

Resource Directory



DSAWM

Down Syndrome Association of West Michigan
Empowering individuals. Supporting communities.

Resources listed are not endorsed by DSAWM, but are a list of options that are available. If you know of additional West Michigan resources, please let us know at 616-956-3488 or director@dsawm.org. For more information, visit dsawm.org/resources.

Table of Contents

Section 1: New & Expectant Parent Resources	page 5
Become a Member	1-1
DSAWM Programs & Services	1-1
Where to Begin	1-3
Get to Know the Community	1-4
Section 2: Early Stages (0-5) Resources	page 11
DSAWM Programs & Services	2-1
Supports Coordination	2-2
Therapy	2-2
Medical	2-8
Financial	2-10
Section 3: School Age (6-13) Resources	page 23
DSAWM Programs & Services	3-1
Education	3-3
Therapy	3-5
Social Programming/Activities	3-11
Respite	3-12
Medical	3-13
Financial	3-15
Section 4: Teen & Adult (14+) Resources	page 39
DSAWM Programs & Services	4-1
Transitions (18-26)	4-3
Therapy	4-8
Social Programming/Activities	4-12
Medical	4-14
Financial	4-15
Section 5: Aging Resources	page 57
DSAWM Programs & Services	5-1
Transitioning into Older Adulthood.....	5-3
Medical.....	5-6
Financial.....	5-7
Section 6: Sibling Resources	page 67
For Younger Siblings	6-1
For Adult Siblings/Caregivers	6-1
Stories from West Michigan Siblings	6-3
Section 7: DS-ASD Dual Diagnosis Resources	page 77
Getting & Understanding a Diagnosis	7-1
DS-ASD Support	7-3
Autism Support.....	7-3
Stories from West Michigan Parents.....	7-4

Section 8: Diversity Resources	page 85
DSAWM Programs & Services	8-1
Families of Color	8-2
LGBTQIA+ Families	8-3
Adoptive Families	8-4
Section 9: Additional Resources	page 89
Down Syndrome Community Supports	9-1
Special Olympics Michigan Unified Sports & Inclusion Center	9-2
Disability Community Supports	9-3
Teacher Information Packet	page 95



New & Expectant Parent Resources

Congratulations on the birth or expected birth of your baby! You probably have lots of questions. You may be grieving the loss of the baby you expected. You may be angry. These feelings are normal. The most important thing for you to keep in mind is that a Down syndrome diagnosis is not as “life changing” as the fact that you have a new baby. And in most ways, your baby will be just like other infants. He or she will need to be fed, held, and loved. There will be many joys in raising your baby, as well as some challenges along the way. Down syndrome is a condition your baby has, but it is not who your baby is. It’s normal to be nervous about what lies ahead.

Know that when you are ready, the DSAWM is here to support you. Many new parents have found that the single most helpful thing they did after receiving a Down syndrome diagnosis was to talk to other parents of children with Down syndrome. When you are ready, please contact our office at **616-956-3488** to speak with our staff who can help you with additional resources, information, and supports. You can also email us at director@dsawm.org.

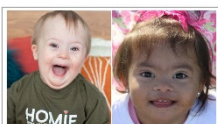
Become a Member

DSAWM’s membership is comprised of over 350 families across 12 West Michigan counties. In addition to the outreach that we do within the community through our partnerships and advocacy initiatives, we also offer a wide variety of programming for our members from birth to adulthood. You can read more about our programs and services on our website at dsawm.org/programs. The annual \$35 membership fee is waived for new parents, so your first year of access to programs, services, and events is free to you and your family! Most importantly, as a DSAWM member you join a community of advocates and families who are all committed to the same mission: embracing Down syndrome, empowering individuals, and promoting opportunities for meaningful lives. To become a member, visit dsawm.org/join.

DSAWM Programs and Services for New & Expectant Parents

Learn more about each program by visiting dsawm.org/programs.

A Guide for New and Expectant Parents



New & Expectant Parent Gifts

DSAWM provides new and expectant parents with accurate, up-to-date, compassionate information from leading Down syndrome and medical experts in the form of our New Parent Packet. Expecting parents can also receive information explaining prenatal testing. When new babies arrive, families receive a gift celebrating their new addition. To request information, contact DSAWM at 616-956-3488 or victoria@dsawm.org for more information.

	<p>Member Financial Assistance</p> <p>DSAWM's Member Financial Assistance Fund is designed to provide financial support to families raising individuals with Down syndrome who need help with certain Down syndrome-related expenses including adoption, education, therapy, adaptive devices, respite, and hospital stays. To apply, visit dsawm.org/programs/financial-assistance.</p>
	<p>Oh, Baby!</p> <p>This baby shower for families who have a child with Down syndrome aged 5 and younger is a celebration and an opportunity for parents and siblings to connect with other families experiencing Down syndrome. Oh, Baby is held in August at the Grand Rapids Children's Museum.</p>
	<p>Parents for Parents</p> <p>Parents for Parents mentors are a group of "veteran" moms and dads who have stood in the shoes of new parents of babies with Down syndrome. If you are interested in being connected to a parent mentor or becoming a mentor, contact DSAWM at 616-956-3488 or director@dsawm.org.</p>
	<p>Weekly Update</p> <p>The Weekly Update newsletter is emailed every Thursday and shares upcoming programs and services from DSAWM and our community partners. For new parents, it is an easy way to get connected and learn about the opportunities available to you and your family. To join the mailing list, visit dsawm.org.</p>
	<p>Access! GR</p> <p>Through a partnership with Access! GR, DSAWM can connect members with the rich arts & cultural scene in West Michigan. Free tickets are available in a limited supply for both ongoing venues and special event venues. Accommodations can be made to make sure the arts are accessible to everyone.</p>
	<p>Holiday Party</p> <p>Every December, DSAWM families gather in Grand Rapids and Kalamazoo to visit with Santa and reconnect with friends. The Grand Rapids Holiday Party is a member-only event and is held at alternating venues around Grand Rapids.</p>
	<p>Member Picnic</p> <p>Each summer, DSAWM families gather at Tunnel Park in Holland for a day of friends, food, and fun in the sun. The Member Picnic is a member only event and is held in July.</p>
	<p>Rock Your Socks Dance</p> <p>Rock your socks off at our annual Rock Your Socks Dance in honor of World Down Syndrome Day (3/21). The event is open to anyone interested in celebrating Down syndrome.</p>



Step Up for Down Syndrome

Step Up for Down Syndrome is the largest Down syndrome awareness event in Michigan and DSAWM's biggest fundraiser. Families, friends, and the public are invited to this annual celebration and walk held each September where we come together to support our loved ones with Down syndrome.

Community Supports

Where to Begin

- ***Supports Coordination: Early On***

Early On Michigan (1800earlyon.org or 1-800-327-5966) provides free services to families who have children (0-3) who have medical problems or are developmentally delayed. Services can include information, evaluation, linking to services, parent network, and financial help.

- ***Finding a Medical Provider for Your Child's Needs***

Looking for a medical provider? The Preferred Medical Provider List is maintained by **Down Syndrome Head Start** and lists doctors, dentists, and other providers recommended by Michigan families experiencing Down syndrome. This list can be viewed at dsawm.org/resources/new-parent-resources. **Please note that Down Syndrome Head Start's website has been down as of November 2018. This list has not been updated since 2017. If you are looking for more up-to-date information, we recommend reaching out on the **Michigan Parents of Children with Down Syndrome Facebook group** at facebook.com/groups/DownSyndromeMichigan.

The Family Center for Children and Youth with Special Health Care Needs (Family Center) (michigan.gov or 1-800-359-3722) is also a helpful resource for Michigan families. The Family Center is the statewide parent-directed center within Children's Special Health Care Services (CSHCS) and the Michigan Department of Health and Human Services (MDHHS). It offers emotional support, information, and connections to community-based resources to families of children and youth with special health care needs, as well as provides parental perspectives and input on health care matters while focusing on families' access to coordinated systems of care.

- ***Paying for Your Child's Healthcare Expenses: CSHCS & CSNF***

Children's Special Health Care Services (CSHCS) of Michigan (michigan.gov or 1-800-359-3722) provides low or no cost supplemental health insurance for a variety of covered medical diagnoses for individuals under 21 years old. While Down syndrome alone is not a qualifying diagnosis, CSHCS covers over 2,700 physical conditions of which many individuals with Down syndrome may experience at least one. To view a complete list of covered conditions and the contact information for each county's CSHCS branch visit michigan.gov/mdhhs.

The Children with Special Needs Fund (michigan.gov/csnfund or 517-241-7420) provides support for children ages 0-21 in Michigan with special health care needs not available through any other funding source. The Fund helps with the purchase of equipment and services that promote optimal health, mobility, and development, enhancing the lives of children and their families.

Get to Know the Community

- **Parent Support Groups**

DSAWM Parents for Parents Mentors are a group of “veteran” moms and dads who provide support for expectant and new parents. If you are interested in being connected to a parent mentor or becoming a mentor, contact DSAWM at 616-956-3488 or director@dsawm.org.

DSAWM Dads’ Night Out, or DNO, invites fathers raising children with Down syndrome to meet at local restaurants and share experience and support. Visit dsawm.org/calendar for upcoming dates or join the [Dads Facebook Page \(Dads Appreciating Down Syndrome – Grand Rapids, MI\)](#).

DSAWM Moms’ Night Out, or MNO, invites mothers raising children with Down syndrome to meet at local restaurants to share experiences and support. Gatherings are held monthly in three locations: Lakeshore (Grand Haven/Muskegon), Grand Rapids, and Kalamazoo. Visit dsawm.org/calendar for upcoming dates.

Facebook Support Groups

- **DSAWM Members and Families** (facebook.com/groups/DSAWMMembersFamilies) is a place for DSAWM members and families to connect, share resources, and give advice and support to others in the Down Syndrome Association of West Michigan community.
- **DSAWM 21 Shades** (facebook.com/groups/dsawm21shades) is open to all families of color and multicultural families who are raising or love a person with Down syndrome in West Michigan.
- **DSAWM Familias Hispanas y Latinas** (facebook.com/groups/dsawmespanol) is open to all DSAWM Hispanic and Latino families.
- **Michigan Parents of Children with Down Syndrome Facebook Group** (facebook.com/groups/DownSyndromeMichigan) is an online community for parents and caregivers in Michigan who have children with Down syndrome and other chromosomal abnormalities. Sharing experiences, asking questions, posting inspiring items, and sharing resources and news from the special needs community are all enthusiastically encouraged!

The Down Syndrome Diagnosis Network maintains a directory of online support groups for families in a variety of topic areas from feeding support to families of color to GI concerns and more. View the directory at dsdiagnosisnetwork.org/resources-for-dsdn-families.

- **National Down Syndrome Organizations**

- **Down Syndrome Diagnosis Network** (dsdiagnosisnetwork.org or 612-460-0765) connects, supports, and provides accurate information to parents – and the medical professionals who serve them – from the time of diagnosis through age 3, while fostering the opportunity for lifelong connections.
- **Down Syndrome Medical Interest Group – USA** (dsmig-usa.org) is a group of health professionals committed to promoting the optimal health care and wellness of individuals with DS across the lifespan.
- **Global Down Syndrome Foundation** (globaldownsyndrome.org or 303-321-6277) is dedicated to significantly improving the lives of people with Down syndrome through Research, Medical Care, Education and Advocacy.
- **LuMind ISD** (lumindidsc.org or 781-825-1300) accelerates research to increase availability of therapeutic, diagnostic, and medical care options and empowers families through education, connections, and support.
- **National Association for Down Syndrome** (nads.org or 630-325-9112) is the oldest organization in the country serving individuals with Down syndrome and their families.
- **National Down Syndrome Society** (ndss.org or 800-221-4602) is a leading human rights organization for all individuals with Down syndrome.
- **National Down Syndrome Congress** (ndsccenter.org or 800-232-6372) is a leading national resource of support and information for anyone touched by or seeking to learn about Down syndrome.

For more information about New & Expectant Parent Resources, visit our website at dsawm.org/resources/new-parent-resources. You are welcome to contact our office with any questions at 616-956-3488 or director@dsawm.org. We are here to support your family!

Follow us!



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[@dsawm](https://www.instagram.com/dsawm)



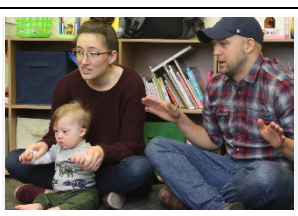




[@dsawm](https://twitter.com/dsawm)

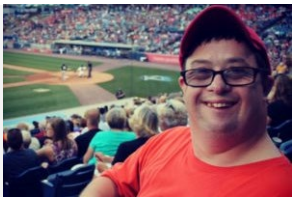




Early Stages (0-5) Resources

DSAWM Early Stages programs and services support families from diagnosis through the early developmental years. Areas of focus include parent support, communication and motor skill development, and socialization.

