increased risk of osteoarthritis. Adults who are overweight or who were previously overweight are at increased risk. Arthritis is painful and can lead to decreased mobility and decreased willingness to participate in activities. For some individuals, the pain can express itself through negative behavioral changes. Untreated pain increases the risk of further immobility and deconditioning due to reluctance to participate in activities or exercise.

Atlantoaxial Instability and Cervical Spine Concerns

The region of the spine located in the neck is called the cervical spine. In adults with Down syndrome, there is increased risk of instability between the the "atlas" and the "axis," the first and second spinal bones in the cervical spine that are located directly below the base of the head. This is known as atlantoaxial instability. If instability is present and arthritis changes occur in the spine, there is increased risk of damage to the spinal cord in that region. A gradual narrowing of the spinal canal may also occur due to development of severe arthritic changes in the bones of the spine. This is called spinal stenosis. When chronic changes occur in the cervical spine that affect the spinal cord, symptoms including weakness in the arms or hands, walking abnormalities or incontinence may be observed.

Remain mindful that the bones of the neck are more vulnerable as adults with Down syndrome grow older.

Osteoporosis

Osteoporosis causes a thinning of bone mass that leads to risk of fracture. People with Down syndrome are at higher risk for disease, especially if there is immobility, low body mass, family history of osteoporosis, early menopause or longtime exposure to certain anti-seizure medications. Osteoporosis is screened for via a bone density test and can be treated through medication, as well as other exercise and lifestyle modifications.

Common Medical Conditions

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Celiac Disease

Celiac disease is a condition where one's body cannot digest wheat gluten and wheat products, causing damage to the lining of the intestine and preventing absorption of certain nutrients. When celiac disease is present it can cause gastrointestinal distress, nutritional deficiencies and sometimes general irritability or behavior changes. There is a higher risk of this condition in individuals with Down syndrome. Celiac disease can be screened for by a blood test but requires a biopsy and evaluation of the small intestine to confirm the diagnosis. A visit with a gastroenterology specialist is usually necessary to formally make the diagnosis. Celiac disease is usually primarily treated with a wheat-free diet.

Alzheimer's Disease

Early-onset Alzheimer's disease is more common in adults with Down syndrome than in the general population. It is important to be aware of the connection between Down syndrome and Alzheimer's disease so that proper surveillance can be done to look for signs or symptoms of the disease. This topic will be discussed in detail in another section.



RECREATION

Participating in social activities helps people feel fulfilled and connected to their community. It is important for all people, including people with Down syndrome to participate in sports, hobbies and other interests

Abbie Rogers Civitan Camp

A camping experience for children and adults with significant disabilities.

50 Fieldstone Hattiesburg, MS 39402

(601) 859-5290

abbierogerscivitancamp.org

ARC of Mississippi

The ARC provides BTY grants to help provide services in-home for children with disabilities. They have an educational specialist on staff who refers families to the appropriate resources.

704 North President Street Jackson, MS 39202

(601) 355-0220

arcms.org

Camp Bratton Green

Camp Bratton Green offers Special Sessions including Camp Able, a ministry of Gray Center. Sessions include camp offerings for campers ages 10+ with Down syndrome or other genetic disorders.

1530 Way Road, Canton, MS 39046

(601) 859-1556

Graycenter.org

Ridgeland, MS Parks & Recreation Special Needs Programs

304 Highway 51, Ridgeland MS 39157

(601) 853-2011

ridgelandms.org/city-departments/recreation-and-parks/programs/

Southern Outdoors Unlimited - Super Hunt

Participants of SOU events get to enjoy the outdoors along with fun activities.

HOOPS

HOOPS Basketball is a program designed for children with special needs. Games are held in January and February utilizing volunteer coaches and assistants.

TOPSoccer

This spring and fall soccer program is offered to children ages 5 and up who are mentally and/or physically challenged. Registration occurs in the summer and winter.

Cameron Arcemont

c/o SMCSO TOPSoccer Program

PO Box 767, Madison, MS 39130

topsoccerms.com



RECREATION CONTINUED

TOPSoccer Jamboree

TOPSoccer Jamboree is designed for boys and girls ages 5-18 with special needs. This event provides a day of fun while teaching basic soccer skills.

Challenger League Baseball

Challenger League is a baseball/softball program adapted for physically/mentally challenged youth.