DSAWM Programs and Services for Early Stages

Learn more about each program by visiting dsawm.org/programs.

	<p>Baby Sign Language</p> <p>With just a few simple signs from American Sign Language, you can start communicating with your child – even before they begin to talk! Signing is fun, easy to do, and great for your child’s development!</p>
	<p>Member Financial Assistance</p> <p>DSAWM’s Member Financial Assistance Fund is designed to provide financial support to families raising individuals with Down syndrome who need help with certain Down syndrome-related expenses including adoption, education, therapy, adaptive devices, respite, and hospital stays.</p>
	<p>Oh, Baby!</p> <p>This baby shower for families who have a child with Down syndrome aged 5 and younger is a celebration and an opportunity for parents and siblings to connect with other families experiencing Down syndrome. Oh, Baby is held in August at the Grand Rapids Children’s Museum.</p>
	<p>Playgroups</p> <p>Playgroups are a fun, social option for promoting development. Playgroup focus varies and includes speech, fine motor, gross motor, communication, and more to meet the various needs of our children.</p>
	<p>Weekly Update</p> <p>The Weekly Update newsletter is emailed every Thursday and shares upcoming programs and services from DSAWM and our community partners. For new parents, it is an easy way to get connected and learn about the opportunities available to you and your family.</p>

	<p>Access! GR</p> <p>Through a partnership with Access! GR, DSAWM can connect members with the rich arts & cultural scene in West Michigan. Free tickets are available in a limited supply for both ongoing venues and special event venues. Accommodations can be made to make sure the arts are accessible to everyone.</p>
	<p>Holiday Party</p> <p>Every December, DSAWM families gather in Grand Rapids and Kalamazoo to visit with Santa and reconnect with friends. The Grand Rapids Holiday Party is a member-only event and is held at the Grand Rapids Public Museum.</p>
	<p>Member Picnic</p> <p>Each summer, DSAWM families gather at Tunnel Park in Holland for a day of friends, food, and fun in the sun. The Member Picnic is a member only event and is held in July.</p>
	<p>Rock Your Socks Dance</p> <p>Rock your socks off at our annual Rock Your Socks Dance in honor of World Down Syndrome Day (3/21). The event is open to anyone interested in celebrating Down syndrome.</p>
	<p>Step Up for Down Syndrome</p> <p>Step Up for Down Syndrome is the largest Down syndrome awareness event in Michigan and DSAWM's biggest fundraiser. Families, friends, and the public are invited to this annual celebration and walk held each September where we come together to support our loved ones with Down syndrome.</p>

Community Supports

Supports Coordination

- **Early On**

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Therapy

Providers listed have indicated that they serve pediatric patients under 18 years of age.

- **Behavior Therapy & Psychology**

- **Defined:** “Applied behavioral analysis (ABA) is a type of therapy that can improve social, communication, and learning skills through positive reinforcement.” – [Healthline](#)
- **West Michigan Providers**

Anchored Family anchoredfamilypsych.com 616-667-9551 Jenison	Hope Network Behavioral Health hopenetwork.org/behavioral-health-services 616-301-8000 Grand Rapids
Behavior Analysts of West Michigan bawmi.com 616-915-2066 (Walker), 616-734-6094 (Kentwood)	Horizons Developmental Resource Center https://www.horizonsdrc.com/ 616-698-0306 Caledonia
BRAINS brainspotential.com 616-365-8920 Grand Rapids	Mark Scheffers, M.Div. LMSW http://www.markscheffers.com/ 269-350-6324 Kalamazoo
Comprehensive Therapy Center therapycenter.org 616-559-1054 Grand Rapids	Pine Rest Christian Mental Health Services pinerest.org 800-678-5500 Grand Rapids
Developmental Enhancement Behavioral Health debh.org 616-499-2218 (Holland), 616-244-2246 (Grandville), 616-604-8492 (Grand Rapids)	Sarah Feaster, LMSW, IMH-E sarahfeaster.com 616-537-2772 Holland
EnCourage Institute for Teaching and Learning, LLC https://encourageinstitute.com/ 616-530-2224 Grand Rapids, Jenison	The Shoreline Center, LLC theshorelinecenter.com 616-935-7606 Grand Haven

- **Feeding Therapy**

- **Defined:** “Feeding therapy, in its simplest form, is when a trained occupational or speech therapist helps teach a child how to eat or eat better.” – [NAPA Center](#)
- Learn more about Feeding Therapy from the [American Speech-Language-Hearing Association](#)
- **West Michigan Providers**

Bronson Outpatient Rehabilitation Center bronsonhealth.com/services/children/treatments/pediatric-rehabilitation 269-544-3230 Kalamazoo	Horizons Developmental Resource Center https://www.horizonsdrc.com/ 616-698-0306 Caledonia
Family Tree Therapies familytreetherapies.com 616-448-7799 Grand Rapids, Rockford	Mary Free Bed Rehabilitation Hospital Pediatric Outpatient Feeding Therapy maryfreebed.com/kids/outpatient 800-528-8989 Grand Rapids
Helen DeVos Intensive Feeding Program spectrumhealth.org/services/helen-devos-childrens-hospital/feeding-programs 616-486-6870 Grand Rapids	The Center for Childhood Development www.thecenterforcd.com 616-667-9551 Jenison, Holland, Kalamazoo
High 5 Speech Therapy high5speechtherapy.com 970-988-6718 Holland, Grand Rapids	Thrive Pediatric Speech & Feeding Therapy, LLC https://www.thrivepediatricsspeech.com/ 616-379-9887 Grandville

- **Music Therapy**

- **Defined:** “Music Therapy is the clinical and evidence-based use of music interventions to accomplish individualized goals within a therapeutic relationship by a credentialed professional who has completed an approved music therapy program.” – [American Music Therapy Association](http://AmericanMusicTherapyAssociation.org)
- **West Michigan Providers**

Edge Water Music Therapy edgewatertherapy.com/our-services-and-programs 269-329-0730 Kalamazoo	West Michigan Music Therapy, LLC westmichiganmt.com Grand Rapids
Franciscan Life Process Center lifeprocesscenter.org/services/music-therapy 616-897-7842 Lowell	Western Michigan University Music Therapy Clinic wmich.edu/musictherapy/clinic 269-387-4679 Kalamazoo
Lakeshore Music Therapy Services sites.google.com/site/lakeshoremusictherapy 616-834-0597 Holland	

- **Occupational Therapy/Sensory Integration**

- **OT Defined:** “Occupational therapists and occupational therapy assistants help people across the lifespan participate in the things they want and need to do

through the therapeutic use of everyday activities (occupations).” – [American Occupational Therapy Association](#).

- **SI Defined:** “Sensory integration involves perceiving, modulating, organizing, and interpreting these sensations to optimize occupational performance and participation.” – [American Occupational Therapy Association](#)
- Learn more about the relationship between Occupational Therapy, Sensory Integration, and Down syndrome at [NDSS.org](#).
- **West Michigan Providers**

BRAINS brainspotential.com 616-365-8920 Grand Rapids	Generation Care generationcare.org 616-935-3300 (Grand Haven), 616-259-4028 (Grand Rapids), 231-737-4374 (Muskegon)
Bronson Outpatient Rehabilitation Center bronsonhealth.com/services/children/treatments/pediatric-rehabilitation 269-544-3230 Kalamazoo	Sensational Steps Therapy sensationalstepstherapy.com 616-402-6997 Grand Haven
Comprehensive Therapy Center therapycenter.org 616-559-1054 Grand Rapids	Sensory Systems Clinic West sensoryclinicwest.com 269-792-2353 Wayland
Conductive Learning Center conductivelearningcenter.org 616-575-0575 Grand Rapids	The Center for Childhood Development thecenterforcd.com 616-667-9551 Jenison, Holland, Kalamazoo
Engage Therapy Center engagetherapycenter.com 616-741-9320 Zeeland	The Shoreline Center, LLC theshorelinecenter.com 616-935-7606 Grand Haven
Family Tree Therapies familytreetherapies.com 616-448-7799 Grand Rapids, Rockford	WMU Marion R. Spear Occupational Therapy Clinic wmich.edu/unifiedclinics/unifiedclinicsaboutot 269-387-7000 Kalamazoo

- **Physical Therapy**

- **Defined:** “Physical therapists are movement experts who improve quality of life through prescribed exercise, hands-on care, and patient education.” – [American Physical Therapy Association](#)
- Learn more about the relationship between Physical Therapy and Down syndrome at [NDSS.org](#).

- **West Michigan Providers**

Bronson Outpatient Rehabilitation Center bronsonhealth.com/services/children/treatments/pediatric-rehabilitation 269-544-3230 Kalamazoo	Generation Care generationcare.org 616-935-3300 (Grand Haven), 616-259-4028 (Grand Rapids), 231-737-4374 (Muskegon)
Comprehensive Therapy Center therapycenter.org 616-559-1054 Grand Rapids	Horizons Developmental Resource Center https://www.horizonsdrc.com/ 616-698-0306 Caledonia
Conductive Learning Center conductivelearningcenter.org 616-575-0575 Grand Rapids	The Center for Childhood Development thecenterforcd.com 616-667-9551 Jenison, Holland, Kalamazoo

- **Recreational Therapy**

- **Defined:** “Recreational therapy, also known as therapeutic recreation, is a systematic process that utilizes recreation and other activity-based interventions to address the assessed needs of individuals with illnesses and/or disabling conditions, as a means to psychological and physical health, recovery and well-being.” – [American Therapeutic Recreation Association](#)
- Examples of Recreational Therapy: Animal Therapy, Athletics/Outdoor Recreation, Hippotherapy (horseback riding), Horticultural Therapy, Visual and Performing Arts. For a listing of day programs and camps that incorporate recreational therapy, visit dsawm.org/school-age-resources and view the dropdowns under the Social Programming/Activities heading.
- **West Michigan Providers**

Life Therapeutic Solutions life-ts.com/Home.aspx 800-925-3152 Wyoming	Legacy Stables & Karin’s Horse Connection (Hippotherapy) karinshorses.com/karins-horse-connection 616-570-1106 Caledonia
Cheff Therapeutic Riding Center (Hippotherapy) cheffcenter.org 269-731-4471 Augusta	Renew Therapeutic Riding Center (Hippotherapy) renewtrc.org 616-227-3639 Holland

- **Speech Therapy**

- **Defined:** “Speech therapy is the assessment and treatment of communication problems and speech disorders.” – [Healthline](#)
- Learn more about the relationship between Speech Therapy and Down syndrome at NDSS.org.

○ **West Michigan Providers**

BRAINS brainspotential.com 616-365-8920 Grand Rapids	High 5 Speech Therapy high5speechtherapy.com 970-988-6718 Holland, Grand Rapids
Bronson Outpatient Rehabilitation Center bronsonhealth.com/services/children/treatments/pediatric-rehabilitation 269-544-3230 Kalamazoo	Horizons Developmental Resource Center https://www.horizonsdrc.com/ 616-698-0306 Caledonia
Building Blocks Therapy Services buildingblocksgr.com 616-259-4207 Grand Rapids	Mitten Speech Therapy mittenspeechtherapy.com 616-730-2184 Grandville
Calvin University Speech and Hearing Clinic calvin.edu/academics/departments-programs/speech-pathology-audiology/speech-clinic/ 616-526-6070 Grand Rapids	South Shore Speech, LLC southshorespeech.com 269-660-1025 Battle Creek
Comprehensive Therapy Center therapycenter.org 616-559-1054 Grand Rapids	The Center for Childhood Development thecenterforcd.com 616-667-9551 Jenison, Holland, Kalamazoo
Duncan Lake Speech Therapy, LLC duncanlakespeechtherapy.com 616-528-0870 Caledonia	The Shoreline Center, LLC theshorelinecenter.com 616-935-7606 Grand Haven
Family Tree Therapies familytreetherapies.com 616-448-7799 Grand Rapids, Rockford	Thrive Pediatric Speech & Feeding Therapy, LLC https://www.thrivepediatricsspeech.com/ 616-379-9887 Grandville
Generation Care generationcare.org 616-935-3300 (Grand Haven), 616-259-4028 (Grand Rapids), 231-737-4374 (Muskegon)	Western Michigan University Speech Therapy Clinic wmich.edu/unifiedclinics/vanriper-0 269-387-7000 Kalamazoo
Grand Haven Speech Partners grandhavenspeech.com 616-414-0891 Grand Haven	

- **Multidisciplinary Therapy**

- **Defined:** Multidisciplinary providers have experience and professional training to practice a variety of therapies.
- **West Michigan Providers**

BRAINS brainspotential.com 616-365-8920 Grand Rapids	High 5 Speech Therapy high5speechtherapy.com 970-988-6718 Holland, Grand Rapids
Bronson Outpatient Rehabilitation Center bronsonhealth.com/services/children/treatments/pediatric-rehabilitation 269-544-3230 Kalamazoo	Horizons Developmental Resource Center https://www.horizonsdrc.com/ 616-698-0306 Caledonia
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Generation Care generationcare.org 616-935-3300 (Grand Haven), 616-259-4028 (Grand Rapids), 231-737-4374 (Muskegon)	

Medical

- **Communicating with Your Physician**

Boston's MassGeneral Hospital For Children (massgeneral.org/children or 888-644-3248) created a Talking to the Doctor Workbook for individuals with Down syndrome that focuses on sharing feelings and asking questions. They also offer remote second opinions to patients and health care providers in the United States. Similarly, **Children's Hospital of Philadelphia** (chop.edu or 800-879-2467) offers a Toolkit for Transitioning to Adult Medical Care for individuals with Down syndrome. View both the workbook and toolkit at dsawm.org/early-stages-resources.

LuMind IDSC (lumindidsc.org or 781-825-1300) has also launched the first-of-its-kind DSC2U, an “online toolkit that provides customized, expert-driven information for people with Down syndrome from age 1 through adulthood. Immediately upon completion of the form, caregivers receive two personalized documents: one for themselves and one to share with their primary healthcare provider. Both documents contain detailed, customized suggestions, follow-up questions, and conversation prompts that are designed to optimize time with a primary care provider and offer caregivers the vocabulary and tools they need to advocate for their loved one.” Learn more at lumindidsc.org.

For support when speaking with dental providers, take a look at **Dentably’s Dental Care Guidance for Caregivers of Patients with Down syndrome** at emergencydentistsusa.com/down-syndrome-and-dental-care.

- ***Finding a Provider***

Looking for a medical provider? The Preferred Medical Provider List is maintained by **Down Syndrome Head Start** and lists doctors, dentists, and other providers recommended by Michigan families experiencing Down syndrome. This list can be viewed at dsawm.org/early-stages-resources. **Please note that Down Syndrome Head Start’s website has been down as of November 2018. This list has not been updated since 2017. If you are looking for more up-to-date information, we recommend reaching out on the **Michigan Parents of Children with Down Syndrome Facebook group** at facebook.com/groups/DownSyndromeMichigan.

Looking for a dentist? The **Special Care Dentistry Association (SCDA)** (scdaonline.org) is a unique international organization of oral health professionals and other individuals who are dedicated to promoting oral health and well-being for people with special needs. A list of Michigan dentists belonging to SCDA can be found on their site. The **Michigan Parents group on Facebook** is also a good resource for finding dental recommendations.

- ***Paying for Your Child’s Healthcare Expenses: CSHCS & CSNF***

Children’s Special Health Care Services (CSHCS) of Michigan (michigan.gov or 1-800-359-3722) provides low or no cost supplemental health insurance for a variety of covered medical diagnoses for individuals under 21 years old. While Down syndrome alone is not a qualifying diagnosis, CSHCS covers over 2,700 physical conditions of which many individuals with Down syndrome may experience at least one. To view a complete list of covered conditions and the contact information for each county’s CSHCS branch visit michigan.gov/mdhhs.

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Financial

- **Local Assistance Programs**

DSAWM Financial Assistance is available to members for expenses related to the following when relating to support, care, or treatment of person with Down syndrome: adoption, respite care, and educational, medical, therapeutic, and adaptive services or devices. DSAWM members are also eligible for our Meal Voucher Program which offsets meal expenses for families whose child with Down syndrome is experiencing an overnight stay in the hospital. Learn more at dsawm.org/programs/financial-assistance.

Family Hope Foundation (familyhopefoundation.org or 616-729-8833) offers scholarships of up to \$1,000 twice a year to West Michigan families for therapies that have little or no insurance coverage.

Lori's Voice (lorisvoice.org) provides funding for equipment, educational resources, or expenses related to medical treatment for individuals up to 21 years old who have neurological, muscular, or other degenerative conditions resulting in permanent impairment or mobility issues.

In need of immediate assistance? Contact **2-1-1**. Michigan 2-1-1 is available 24/7 via phone, text, or online search to connect callers with local community-based organizations across the state that provide support and assistance to those in need. Access their online resources at mi211.org.

- **National Assistance Programs**

- **AMBUCS** (ambucs.org) provides AmTrykes, therapeutic tricycles for children and adults with disabilities, including children with low muscle tone
- **Apraxia Kids** (apraxia-kids.org) provides speech tablets and protective cases to children with a diagnosis of apraxia of speech to aid in communication
- **Cerner Charitable Foundation** (cernercharitablefoundation.org) provides financial assistance for medical care, medical devices, vehicle modification, and travel for those 18 and younger with a disability
- **Different Needz Foundation** (differentneedzfoundation.org) provides grants for medical equipment and/or services, including developmental therapies
- **Friendship Circle's Great Bike Giveaway** (greatbikegiveaway.com) provides an opportunity for children and teens to win an adaptive bike as well as provides a fundraising platform to purchase a bike at a discounted price
- **LifeLine Pilots** (lifelinepilots.org) provides free medical and compassion flights to patients in the Midwest with financial need
- **Maggie Welby Foundation** (maggiewelby.org) provides scholarships to children in kindergarten thru 12th grade whose families demonstrate financial need
- **McLindon Family Foundation** (mclindonfamilyfoundation.org) provides adaptive bicycles for children with special needs
- **Microsoft** (microsoft.com) provides scholarships to promising high school seniors with disabilities who plan to attend a vocational or academic college and target a career in the technology industry

- **Modest Needs** (modestneeds.org) provides short-term financial help for families in crisis situations
- **Montana Melin Foundation** (montanamelinfoundation.com) provides financial assistance to the families of children with Down Syndrome that are facing medical hardships
- **My Gym Foundation** (mygymfoundation.org) provides grants for the purchase of medical and therapy equipment for children with special needs under 18 years old
- **NDSS** (ndss.org) provides scholarships to individuals with Down syndrome in the areas of post-secondary education, entrepreneurship, and self-advocacy
- **Needy Meds** (needymeds.org) provides discounted and free medication programs and other services for low income families
- **Parker Lee Project** (theparkerleeproject.org) provides medical supplies and equipment to children at no cost, including enteral supplies, formula, and incontinence supplies
- **Project Angel Fares** (projectangelfares.com) grants all-expenses-paid trips to children with special needs to visit Morgan's Wonderland – an ultra-accessible theme park in Texas
- **Ruby's Rainbow** (rubysrainbow.org) provides scholarships to individuals with Down syndrome who are pursuing post-secondary education, enrichment, or vocational classes
- **Small Steps in Speech** (smallstepsinspeech.org) grants funds for speech and language disorder therapies for people aged 3-22 years old
- **Special Kids Photography of America** (specialkidsphotography.com) provides grants for family pictures
- **Stepping Stones for Stella** (steppingstonesforstella.org) provides buggies for children with special needs to enjoy outdoors to its fullest
- **UnitedHealthcare Children's Foundation** (uhccf.org) offers grants for kids 16 years old or younger for services health insurance does not cover
- **Wheelchairs 4 Kids** (wheelchairs4kids.org) provides wheelchairs, home and vehicle modifications, as well as other assistive and therapeutic devices for children that have limited mobility
- **Wings of Mercy** (wingseastmi.org) provides free medical flights to patients in eastern Michigan with financial need

For more information about Early Stages Resources, visit our website at dsawm.org/early-stages-resources. You are welcome to contact our office with any questions at 616-956-3488 or director@dsawm.org. We are here to support your family!

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DSAWM






Down Syndrome Association of West Michigan
Empowering individuals. Supporting communities.




School Age (6-13) Resources

DSAWM School Age programs are designed to supplement educational services. Areas of focus include motor skill development, socialization, and building a foundation for a healthy lifestyle.

DSAWM Programs and Services for School Age

Learn more about each program by visiting dsawm.org/programs.

	<p>Buddy Up Tennis</p> <p>Buddy Up Tennis teaches children and teens with Down syndrome the game of tennis while supporting healthy activity and motor function. Athletes aged 5 and older work with professional coaches and one-on-one Buddies.</p>
	<p>Friends Just Like Me</p> <p>Each spring, families experiencing Down syndrome are invited to Grand Rapids Children's Museum for a private event to meet other families on the same journey. Friends Just Like Me is held in May.</p>
	<p>iCan Bike Camp</p> <p>Every even-numbered summer, DSAWM hosts a week-long iCan Bike Camp where children with disabilities ages 8 and older can learn to ride a typical two-wheeled bicycle using proven, research-based methods.</p>
	<p>Member Financial Assistance</p> <p>DSAWM's Member Financial Assistance Fund is designed to provide financial support to families raising individuals with Down syndrome who need help with certain Down syndrome-related expenses including adoption, education, therapy, adaptive devices, respite, and hospital stays.</p>
	<p>Playgroups</p> <p>Playgroups are a fun, social option for promoting development. Playgroup focus varies and includes speech, fine motor, gross motor, communication, and more to meet the various needs of our children.</p>

	<p>Water Ski Clinic</p> <p>DSAWM hosts an Adaptive Water Ski Clinic in partnership with Kentwood Parks and Recreation every summer that focuses on sitting and standing skiing. The clinic is held on Reeds Lake every July.</p>
	<p>Weekly Update</p> <p>The Weekly Update newsletter is emailed every Thursday and shares upcoming programs and services from DSAWM and our community partners. For new parents, it is an easy way to get connected and learn about the opportunities available to you and your family.</p>
	<p>Access! GR</p> <p>Through a partnership with Access! GR, DSAWM can connect members with the rich arts & cultural scene in West Michigan. Free tickets are available in a limited supply for both ongoing venues and special event venues. Accommodations can be made to make sure the arts are accessible to everyone.</p>
	<p>Holiday Party</p> <p>Every December, DSAWM families gather in Grand Rapids and Kalamazoo to visit with Santa and reconnect with friends. The Grand Rapids Holiday Party is a member-only event and is held at the Grand Rapids Public Museum.</p>
	<p>Member Picnic</p> <p>Each summer, DSAWM families gather at Tunnel Park in Holland for a day of friends, food, and fun in the sun. The Member Picnic is a member only event and is held in July.</p>
	<p>Rock Your Socks Dance</p> <p>Rock your socks off at our annual Rock Your Socks Dance in honor of World Down Syndrome Day (3/21). The event is open to anyone interested in celebrating Down syndrome.</p>
	<p>Step Up for Down Syndrome</p> <p>Step Up for Down Syndrome is the largest Down syndrome awareness event in Michigan and DSAWM's biggest fundraiser. Families, friends, and the public are invited to this annual celebration and walk held each September where we come together to support our loved ones with Down syndrome.</p>

Community Supports

Education

- ***Inclusion, IEP Support, & Advocacy***

Questions or concerns about your child's education? Michigan Alliance for Families (michiganallianceforfamilies.org or 800-552-4821) is the leading statewide resource to connect families of children with disabilities to resources to help improve their children's education. The organization and its parent mentors are available year-round to help facilitate parent involvement as a means of improving educational services and outcomes for students with disabilities.

IEP Support & Advocacy

Kent ISD collaborated with the **Parent Advisors for Special Education (PASE)** to develop an informational handbook to make the IEP process more manageable and user friendly for parents. View the handbook at dsawm.org/school-age-resources.

Down Syndrome: Guidelines for Inclusive Education was created by NDSS and Down Syndrome Education International with the aim to improve the development and educational outcomes for individuals with Down syndrome from birth to adult life by providing educators, therapists, early interventionists, parents and school districts with a guide to evidence-based practices. The guide is available to download at ndss.org.

Many school districts have **parent advisory committees (PACs)** that represent and advocate for students who receive special education services.