Mississippi Coalition for Citizens with Disabilities

The MSCCD is a coalition of organizations and individuals who have joined to advocate for and promote the full and equal participation of all Mississippians with disabilities in all aspects of life.

2 Old River Place, Suite M Jackson, MS 39202

(601) 969-0601

msccd.org

MSU – T.K. Martin Center for Technology and Disability

The Mission of the T.K. Martin Center for Technology and Disability is to ensure that persons with disabilities are able to continually benefit from technological solutions and advances in the field of assistive technology.

Mississippi State University

P.O. Box 9736, Mississippi State, MS 39762

(662) 325-1028

tkmartin.msstate.edu

Project Start

Project Start provides on a loan-basis appropriate technology-related services for Mississippians with disabilities.

P.O. Box 1698, Jackson, MS 39215-1698

1-800-852-8328

(601) 853-5249

msprojectstart.org

RideABILITY

RideABILITY is a NARHA member therapeutic riding center that proudly serves the Jackson, MS metro area. They offer classes that help build confidence, balance, strength, and coordination while students learn to ride horses.

RideABILITY

P.O. Box 5061 Brandon, MS 39047 (601) 750-6735

Special Olympics of Mississippi

Offers a variety of sports opportunities for individuals with special needs.

15 Olympic Way Madison, MS 39110

(601) 856-7748

specialolympicsms.org

The purpose of the Intellectual Disabilities Participant Registry is to engage with families of children and adults with intellectual disabilities interested in participating in psychological research studies. The studies that they work with address topics such as memory, language, and learning. Families can help researchers better understand intellectual disability and how to meet its challenges by enrolling in the participant registry.

University of Alabama Intellectual Disabilities Participation Registry

PO Box 870348
The University of Alabama Tuscaloosa, AL 35487
(205) 348-4253
uaidpr.ua.edu

Boy Scouts of America

www.scouting.org

Clinton, MS Parks & Recreation

ABILITIES PROGRAM

The ABILITIES Programs includes a variety of sports, events and activities scheduled throughout the year for individuals ages 6+ with disabilities. Includes: TOPSoccer, Tennis, Challenger League Baseball, Basketball and Bowling
300 Jefferson Street, Clinton, MS 39060
(601) 924-6387

Camp Sunshine

Junior Auxiliary of McComb is a non-profit organization that strives to help individuals with special needs enjoy a camp experience.

Betsy Murrell, Director
(601)810-2828 najanet.org

High Hopes Farms

The therapeutic horseback riding program at High Hopes Farms in Madison, MS is a PATH (Professional Horsemanship International) instructor member facility that serves clients with disabilities.

196 W. Sowell Road Madison, MS 39110 (601) 859-5031

Hope Hollow

Hope Hollow works to enrich the lives of children and adults with special needs by providing fun, meaningful camps and programs in a Christian based environment filled with love, adventure, compassion, and fellowship.

910A Catlett Road Canton, MS 39046 (601) 859-5290 hopehollowms.org

Joni and Friends

Joni and Friends works together with local churches and organizations, forming outreach programs throughout the community and ministering hope and the message of Christ to those who face daily challenges of life with a disability.

(601) 594-0148
joniandfriends.org/jackson



Churches with Special Needs Programs

- Broadmoor Baptist Church – Madison
- Pear Orchard Presbyterian Church
- First Baptist Church - Jackson
- Ridgecrest Baptist Church
- First Baptist Church-Brandon
- Morrison Heights Baptist Church - Clinton

Living Independence for Everyone (LIFE of Mississippi) www.lifeofms.com provides information and referral, peer support, skills training, community transition and advocacy.
1304 Vine Street, Jackson, MS 39402

NTACT provides information and resources for transition/Post-Secondary
www.transitionta.org/toolkitpet

DS Works is an employment program that seeks to increase access to workforce for all people with Down Syndrome.
<https://www.ndss.org/work/dsworks/>

Pearl River Community College The Workforce Team at PRCC has several regularly occurring non-credit courses called “Pinebelt Works” that are basic manufacturing skills courses to teach soft skills, job safety, and industry specific skill sets.
<http://www.prcc.edu/workforcere-training>

Goodwill of Mississippi-Hattiesburg is a non-profit that assists with training and employment skills.
goodwill.org



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CENTRAL MISSISSIPPI DOWN SYNDROME SOCIETY