Allegan AESA alleganaesa.org 269-512-7700	Kent ISD kentisd.org 616-364-1333	Ottawa Area ISD oaisd.org 616- 738-8940
Barry ISD barryisd.org 269- 945-9545	Mecosta-Osceola ISD moisd.org 231-796-3543	Van Buren ISD vbisd.org 269-674-8001
Ionia County ISD ioniaisd.org 616-527-4900	Montcalm Area ISD maisd.com 616-225-4700	West Shore (Oceana) ESD wsesd.org 231- 757-3716
Kalamazoo RESA kresa.org 269-250-9200	Muskegon Area ISD muskegonisd.org 231-777-2637	

Need an educational advocate's expertise, advice, or mediation support? Contact one of these organizations or individuals:

ACCESS Education accesseducationmi.com 888- 834-4340	Dispute Resolution Center of West Michigan drcwm.org 616-774-0121
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The Arc of Michigan arcmi.org 800-292-7851	Michigan Alliance for Families michiganallianceforfamilies.org 800-552-4821
Council of Parent Attorneys & Advocates copaa.org	Wrightslaw Yellow Pages for Kids yellowpagesforkids.com

State Law Resources & Mediation Options

- **Family Matters** (michigan.gov or 1-888-320-8384) is an outreach effort from the Michigan Department of Education's Office of Special Education to provide parents with information about special education and other resources.
- **Special Education Mediation Services** (mikids1st.org or 833-543-7178) provides mediation, facilitation, and training services for working through disagreements so that children with disabilities promptly receive the services they need to develop and succeed in school.
- For more information about the **Michigan Department of Education Special Education** branch, visit michigan.gov or call 888-320-8384.
- View a comprehensive overview of **Michigan Special Education Laws & Regulations** at michigan.gov.

Federal Law Resources

- **IDEA (Individuals with Disabilities Education Act)** is a law that makes available a free appropriate public education to eligible children with disabilities throughout the nation and ensures special education and related services to those children. Learn more at sites.ed.gov/idea.
- **Section 504** ensures children with disabilities have equal access to education, including accommodations and modifications. Learn more at wrightslaw.com/info/sec504.index.htm.
- **Wrightslaw** is a nationally recognized source for reliable information about special education law and advocacy. Learn more at wrightslaw.com.

Teacher Information Packet

We also encourage parents to share our Teacher Information Packet with educators working with your children. The packet is for educators of students with Down syndrome in grades K-5 and is intended to assist each classroom teacher in (1) getting to know his or her student with Down syndrome and (2) building a comfortable and effective learning environment for every student.

The material addresses a wide range of subjects—from subject adaptation and student supports to social inclusion. A Getting to Know Me section is included for parents/caregivers and their children to complete together, as is a sample letter to distribute to parents of the other students in your child's class. Download the packet at dsawm.org/school-age-resources.

Therapy

Providers listed have indicated that they serve pediatric patients under 18 years of age.

- **Behavior Therapy & Psychology**

- **Defined:** “Applied behavioral analysis (ABA) is a type of therapy that can improve social, communication, and learning skills through positive reinforcement.” – [Healthline](#)
- **West Michigan Providers**

Anchored Family anchoredfamilypsych.com 616-667-9551 Jenison	Hope Network Behavioral Health hopenetwork.org/behavioral-health-services 616-301-8000 Grand Rapids
Behavior Analysts of West Michigan bawmi.com 616-915-2066 (Walker), 616-734-6094 (Kentwood)	Horizons Developmental Resource Center https://www.horizonsdrc.com/ 616-698-0306 Caledonia
BRAINS brainspotential.com 616-365-8920 Grand Rapids	Mark Scheffers, M.Div. LMSW http://www.markscheffers.com/ 269-350-6324 Kalamazoo
Comprehensive Therapy Center therapycenter.org 616-559-1054 Grand Rapids	Pine Rest Christian Mental Health Services pinerest.org 800-678-5500 Grand Rapids
Developmental Enhancement Behavioral Health debh.org 616-499-2218 (Holland), 616-244-2246 (Grandville), 616-604-8492 (Grand Rapids)	Sarah Feaster, LMSW, IMH-E sarahfeaster.com 616-537-2772 Holland
EnCourage Institute for Teaching and Learning, LLC https://encourageinstitute.com/ 616-530-2224 Grand Rapids, Jenison	The Shoreline Center, LLC theshorelinecenter.com 616-935-7606 Grand Haven

- **Feeding Therapy**

- **Defined:** “Feeding therapy, in its simplest form, is when a trained occupational or speech therapist helps teach a child how to eat or eat better.” – [NAPA Center](#)
- Learn more about Feeding Therapy from the [American Speech-Language-Hearing Association](#)

- **West Michigan Providers**

Bronson Outpatient Rehabilitation Center bronsonhealth.com/services/children/treatments/pediatric-rehabilitation 269-544-3230 Kalamazoo	Horizons Developmental Resource Center https://www.horizonsdrc.com/ 616-698-0306 Caledonia
Family Tree Therapies familytreetherapies.com 616-448-7799 Grand Rapids, Rockford	Mary Free Bed Rehabilitation Hospital Pediatric Outpatient Feeding Therapy maryfreebed.com/kids/outpatient 800-528-8989 Grand Rapids
Helen DeVos Intensive Feeding Program spectrumhealth.org/services/helen-devos-childrens-hospital/feeding-programs 616-486-6870 Grand Rapids	The Center for Childhood Development www.thecenterforcd.com 616-667-9551 Jenison, Holland, Kalamazoo
High 5 Speech Therapy high5speechtherapy.com 970-988-6718 Holland, Grand Rapids	Thrive Pediatric Speech & Feeding Therapy, LLC https://www.thrivepediatricspeech.com/ 616-379-9887 Grandville

- **Music Therapy**

- **Defined:** “Music Therapy is the clinical and evidence-based use of music interventions to accomplish individualized goals within a therapeutic relationship by a credentialed professional who has completed an approved music therapy program.” – [American Music Therapy Association](http://americanmusictherapy.org/)
- **West Michigan Providers**

Edge Water Music Therapy edgewatertherapy.com/our-services-and-programs 269-329-0730 Kalamazoo	West Michigan Music Therapy, LLC westmichiganmt.com Grand Rapids
Franciscan Life Process Center lifeprocesscenter.org/services/music-therapy 616-897-7842 Lowell	Western Michigan University Music Therapy Clinic wmich.edu/musictherapy/clinic 269-387-4679 Kalamazoo
Lakeshore Music Therapy Services sites.google.com/site/lakeshoremusictherapy 616-834-0597 Holland	

- **Occupational Therapy/Sensory Integration**

- **OT Defined:** “Occupational therapists and occupational therapy assistants help people across the lifespan participate in the things they want and need to do through the therapeutic use of everyday activities (occupations).” – [American Occupational Therapy Association](#).
- **SI Defined:** “Sensory integration involves perceiving, modulating, organizing, and interpreting these sensations to optimize occupational performance and participation.” – [American Occupational Therapy Association](#)
- Learn more about the relationship between Occupational Therapy, Sensory Integration, and Down syndrome at [NDSS.org](#).
- **West Michigan Providers**

BRAINS brainspotential.com 616-365-8920 Grand Rapids	Generation Care generationcare.org 616-935-3300 (Grand Haven), 616-259-4028 (Grand Rapids), 231-737-4374 (Muskegon)
Bronson Outpatient Rehabilitation Center bronsonhealth.com/services/children/treatments/pediatric-rehabilitation 269-544-3230 Kalamazoo	Sensational Steps Therapy sensationalstepstherapy.com 616-402-6997 Grand Haven
Comprehensive Therapy Center therapycenter.org 616-559-1054 Grand Rapids	Sensory Systems Clinic West sensoryclinicwest.com 269-792-2353 Wayland
Conductive Learning Center conductivelearningcenter.org 616-575-0575 Grand Rapids	The Center for Childhood Development thecenterforcd.com 616-667-9551 Jenison, Holland, Kalamazoo
Engage Therapy Center engagetherapycenter.com 616-741-9320 Zeeland	The Shoreline Center, LLC theshorelinecenter.com 616-935-7606 Grand Haven
Family Tree Therapies familytreetherapies.com 616-448-7799 Grand Rapids, Rockford	WMU Marion R. Spear Occupational Therapy Clinic wmich.edu/unifiedclinics/unifiedclinicsaboutot 269-387-7000 Kalamazoo

- **Physical Therapy**

- **Defined:** “Physical therapists are movement experts who improve quality of life through prescribed exercise, hands-on care, and patient education.” – [American Physical Therapy Association](#)
- Learn more about the relationship between Physical Therapy and Down syndrome at [NDSS.org](#).
- **West Michigan Providers**

Bronson Outpatient Rehabilitation Center bronsonhealth.com/services/children/treatments/pediatric-rehabilitation 269-544-3230 Kalamazoo	Generation Care generationcare.org 616-935-3300 (Grand Haven), 616-259-4028 (Grand Rapids), 231-737-4374 (Muskegon)
Comprehensive Therapy Center therapycenter.org 616-559-1054 Grand Rapids	Horizons Developmental Resource Center https://www.horizonsdrc.com/ 616-698-0306 Caledonia
Conductive Learning Center conductivelearningcenter.org 616-575-0575 Grand Rapids	The Center for Childhood Development thecenterforcd.com 616-667-9551 Jenison, Holland, Kalamazoo

- **Recreational Therapy**

- **Defined:** “Recreational therapy, also known as therapeutic recreation, is a systematic process that utilizes recreation and other activity-based interventions to address the assessed needs of individuals with illnesses and/or disabling conditions, as a means to psychological and physical health, recovery and well-being.” – [American Therapeutic Recreation Association](#)
- Examples of Recreational Therapy: Animal Therapy, Athletics/Outdoor Recreation, Hippotherapy (horseback riding), Horticultural Therapy, Visual and Performing Arts. For a listing of day programs and camps that incorporate recreational therapy, visit dsawm.org/school-age-resources and view the dropdowns under the Social Programming/Activities heading.
- **West Michigan Providers**

Life Therapeutic Solutions life-ts.com/Home.aspx 800-925-3152 Wyoming	Legacy Stables & Karin’s Horse Connection (Hippotherapy) karinshorses.com/karins-horse-connection 616-570-1106 Caledonia
Cheff Therapeutic Riding Center (Hippotherapy) cheffcenter.org 269-731-4471 Augusta	Renew Therapeutic Riding Center (Hippotherapy) renewtrc.org 616-227-3639 Holland

- **Speech Therapy**

- **Defined:** “Speech therapy is the assessment and treatment of communication problems and speech disorders.” – [Healthline](#)
- Learn more about the relationship between Speech Therapy and Down syndrome at [NDSS.org](#).
- **West Michigan Providers**

BRAINS brainspotential.com 616-365-8920 Grand Rapids	High 5 Speech Therapy high5speechtherapy.com 970-988-6718 Holland, Grand Rapids
Bronson Outpatient Rehabilitation Center bronsonhealth.com/services/children/treatments/pediatric-rehabilitation 269-544-3230 Kalamazoo	Horizons Developmental Resource Center https://www.horizonsdrc.com/ 616-698-0306 Caledonia
Building Blocks Therapy Services buildingblocksgsr.com 616-259-4207 Grand Rapids	Mitten Speech Therapy mittenspeechtherapy.com 616-730-2184 Grandville
Calvin University Speech and Hearing Clinic calvin.edu/academics/departments-programs/speech-pathology-audiology/speech-clinic/ 616-526-6070 Grand Rapids	South Shore Speech, LLC southshorespeech.com 269-660-1025 Battle Creek
Comprehensive Therapy Center therapycenter.org 616-559-1054 Grand Rapids	The Center for Childhood Development thecenterforcd.com 616-667-9551 Jenison, Holland, Kalamazoo
Duncan Lake Speech Therapy, LLC duncanlakespeechtherapy.com 616-528-0870 Caledonia	The Shoreline Center, LLC theshorelinecenter.com 616-935-7606 Grand Haven
Family Tree Therapies familytreetherapies.com 616-448-7799 Grand Rapids, Rockford	Thrive Pediatric Speech & Feeding Therapy, LLC https://www.thrivepediatricspeech.com/ 616-379-9887 Grandville

Generation Care generationcare.org 616-935-3300 (Grand Haven), 616-259-4028 (Grand Rapids), 231-737-4374 (Muskegon)	Western Michigan University Speech Therapy Clinic wmich.edu/unifiedclinics/vanriper-0 269-387-7000 Kalamazoo
Grand Haven Speech Partners grandhavenspeech.com 616-414-0891 Grand Haven	

- **Multidisciplinary Therapy**

- **Defined:** Multidisciplinary providers have experience and professional training to practice a variety of therapies.
- **West Michigan Providers**

BRAINS brainspotential.com 616-365-8920 Grand Rapids	High 5 Speech Therapy high5speechtherapy.com 970-988-6718 Holland, Grand Rapids
Bronson Outpatient Rehabilitation Center bronsonhealth.com/services/children/treatments/pediatric-rehabilitation 269-544-3230 Kalamazoo	Horizons Developmental Resource Center https://www.horizonsdrc.com/ 616-698-0306 Caledonia
Comprehensive Therapy Center therapycenter.org 616-559-1054 Grand Rapids	The Center for Childhood Development thecenterforcd.com 616-667-9551 Jenison, Holland, Kalamazoo
Conductive Learning Center conductivelearningcenter.org 616-575-0575 Grand Rapids	The Shoreline Center, LLC theshorelinecenter.com 616-935-7606 Grand Haven
Family Tree Therapies familytreetherapies.com 616-448-7799 Grand Rapids, Rockford	Thrive Pediatric Speech & Feeding Therapy, LLC https://www.thrivepediatricsspeech.com/ 616-379-9887 Grandville
Generation Care generationcare.org 616-935-3300 (Grand Haven), 616-259-4028 (Grand Rapids), 231-737-4374 (Muskegon)	

Social Programming / Activities

- Arts**

Artists Creating Together artistscreatingtogether.org 616-885-5866 Grand Rapids	The Habitat Performing Arts Center Adaptive Dance thehabitatpac.com/adaptive-dance Kalamazoo
Grand Rapids Ballet Explorer Dance grballet.com/grand-rapids-ballet-school/adaptive-dance 616-454-4771 Grand Rapids	

- Athletics**

All Starz Bowling League hosted at Eastbrook Lanes 616-644-4567 or sgbowl2000@yahoo.com (League Coordinator: Betty Goldman) Grand Rapids	Special Olympics Michigan somi.org/southwest-region 616-583-1202 Multiple locations
American Youth Soccer Organization (AYSO) VIP Program ayso.org/play/vip Multiple locations	West Michigan Miracle League wmml.org 616-481-0481 Rockford
Kentwood Parks and Recreation Adaptive Recreation kentwood.us/city_services/city_department/s/parks_and_recreation/adaptive.php 616-656-5270 Kentwood	

- Animals/Nature**

Fellinlove Farm fellinlovefarm.com 616-283-7555 Holland	The Lemonade Farmhouse facebook.com/thelemonadefarmhouse 616-808-1114 Allendale
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- Camps**

Camp Sunshine campsunshinemichigan.org Holland Ages 12-50	O.U.R. Camp ourcampinc.org Northville Ages 3-13
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IKUS (Indian Trails Camp) ikuslife.org/services/indian-trails-camp Grand Rapids	Camp Grace Bentley campgracebentley.org Burtchville Ages 6-17
Skyline Camp & Retreat Center campskyline.org/special-needs-camps Birmingham Ages 13+	St. Francis Camp saintfranciscamp.org/summer-camp.htm Jerome Ages 8+
CranHill Ranch Friendship Camp cranhillranch.com/summer-camps Rodney Ages 15+	Christian Reformed Conference Grounds crcg.org/camping/special-needs-week Grand Haven Ages 5+
Pioneer Trails Day Camp pioneerresources.org/pioneer-trails Muskegon Ages 6-26	Camp Roger camproger.org Rockford Grades K-9
Pine Ridge Bible Camp – Freddy’s Friends pineridgecamp.com/special-needs-camps Cedar Springs Ages 14+	Camp Geneva campgeneva.org Holland Ages 6+
Bloomfield SCAMP bloomfieldscamp.com West Bloomfield Ages 3-26	Spring Hill Camp springhillexperiences.com Ada, Evar
Clarkston SCAMP clarkstonscamp.org Clarkston Ages 3-40	Camp Tall Turf tallturf.org Grand Rapids
Sidekicks West Michigan sidekickswestmichigan.com locations vary **provide day activities for individuals of all ages	

Respite

- **Understanding Respite**

Respite care provides the primary caregiver(s) with temporary relief from caregiving, while their loved one continues to receive care in a safe environment. Respite services can take place in your home or at day centers or overnight facilities.

The Family Guide to Respite for Children in Michigan was created by the state to help caregivers understand and find respite in the state for children aged 0-18. Find the guide online at michigan.gov.

- ***Finding a Provider***

- **ARCH National Respite Network** (archrespite.org) a directory of certified respite providers across the state. Use their directory to search for a provider in your area.
- **Network 180** (network180.org or 616-336-3909), the community mental health authority for Kent county, maintains a directory of contracted providers and their services, including respite. Find it on their website at network180.org/locate-services.
- **ASK Family Services** (askforkids.org or 269-343-5896) in Kalamazoo has a Family Care Coordination program that provides services to families of children with mental health or developmental challenges in Kalamazoo county, including identifying local providers.
- Some parents have had success searching for providers on popular sites like **care.com** or by posting on college job boards. Students studying in areas including occupational therapy and special education are often searching for opportunities to gain experience working with individuals with special needs.

- ***Annual Respite Events***

Several annual respite events are hosted by organizations around the country for parents and families.

- **A Mother's Rest** provides weekend respite opportunities for parents and caregivers of children with physical and cognitive disabilities, foster/adoptive parents, special educators, spouses caring for injured or chronically ill husbands/wives, spouses of Wounded Warriors, as well as those caring for their own parents facing Alzheimer's/Dementia and other age-related illnesses at home. Learn more at amothersrest.org.
- **DSDN Rockin' Mom & Dad Retreats** are offered annually for parents of children with Down syndrome. Learn more at dsdiagnosisnetwork.org/dsdn-retreat.
- **LuMIND IDSC Family Weekend** is offered every September for families who have a child with Down syndrome to enjoy a fun-filled weekend at Great Wolf Lodge. Learn more at lumindidsc.org.

Medical

- ***Communicating with Your Physician***

Boston's MassGeneral Hospital For Children (massgeneral.org/children or 888-644-3248) created a Talking to the Doctor Workbook for individuals with Down syndrome that focuses on sharing feelings and asking questions. They also offer remote second opinions to patients and health care providers in the United States. Similarly, **Children's Hospital of Philadelphia** (chop.edu or 800-879-2467) offers a Toolkit for Transitioning to Adult Medical Care for individuals with Down syndrome. View both the workbook and toolkit at dsawm.org/school-age-resources.

LuMind IDSC (lumindidsc.org or 781-825-1300) has also launched the first-of-its-kind DSC2U, an “online toolkit that provides customized, expert-driven information for people with Down syndrome from age 1 through adulthood. Immediately upon completion of the form, caregivers receive two personalized documents: one for themselves and one to share with their primary healthcare provider. Both documents contain detailed, customized suggestions, follow-up questions, and conversation prompts that are designed to optimize time with a primary care provider and offer caregivers the vocabulary and tools they need to advocate for their loved one.” Learn more at lumindidsc.org.

For support when speaking with dental providers, take a look at **Dentably’s Dental Care Guidance for Caregivers of Patients with Down syndrome** at emergencydentistsusa.com/down-syndrome-and-dental-care.

- ***Finding a Provider***

Looking for a medical provider? The Preferred Medical Provider List is maintained by **Down Syndrome Head Start** and lists doctors, dentists, and other providers recommended by Michigan families experiencing Down syndrome. This list can be viewed at dsawm.org/school-age-resources. **Please note that Down Syndrome Head Start’s website has been down as of November 2018. This list has not been updated since 2017. If you are looking for more up-to-date information, we recommend reaching out on the **Michigan Parents of Children with Down Syndrome Facebook group** at facebook.com/groups/DownSyndromeMichigan.

Looking for a dentist? The **Special Care Dentistry Association (SCDA)** (scaonline.org) is a unique international organization of oral health professionals and other individuals who are dedicated to promoting oral health and well-being for people with special needs. A list of Michigan dentists belonging to SCDA can be found on their site. The **Michigan Parents group on Facebook** is also a good resource for finding dental recommendations.

- ***Paying for Your Child’s Healthcare Expenses: CSHCS & CSNF***

Children’s Special Health Care Services (CSHCS) of Michigan (michigan.gov or 1-800-359-3722) provides low or no cost supplemental health insurance for a variety of covered medical diagnoses for individuals under 21 years old. While Down syndrome alone is not a qualifying diagnosis, CSHCS covers over 2,700 physical conditions of which many individuals with Down syndrome may experience at least one. To view a complete list of covered conditions and the contact information for each county’s CSHCS branch visit michigan.gov/mdhhs.

The Children with Special Needs Fund (michigan.gov/csnfund or 517-241-7420) provides support for children ages 0-21 in Michigan with special health care needs not available through any other funding source. The Fund helps with the purchase of equipment and services that promote optimal health, mobility, and development, enhancing the lives of children and their families.

Financial

- **Local Assistance Programs**

DSAWM Financial Assistance is available to members for expenses related to the following when relating to support, care, or treatment of person with Down syndrome: adoption, respite care, and educational, medical, therapeutic, and adaptive services or devices. DSAWM members are also eligible for our Meal Voucher Program which offsets meal expenses for families whose child with Down syndrome is experiencing an overnight stay in the hospital. Learn more at dsawm.org/programs/financial-assistance.

Family Hope Foundation (familyhopefoundation.org or 616-729-8833) offers scholarships of up to \$1,000 twice a year to West Michigan families for therapies that have little or no insurance coverage.

Lori's Voice (lorisvoice.org) provides funding for equipment, educational resources, or expenses related to medical treatment for individuals up to 21 years old who have neurological, muscular, or other degenerative conditions resulting in permanent impairment or mobility issues.

In need of immediate assistance? Contact **2-1-1**. Michigan 2-1-1 is available 24/7 via phone, text, or online search to connect callers with local community-based organizations across the state that provide support and assistance to those in need. Access their online resources at mi211.org.

- **National Assistance Programs**

- **AMBUCS** (ambucs.org) provides AmTrykes, therapeutic tricycles for children and adults with disabilities, including children with low muscle tone
- **Apraxia Kids** (apraxia-kids.org) provides speech tablets and protective cases to children with a diagnosis of apraxia of speech to aid in communication
- **Cerner Charitable Foundation** (cernercharitablefoundation.org) provides financial assistance for medical care, medical devices, vehicle modification, and travel for those 18 and younger with a disability
- **Different Needz Foundation** (differentneedzfoundation.org) provides grants for medical equipment and/or services, including developmental therapies
- **Friendship Circle's Great Bike Giveaway** (greatbikegiveaway.com) provides an opportunity for children and teens to win an adaptive bike as well as provides a fundraising platform to purchase a bike at a discounted price
- **LifeLine Pilots** (lifelinepilots.org) provides free medical and compassion flights to patients in the Midwest with financial need
- **Maggie Welby Foundation** (maggiewelby.org) provides scholarships to children in kindergarten thru 12th grade whose families demonstrate financial need
- **McLindon Family Foundation** (mclindonfamilyfoundation.org) provides adaptive bicycles for children with special needs
- **Microsoft** (microsoft.com) provides scholarships to promising high school seniors with disabilities who plan to attend a vocational or academic college and target a career in the technology industry

- **Modest Needs** (modestneeds.org) provides short-term financial help for families in crisis situations
- **Montana Melin Foundation** (montanamelinfoundation.com) provides financial assistance to the families of children with Down Syndrome that are facing medical hardships
- **My Gym Foundation** (mygymfoundation.org) provides grants for the purchase of medical and therapy equipment for children with special needs under 18 years old
- **NDSS** (ndss.org) provides scholarships to individuals with Down syndrome in the areas of post-secondary education, entrepreneurship, and self-advocacy
- **Needy Meds** (needymeds.org) provides discounted and free medication programs and other services for low income families
- **Parker Lee Project** (theparkerleeproject.org) provides medical supplies and equipment to children at no cost, including enteral supplies, formula, and incontinence supplies
- **Project Angel Fares** (projectangelfares.com) grants all-expenses-paid trips to children with special needs to visit Morgan's Wonderland – an ultra-accessible theme park in Texas
- **Ruby's Rainbow** (rubysrainbow.org) provides scholarships to individuals with Down syndrome who are pursuing post-secondary education, enrichment, or vocational classes
- **Small Steps in Speech** (smallstepsinspeech.org) grants funds for speech and language disorder therapies for people aged 3-22 years old
- **Special Kids Photography of America** (specialkidsphotography.com) provides grants for family pictures
- **Stepping Stones for Stella** (steppingstonesforstella.org) provides buggies for children with special needs to enjoy outdoors to its fullest
- **UnitedHealthcare Children's Foundation** (uhccf.org) offers grants for kids 16 years old or younger for services health insurance does not cover
- **Wheelchairs 4 Kids** (wheelchairs4kids.org) provides wheelchairs, home and vehicle modifications, as well as other assistive and therapeutic devices for children that have limited mobility
- **Wings of Mercy** (wingseastmi.org) provides free medical flights to patients in eastern Michigan with financial need

For more information about School Age Resources, visit our website at dsawm.org/school-age-resources. You are welcome to contact our office with any questions at 616-956-3488 or director@dsawm.org. We are here to support your family!

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[@dsawm](https://twitter.com/dsawm)









Teen & Adult (14+) Resources

DSAWM Teen & Adult programs are designed to support the transition to adulthood and beyond. Areas of focus include developing skills to create independence, leading a healthy lifestyle, and community integration.

DSAWM Programs and Services for Teens & Adults

Learn more about each program by visiting dsawm.org/programs.

	<p>Book Club</p> <p>Teens and adults aged 16 and older with Down syndrome meet to discuss books selected by Next Chapter Book Club. Book Club meets twice a month and is open to all reading levels, including non-readers.</p>
	<p>Buddy Up Tennis</p> <p>Buddy Up Tennis teaches children and teens with Down syndrome the game of tennis while supporting healthy activity and motor function. Athletes aged 5 and older work with professional coaches and one-on-one Buddies.</p>
	<p>Cooking Capers</p> <p>Teens and adults with Down syndrome aged 16 and older learn culinary terminology, cooking methods, measurement, and kitchen safety while crafting a delicious, healthy, gluten-free meal. Cooking Capers meets twice a month during the school year.</p>
	<p>iCan Bike Camp</p> <p>Every even-numbered summer, DSAWM hosts a week-long iCan Bike Camp where children with disabilities ages 8 and older can learn to ride a typical two-wheeled bicycle using proven, research-based methods.</p>
	<p>Member Financial Assistance</p> <p>DSAWM's Member Financial Assistance Fund is designed to provide financial support to families raising individuals with Down syndrome who need help with certain Down syndrome-related expenses including adoption, education, therapy, adaptive devices, respite, and hospital stays.</p>

	<p>Rapid Runners</p> <p>In this summer running program, teens and adults with Down syndrome aged 14 and older train for a 5K race by following individualized training plans based on the Couch to 5K program.</p>
	<p>Shape Up</p> <p>Shape Up is a health and fitness program for people with Down syndrome aged 14 and older. The weekly class consists of 45 minutes of nutrition instruction and 45 minutes of aerobic exercise.</p>
	<p>Skill Building Series</p> <p>The Skill Building Series teaches life skills such as grocery shopping, resume preparation, public speaking, and navigating the city to foster independence for teens and adults with Down syndrome.</p>
	<p>Water Ski Clinic</p> <p>DSAWM hosts an Adaptive Water Ski Clinic in partnership with Kentwood Parks and Recreation every summer that focuses on sitting and standing skiing. The clinic is held on Reeds Lake every July.</p>
	<p>Weekly Update</p> <p>The Weekly Update newsletter is emailed every Thursday and shares upcoming programs and services from DSAWM and our community partners. For new parents, it is an easy way to get connected and learn about the opportunities available to you and your family.</p>
	<p>Access! GR</p> <p>Through a partnership with Access! GR, DSAWM can connect members with the rich arts & cultural scene in West Michigan. Free tickets are available in a limited supply for both ongoing venues and special event venues. Accommodations can be made to make sure the arts are accessible to everyone.</p>
	<p>Holiday Party</p> <p>Every December, DSAWM families gather in Grand Rapids and Kalamazoo to visit with Santa and reconnect with friends. The Grand Rapids Holiday Party is a member-only event and is held at the Grand Rapids Public Museum.</p>
	<p>Member Picnic</p> <p>Each summer, DSAWM families gather at Tunnel Park in Holland for a day of friends, food, and fun in the sun. The Member Picnic is a member only event and is held in July.</p>



Rock Your Socks Dance

Rock your socks off at our annual Rock Your Socks Dance in honor of World Down Syndrome Day (3/21). The event is open to anyone interested in celebrating Down syndrome.



Step Up for Down Syndrome

Step Up for Down Syndrome is the largest Down syndrome awareness event in Michigan and DSAWM's biggest fundraiser. Families, friends, and the public are invited to this annual celebration and walk held each September where we come together to support our loved ones with Down syndrome.

Community Supports

Transitions (18-26)

- **Getting Services**

Once your child turns 18, a number of resources are available to assist in the process of transitioning to adulthood. Begin by connecting with your county's **Community Mental Health** organization. The organization will assign a Supports Coordinator to assist with everything from understanding benefits to identifying housing options to CLS (community living supports) coordination.

Network 180 (Kent County) network180.org 616-336-3909	Ottawa County Community Mental Health (Ottawa County) miottawa.org/health/cmh 616-392-1873	Integrated Services of Kalamazoo (Kalamazoo County) iskzoo.org 269-373-6000
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Find your county's CMH provider by visiting michigan.gov/mdhhs.

If you need assistance getting started, **Disability Advocates of Kent County's Family Support** team is available to answer your questions and offer guidance. Visit dakc.us/family-support or call 616-949-1100.

- **Benefits & Guardianship**

Understanding what government and financial benefits your child qualifies for upon turning 18 is critical to navigating the transitions process, especially as you consider what guardianship options are the best fit for your child and family. While your Community Mental Health Supports Coordinator should provide you with this information, the organizations below are also knowledgeable and prepared to answer your questions about benefits and guardianship.

- **The Arc** (thearc.org or 202-534-3700) provides information and guidance on a number of topics including Social Security benefits, Medicaid, and community mental health services. Visit their website at thearc.org and use the Find a Chapter button to search for your local Arc office.

- **Disability Advocates of Kent County** (dakc.us or 616-949-1100) has two departments that may be utilized for questions related to benefits and guardianship. Their Benefits Planning team can assist with SSI/SSDI and DHHS applications, explain benefit interactions, and help you plan for the future. Their Family Support team can answer questions about Independent Living Skills, Self Determination, Financial Transition Planning and Supplemental Income Resources, Accessing Community Living and Home Help Supports, and Guardianship and Power of Attorney.
- **Parent/Caregiver Packet: Guardianship, Power of Attorney, and Social Security** was compiled in 2019 by a DAKC's Family Support staff member. Please note that some information may now be out-of-date, but the packet should provide a good overview of the topics presented. View the packet by visiting dsawm.org/teen-adult-resources.
- **Michigan Alliance for Families** (michiganallianceforfamilies.org or 800-552-4821) offers extensive online resources, including pre-recorded and live webinars, about guardianship and alternative options, as well as supported decision making.

Something you may want to consider when reviewing benefits is a **MiABLE Account**. MiABLE accounts allow people with disabilities to save for current and future expenses without jeopardizing eligibility for government benefits. Visit savewithable.com to learn more.

The National Down Syndrome Society recently published **Financial Wellness: A Guide for Individuals with Disabilities, their Families and Caregivers** in partnership with the Voya Cares program at Voya Financial to provide comprehensive information and solutions to address the unique, and oftentimes fluctuating, financial needs of the disability community. Visit ndss.org to access the guide.

• **Education**

In the state of Michigan, students receiving special education services are eligible to continue receiving those services to age 26. As your child approaches 18 years old, consider contacting special education agencies or your school district's ISD to discuss options available to your child.

- **Michigan Alliance for Families** (michiganallianceforfamilies.org or 800-552-4821) is the leading statewide resource to connect families of children with disabilities to resources to help improve their children's education. Their website has a section dedicated solely to Transition To Adulthood. Topics covered include Adult Service Agencies, Alternatives to Guardianship, Career/ Employment, Postsecondary Education and Training, Rights and Responsibilities, Self-Advocacy, Self-Determination, Transition Law, and Transition IEP.
- **Transitions in the School System** was compiled by Lizabeth Ensing of Forest Hills Transition Center to help parents understand the transitions process and view the postsecondary options available to their children in West Michigan. View the packet by visiting dsawm.org/teen-adult-resources.

Collegiate Opportunities

- **Noorthoek Academy** (<https://www.noorthoekacademy.org> or 616-234-4123) is a non-profit organization that provides an affordable college experience, offering continuing education in the arts and sciences for adults with learning challenges and other intellectual disabilities in partnership with Grand Rapids Community College.
- **Ready For Life** (<https://rflnetwork.org> or 616-248-3775) provides post-secondary educational experiences at Hope College and Calvin College for college-aged individuals diagnosed with cognitive, learning, or social disabilities.
- **University of Cincinnati Transition and Access Program** (cech.uc.edu) provides a four-year college experience for individuals with mild to moderate intellectual or developmental disabilities.

If your child plans to attend a university, community college or post-secondary institution, **Ruby's Rainbow** is an awesome nonprofit that grants scholarships to students with Down syndrome who are seeking post-secondary education, including enrichment or vocational classes. Visit rubysrainbow.org or call 512-879-7801 to learn more.

The **National Down Syndrome Society** also offers several scholarship opportunities to individuals with Down syndrome in the areas of post-secondary education, entrepreneurship, and self-advocacy. Visit ndss.org/engage/ndss-scholarships to learn more.

• **Employment**

Preparing for Employment

- **Disability Advocates of Kent County's Youth Transition Services** (dakc.us/youth-transition-services or 616-949-1100) provides youth aged 14+ with tools to ensure a successful transition into adulthood and independence.
- **IKUS** (ikuslife.org or 616-677-5251) in Ottawa county, offers a skill-building program for adults 18+ designed to assist individuals with disabilities with vocational, safety, and community living training, all in a community workforce or volunteer setting.

Finding Employment

- **Beyond26** (beyondtwentysix.org or 616-884-6400) helps adults with disabilities over 18 find job and volunteer opportunities in West Michigan.
- **ASK Family Services** (askforkids.org or 269-343-5896) in Kalamazoo has a Family Care Coordination program that, among other services, helps with planning, linking, and coordinating of community resources and services for individuals with disabilities and their families.
- **Michigan Alliance for Families** (michiganallianceforfamilies.org or 800-552-4821) offers an extensive employment guide on their website for those with disabilities who are preparing for their first job.

As individuals with disabilities secure employment, they may find NDSS' **Financial Wellness: A Guide for Individuals with Disabilities, their Families and Caregivers** helpful in their personal financial planning. The guide was created in partnership with the

Voya Cares program at Voya Financial to provide comprehensive information and solutions to address the unique, and oftentimes fluctuating, financial needs of the disability community. Visit ndss.org to access the guide.

- **Housing**

Considering where to live is a big step for every young person transitioning to adulthood. Some individuals may prefer to live at home. Others may seek a group home environment or be eager to pursue independent living. Maybe a combination of independence and support is ideal. Fortunately, West Michigan has housing options to fit each of these preferences.

AFC (Adult Foster Care)/Group Home

Cameo House 616-837-1106 Coopersville	MOKA moka.org/residential-homes 800-644-2434 Muskegon, Ottawa, Kent, and Allegan counties
David's House dhmin.org 616-247-7861 Grand Rapids	Pine Rest pinerest.org/services/residential-services/pine-rest-christian-homes 616-281-0061 Grand Rapids
Hope Network Adult Foster Care hopenetwork.org 616-301-8000 Grand Rapids	Samaritas samaritas.org/Building-Communities/Disability-Support 231-722-2400 Grand Rapids, Muskegon

Network 180 maintains a directory of West Michigan AFC homes on their website at network180.org.

Independent Living

Heritage Hill Association heritagehillweb.org/properties 616-459-8950 Grand Rapids	Michigan State Housing Development Authority affordablehousing.com Locations vary
Inner City Christian Federation (ICCF) iccf.org/homes 616-336-9333 Grand Rapids	

Independent Living with Onsite Support

David's House dhmin.org 616-247-7861 Grand Rapids	MOKA moka.org/residential-homes 800-644-2434 Muskegon, Ottawa, Kent, and Allegan counties
Dwelling Place dwellingplacegr.org/support-services 616-454-0928 Grand Rapids	Pine Rest pinerest.org/services/residential-services/pine-rest-christian-homes 616-281-0061 Grand Rapids
Gracious Grounds graciousgrounds.org 616-414-9209 Grand Haven	Samaritas samaritas.org/Building-Communities/Disability-Support 231-722-2400 Grand Rapids, Muskegon
Grand Rapids Housing Commission grhousing.org/senior-apartments.php 616-235-2600 Grand Rapids	Thresholds threshnet.org/how-we-can-help/residential 616-455-0960 Grand Rapids

Questions about housing options in West Michigan? Contact **OASIS Community of West Michigan** (oasiscommunity.info). Oasis works to discover housing alternatives that will provide adults with disabilities a safe place to live with greater independence, social connectivity, and lead purpose-filled enjoyable lives.

- **Transportation**

The transportation providers below provide services to West Michigan residents with disabilities.

- **GO!Bus** (ridetherapid.org/additional-services/go-bus or 616-776-1100) is a shared ride, advanced reservation, ADA paratransit service intended to provide a comparable level of transportation to that which is provided by a The Rapid fixed-route bus in Kent county.
- **Hope Network** (hopenetwork.org/transportation-services or 616-243-0876) owns and operates a fleet of 63 vehicles, and offers more than 60 professionally trained staff to provide door-to-door transportation for individuals with disabilities in Kent and Ottawa counties.
- **Lakeshore Ride Link** (lakeshoreridelink.org/transport-for-disabled-people) connects individuals with disabilities with transportation services in Kent, Ottawa, Allegan, and Muskegon counties.

Disability Network Southwest Michigan maintains a directory of transportation providers in Kalamazoo and surrounding areas on their website at dnswm.org.

Therapy

Providers listed below have indicated that they serve patients over 18 years of age. Please visit the School Age Resources page on our website at dsawm.org/school-age-resources for a listing of providers who serve patients younger than 18.

- **Behavior Therapy & Psychology**

- **Defined:** “Applied behavioral analysis (ABA) is a type of therapy that can improve social, communication, and learning skills through positive reinforcement.” – [Healthline](https://www.healthline.com/health/behavioral-analysis)
- **West Michigan Providers**

BRAINS brainspotential.com 616-365-8920 Grand Rapids	Horizons Developmental Resource Center https://www.horizonsdrc.com/ 616-698-0306 Caledonia
Comprehensive Therapy Center therapycenter.org 616-559-1054 Grand Rapids	Pine Rest Christian Mental Health Services pinerest.org 800-678-5500 Grand Rapids
Hope Network Behavioral Health hopenetwork.org/behavioral-health-services 616-301-8000 Grand Rapids	The Shoreline Center, LLC theshorelinecenter.com 616-935-7606 Grand Haven

- **Feeding Therapy**

- **Defined:** “Feeding therapy, in its simplest form, is when a trained occupational or speech therapist helps teach a child how to eat or eat better.” – [NAPA Center](https://www.napa-center.org/)
- Learn more about Feeding Therapy from the [American Speech-Language-Hearing Association](https://www.asha.org/feeding-therapy)
- **West Michigan Providers**

Horizons Developmental Resource Center https://www.horizonsdrc.com/ 616-698-0306 Caledonia

- **Music Therapy**

- **Defined:** “Music Therapy is the clinical and evidence-based use of music interventions to accomplish individualized goals within a therapeutic relationship by a credentialed professional who has completed an approved music therapy program.” – [American Music Therapy Association](https://www.musictherapy.org/)

- **West Michigan Providers**

Edge Water Music Therapy edgewatertherapy.com/our-services-and-programs 269-329-0730 Kalamazoo	West Michigan Music Therapy, LLC westmichiganmt.com Grand Rapids
Franciscan Life Process Center lifeprocesscenter.org/services/music-therapy 616-897-7842 Lowell	Western Michigan University Music Therapy Clinic wmich.edu/musictherapy/clinic 269-387-4679 Kalamazoo
Lakeshore Music Therapy Services sites.google.com/site/lakeshoremusictherapy 616-834-0597 Holland	

- **Occupational Therapy/Sensory Integration**

- **OT Defined:** “Occupational therapists and occupational therapy assistants help people across the lifespan participate in the things they want and need to do through the therapeutic use of everyday activities (occupations).” – [American Occupational Therapy Association](http://AmericanOccupationalTherapyAssociation.org).
- **SI Defined:** “Sensory integration involves perceiving, modulating, organizing, and interpreting these sensations to optimize occupational performance and participation.” – [American Occupational Therapy Association](http://AmericanOccupationalTherapyAssociation.org)
- Learn more about the relationship between Occupational Therapy, Sensory Integration, and Down syndrome at NDSS.org.
- **West Michigan Providers**

BRAINS brainspotential.com 616-365-8920 Grand Rapids	Sensory Systems Clinic West sensoryclinicwest.com 269-792-2353 Wayland
Comprehensive Therapy Center therapycenter.org 616-559-1054 Grand Rapids	The Shoreline Center, LLC theshorelinecenter.com 616-935-7606 Grand Haven
Generation Care generationcare.org 616-935-3300 (Grand Haven), 616-259-4028 (Grand Rapids), 231-737-4374 (Muskegon)	WMU Marion R. Spear Occupational Therapy Clinic wmich.edu/unifiedclinics/unifiedclinicsaboutot 269-387-7000 Kalamazoo

- **Physical Therapy**

- **Defined:** “Physical therapists are movement experts who improve quality of life through prescribed exercise, hands-on care, and patient education.” – [American Physical Therapy Association](#)
- Learn more about the relationship between Physical Therapy and Down syndrome at [NDSS.org](#).
- **West Michigan Providers**

Comprehensive Therapy Center therapycenter.org 616-559-1054 Grand Rapids	Generation Care generationcare.org 616-935-3300 (Grand Haven), 616-259-4028 (Grand Rapids), 231-737-4374 (Muskegon)
Conductive Learning Center conductivelearningcenter.org 616-575-0575 Grand Rapids	Horizons Developmental Resource Center https://www.horizonsdrc.com/ 616-698-0306 Caledonia

- **Recreational Therapy**

- **Defined:** “Recreational therapy, also known as therapeutic recreation, is a systematic process that utilizes recreation and other activity-based interventions to address the assessed needs of individuals with illnesses and/or disabling conditions, as a means to psychological and physical health, recovery and well-being.” – [American Therapeutic Recreation Association](#)
- Examples of Recreational Therapy: Animal Therapy, Athletics/Outdoor Recreation, Hippotherapy (horseback riding), Horticultural Therapy, Visual and Performing Arts. For a listing of day programs and camps that incorporate recreational therapy, turn to page 13.
- **West Michigan Providers**

Life Therapeutic Solutions life-ts.com/Home.aspx 800-925-3152 Wyoming	Legacy Stables & Karin's Horse Connection (Hippotherapy) karinshorses.com/karins-horse-connection 616-570-1106 Caledonia
Cheff Therapeutic Riding Center (Hippotherapy) cheffcenter.org 269-731-4471 Augusta	Renew Therapeutic Riding Center (Hippotherapy) renewtrc.org 616-227-3639 Holland

- **Speech Therapy**

- **Defined:** “Speech therapy is the assessment and treatment of communication problems and speech disorders.” – [Healthline](#)
- Learn more about the relationship between Speech Therapy and Down syndrome at [NDSS.org](#).

- **West Michigan Providers**

BRAINS brainspotential.com 616-365-8920 Grand Rapids	Horizons Developmental Resource Center https://www.horizonsdrc.com/ 616-698-0306 Caledonia
Calvin University Speech and Hearing Clinic calvin.edu/academics/departments-programs/speech-pathology-audiology/speech-clinic/ 616-526-6070 Grand Rapids	The Shoreline Center, LLC theshorelinecenter.com 616-935-7606 Grand Haven
Duncan Lake Speech Therapy, LLC duncanlakespeechtherapy.com 616-528-0870 Caledonia	Western Michigan University Speech Therapy Clinic wmich.edu/unifiedclinics/vanriper-0 269-387-7000 Kalamazoo
Generation Care generationcare.org 616-935-3300 (Grand Haven), 616-259-4028 (Grand Rapids), 231-737-4374 (Muskegon)	

- **Multidisciplinary Therapy**

- **Defined:** Multidisciplinary providers have experience and professional training to practice a variety of therapies.
- **West Michigan Providers**

BRAINS brainspotential.com 616-365-8920 Grand Rapids	Horizons Developmental Resource Center https://www.horizonsdrc.com/ 616-698-0306 Caledonia
Comprehensive Therapy Center therapycenter.org 616-559-1054 Grand Rapids	The Shoreline Center, LLC theshorelinecenter.com 616-935-7606 Grand Haven
Generation Care generationcare.org 616-935-3300 (Grand Haven), 616-259-4028 (Grand Rapids), 231-737-4374 (Muskegon)	

Social Programming / Activities

- **Arts**

Artists Creating Together artistscreatingtogether.org 616-885-5866 Grand Rapids	Grand Rapids Ballet Explorer Dance grballet.com/grand-rapids-ballet-school/adaptive-dance 616-454-4771 Grand Rapids
Arts in Motion artsinmotionstudio.org 616-446-7452 Grand Rapids	The Habitat Performing Arts Center Adaptive Dance thehabitatpac.com/adaptive-dance Kalamazoo

- **Athletics**

All Starz Bowling League hosted at Eastbrook Lanes 616-644-4567 or sgbowl2000@yahoo.com (League Coordinator: Betty Goldman) Grand Rapids	Special Olympics Michigan somi.org/southwest-region 616-583-1202 Multiple locations
American Youth Soccer Organization (AYSO) VIP Program ayso.org/play/vip Multiple locations	West Michigan Miracle League wmml.org 616-481-0481 Rockford
Kentwood Parks and Recreation Adaptive Recreation kentwood.us/city_services/city_department/s/parks_and_recreation/adaptive.php 616-656-5270 Kentwood	

- **Animals/Nature**

Fellinlove Farm fellinlovefarm.com 616-283-7555 Holland	Growing Roots (ages 16+) wegrowroots.org 616-516-6777 Wayland
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- **Social Recreation**

Compassionate Heart Ministries Club 404 compheart.org/clubs 616-834-0501 Zeeland	Sarah Care sarahcare.com/activities 616-530-6700 (Wyoming), 616-364-6800 (Grand Rapids)
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Heritage Homes Social Rec Program heritagehomesinc.org/social-rec-program.html 616-895-7104 Ottawa county	Sheldon House www.sheldonhouse.net 616-242-6058 Grand Rapids
IKUS R.E.C. Connect ikuslife.org/rec-connect 616-677-5251 Ottawa county	Sidekicks West Michigan sidekickswestmichigan.com Locations vary
Just Like Home justlikehomeionia.com 616-523-4310 Ionia	

- **Camps**

Camp Sunshine campsunshinemichigan.org Holland Ages 12-50	Bloomfield SCAMP bloomfieldscamp.com West Bloomfield Ages 3-26
IKUS (Indian Trails Camp) ikuslife.org/services/indian-trails-camp Grand Rapids	Clarkston SCAMP clarkstonscamp.org Clarkston Ages 3-40
Skyline Camp & Retreat Center campskyline.org/special-needs-camps Birmingham Ages 13+	St. Francis Camp saintfranciscamp.org/summer-camp.htm Jerome Ages 8+
CranHill Ranch Friendship Camp cranhillranch.com/summer-camps Rodney Ages 15+	Camp Grace Bentley campgracebentley.org Burtchville Ages 6-17
Pioneer Trails Day Camp pioneerresources.org/pioneer-trails Muskegon Ages 6-26	Christian Reformed Conference Grounds crcg.org/camping/special-needs-week Grand Haven Ages 5+
Pine Ridge Bible Camp – Freddy’s Friends pineridgecamp.com/special-needs-camps Cedar Springs Ages 14+	Spring Hill Camp springhillexperiences.com Ada, Evar

Medical

- ***Communicating with Your Physician***

Boston's MassGeneral Hospital For Children (massgeneral.org/children or 888-644-3248) created a Talking to the Doctor Workbook for individuals with Down syndrome that focuses on sharing feelings and asking questions. They also offer remote second opinions to patients and health care providers in the United States. Similarly, **Children's Hospital of Philadelphia** (chop.edu or 800-879-2467) offers a Toolkit for Transitioning to Adult Medical Care for individuals with Down syndrome. View both the workbook and toolkit at dsawm.org/school-age-resources.

LuMind IDSC (lumindidsc.org or 781-825-1300) has also launched the first-of-its-kind DSC2U, an "online toolkit that provides customized, expert-driven information for people with Down syndrome from age 1 through adulthood. Immediately upon completion of the form, caregivers receive two personalized documents: one for themselves and one to share with their primary healthcare provider. Both documents contain detailed, customized suggestions, follow-up questions, and conversation prompts that are designed to optimize time with a primary care provider and offer caregivers the vocabulary and tools they need to advocate for their loved one." Learn more at lumindidsc.org.

For support when speaking with dental providers, take a look at **Dentably's Dental Care Guidance for Caregivers of Patients with Down syndrome** at emergencydentistsusa.com/down-syndrome-and-dental-care.

- ***Finding a Provider***

Looking for a medical provider? The Preferred Medical Provider List is maintained by **Down Syndrome Head Start** and lists doctors, dentists, and other providers recommended by Michigan families experiencing Down syndrome. This list can be viewed at dsawm.org/school-age-resources. **Please note that Down Syndrome Head Start's website has been down as of November 2018. This list has not been updated since 2017. If you are looking for more up-to-date information, we recommend reaching out on the **Michigan Parents of Children with Down Syndrome Facebook group** at facebook.com/groups/DownSyndromeMichigan.

Looking for a dentist? The **Special Care Dentistry Association (SCDA)** (scdaonline.org) is a unique international organization of oral health professionals and other individuals who are dedicated to promoting oral health and well-being for people with special needs. A list of Michigan dentists belonging to SCDA can be found on their site. The **Michigan Parents group on Facebook** is also a good resource for finding dental recommendations.

- ***Paying for Your Child's Healthcare Expenses***

Children's Special Health Care Services (CSHCS) of Michigan (michigan.gov or 1-800-359-3722) provides low or no cost supplemental health insurance for a variety of covered medical diagnoses for individuals under 21 years old. While Down syndrome alone is not a qualifying diagnosis, CSHCS covers over 2,700 physical conditions of which many individuals with Down syndrome may experience at least one. To view a complete list of covered conditions and the contact information for each county's CSHCS branch visit michigan.gov/mdhhs.

The Children with Special Needs Fund (michigan.gov/csnfund or 517-241-7420) provides support for children ages 0-21 in Michigan with special health care needs not available through any other funding source. The Fund helps with the purchase of equipment and services that promote optimal health, mobility, and development, enhancing the lives of children and their families.

Individuals with disabilities are eligible for **Social Security** and **Medicaid** upon turning 18. For more information about applying for or utilizing benefits, contact the **Disability Advocates of Kent County's Family Support** department by visiting or dakc.us/family-support or calling 616-949-1100, or by contacting your local **Arc** office. Visit The Arc's website at thearc.org and use the Find a Chapter button to search for your local Arc office.

- ***Sexual Health & Well-being***

Questions or looking to learn more about relationships or your sexual health and well-being? The **YWCA of West Central Michigan** offers a Healthy Relationships class every spring and fall for adults with disabilities. Healthy Relationships is a free 8 week class about relationships and sexual health for people with intellectual and developmental disabilities. The Healthy Relationships group will give you tools and skills to be safe and happy in your relationships. Learn more at ywcawcmi.org or call 616-426-3752.

Have you or a loved one with a disability experienced sexual abuse? **WEAVE, or Working to End Abuse and Violence for Everyone**, is a local collaboration between the YWCA West Central Michigan, MOKA, Spectrum Community Services, Thresholds, and Hope Network Developmental and Community Services. Committed to serving individuals through a culture of gentleness, these organizations came together with the vision that all individuals with intellectual or developmental disabilities who have experienced sexual abuse will have access to compassionate and highly skilled professionals. If you or someone you know has experienced sexual abuse or assault, WEAVE is available to provide support and resources. Learn more at <https://www.ywcawcmi.org/our-services/weave> or by calling the 24-hour confidential helpline at 616-454-9922.

Financial

- ***Local Assistance Programs***

DSAWM Financial Assistance is available to members for expenses related to the following when relating to support, care, or treatment of person with Down syndrome: adoption, respite care, and educational, medical, therapeutic, and adaptive services or devices. DSAWM members are also eligible for our Meal Voucher Program which offsets meal expenses for families whose child with Down syndrome is experiencing an overnight stay in the hospital. Learn more at dsawm.org/programs/financial-assistance.

Family Hope Foundation (familyhopefoundation.org or 616-729-8833) offers scholarships of up to \$1,000 twice a year to West Michigan families for therapies that have little or no insurance coverage.

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- **My Gym Foundation** (mygymfoundation.org) provides grants for the purchase of medical and therapy equipment for children with special needs under 18 years old
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- **Project Angel Fares** (projectangelfares.com) grants all-expenses-paid trips to children with special needs to visit Morgan's Wonderland – an ultra-accessible theme park in Texas
- **Ruby's Rainbow** (rubysrainbow.org) provides scholarships to individuals with Down syndrome who are pursuing post-secondary education, enrichment, or vocational classes
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- **Special Kids Photography of America** (specialkidsphotography.com) provides grants for family pictures
- **Stepping Stones for Stella** (steppingstonesforstella.org) provides buggies for children with special needs to enjoy outdoors to its fullest
- **UnitedHealthcare Children's Foundation** (uhccf.org) offers grants for kids 16 years old or younger for services health insurance does not cover
- **Wheelchairs 4 Kids** (wheelchairs4kids.org) provides wheelchairs, home and vehicle modifications, as well as other assistive and therapeutic devices for children that have limited mobility
- **Wings of Mercy** (wingseastmi.org) provides free medical flights to patients in eastern Michigan with financial need

For more information about Teen & Adult Resources, visit our website at dsawm.org/teen-adult-resources. You are welcome to contact our office with any questions at 616-956-3488 or director@dsawm.org. We are here to support your family!

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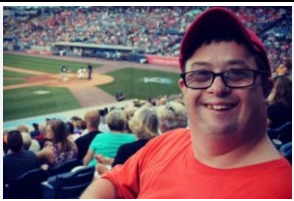


Aging Resources



Aging individuals are invited to participate in any of DSAWM's All Ages or Teen and Adult programs. DSAWM also offers a few select programs specifically for mid-aged and older adults, including our Aging with Down Syndrome Support Group. Resources relevant to this stage of development include transitions coordination, medical support, and financial assistance.

DSAWM Programs and Services for Aging Adults

Learn more about each program by visiting dsawm.org/programs.

	Aging with Down Syndrome Caregivers of individuals with Down syndrome over the age of 30 are invited to this support group sponsored by DSAWM and Alzheimer's Association. Participants share experiences and discuss the process of caring for loved ones growing older with Down syndrome.
	Book Club Teens and adults aged 16 and older with Down syndrome meet to discuss books selected by Next Chapter Book Club. Book Club meets twice a month and is open to all reading levels, including non-readers.
	Buddy Up Tennis Buddy Up Tennis teaches individuals with Down syndrome the game of tennis while supporting healthy activity and motor function. Athletes aged 5 and older work with professional coaches and one-on-one Buddies.
	Cooking Capers Teens and adults with Down syndrome aged 16 and older learn culinary terminology, cooking methods, measurement, and kitchen safety while crafting a delicious, healthy, gluten-free meal. Cooking Capers meets twice a month during the school year.
	Member Financial Assistance DSAWM's Member Financial Assistance Fund is designed to provide financial support to families raising individuals with Down syndrome who need help with certain Down syndrome-related expenses including adoption, education, therapy, adaptive devices, respite, and hospital stays.

	<p>Rapid Runners</p> <p>In this summer running program, teens and adults with Down syndrome aged 14 and older train for a 5K race by following individualized training plans based on the Couch to 5K program.</p>
	<p>Shape Up</p> <p>Shape Up is a health and fitness program for people with Down syndrome aged 14 and older. The weekly class consists of 45 minutes of nutrition instruction and 45 minutes of aerobic exercise.</p>
	<p>Skill Building Series</p> <p>The Skill Building Series teaches life skills such as grocery shopping, resume preparation, public speaking, and navigating the city to foster independence for teens and adults with Down syndrome.</p>
	<p>Water Ski Clinic</p> <p>DSAWM hosts an Adaptive Water Ski Clinic in partnership with Kentwood Parks and Recreation every summer that focuses on sitting and standing skiing. The clinic is held on Reeds Lake every July.</p>
	<p>Weekly Update</p> <p>The Weekly Update newsletter is emailed every Thursday and shares upcoming programs and services from DSAWM and our community partners. For new parents, it is an easy way to get connected and learn about the opportunities available to you and your family.</p>
	<p>Access! GR</p> <p>Through a partnership with Access! GR, DSAWM can connect members with the rich arts & cultural scene in West Michigan. Free tickets are available in a limited supply for both ongoing venues and special event venues. Accommodations can be made to make sure the arts are accessible to everyone.</p>
	<p>Holiday Party</p> <p>Every December, DSAWM families gather in Grand Rapids and Kalamazoo to visit with Santa and reconnect with friends. The Grand Rapids Holiday Party is a member-only event and is held at the Grand Rapids Public Museum.</p>
	<p>Member Picnic</p> <p>Each summer, DSAWM families gather at Tunnel Park in Holland for a day of friends, food, and fun in the sun. The Member Picnic is a member only event and is held in July.</p>

	<p>Rock Your Socks Dance Rock your socks off at our annual Rock Your Socks Dance in honor of World Down Syndrome Day (3/21). The event is open to anyone interested in celebrating Down syndrome.</p>
	<p>Step Up for Down Syndrome Step Up for Down Syndrome is the largest Down syndrome awareness event in Michigan and DSAWM's biggest fundraiser. Families, friends, and the public are invited to this annual celebration and walk held each September where we come together to support our loved ones with Down syndrome.</p>

Community Supports

Transitioning Into Older Adulthood

- **Day Programming**

The social programs below are open to West Michigan residents aged 18+.

- **Arts**

<p>Artists Creating Together artistscreatingtogether.org 616-885-5866 Grand Rapids</p>	<p>The Habitat Performing Arts Center Adaptive Dance thehabitatpac.com/adaptive-dance Kalamazoo</p>
<p>Arts in Motion artsinmotionstudio.org 616-446-7452 Grand Rapids</p>	

- **Athletics**

<p>All Starz Bowling League hosted at Eastbrook Lanes 616-644-4567 or sgbowl2000@yahoo.com (League Coordinator: Betty Goldman) Grand Rapids</p>	<p>Special Olympics Michigan somi.org/southwest-region 616-583-1202 Multiple locations</p>
<p>Kentwood Parks and Recreation Adaptive Recreation kentwood.us/city_services/city_departments/parks_and_recreation/adaptive.php 616-656-5270 Kentwood</p>	<p>West Michigan Miracle League wmml.org 616-481-0481 Rockford</p>

- **Animals/Nature**

Fellinlove Farm fellinlovefarm.com 616-283-7555 Holland	Growing Roots (ages 16+) wegrowroots.org 616-516-6777 Wayland
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- **Social Recreation**

Compassionate Heart Ministries Club 404 compheart.org/clubs 616-834-0501 Zeeland	Just Like Home justlikehomeionia.com 616-523-4310 Ionia
Heritage Homes Social Rec Program heritagehomesinc.org/social-rec-program.html 616-895-7104 Ottawa county	Sarah Care sarahcare.com/activities 616-530-6700 (Wyoming), 616-364-6800 (Grand Rapids)
IKUS R.E.C. Connect ikuslife.org/rec-connect 616-677-5251 Ottawa county	Sheldon House www.sheldonhouse.net 616-242-6058 Grand Rapids

- **Housing (Assisted Living & AFC Homes)**

Identifying an Assisted Living/AFC Home for Your Loved One with Down Syndrome

- **Network 180** (network180.org or 616-336-3909) maintains a directory of accredited AFC (adult foster care) homes in West Michigan on their website at network180.com.
- **Disability Advocates of Kent County's Occupational Therapy Department** (network180.org or 616-949-1100) offers a thorough assessment of the person, home, and environment to identify barriers to independent living to residents in Kent, Ionia, Montcalm, Mecosta, and Osceola counties. DAKC can be reached at 616-949-1100.
- **Oasis Community** (oasiscommunity.info) is focused on answering the call of Kent and Ottawa counties' growing adult disabled population by creating sustainable housing within inclusive neighborhoods throughout West Michigan. Oasis is available to answer your housing questions through the contact form on their website.
- **The Arc of Kalamazoo** (communityadvocates.org or 269-342-9801) offers a program called After I'm Gone that is intended to assist families in planning for the future of a loved one with a disability, including identifying area housing options. To learn more, visit communityadvocates.org/after-im-gone or contact 269-342-9801.
- **Disability Network Lakeshore** (dnlakeshore.org or 616-396-5326) is available to assist lakeshore area residents in transitioning into assisted and independent living

facilities. Visit dnlakeshore.org/nursing-home-transition or contact 616-396-5326 for more information.

Housing Options as Recommended by DSAWM Families

Cameo House 616-837-1106 Coopersville	Hope Network Adult Foster Care hopenetwork.org 616-301-8000 Grand Rapids
David's House dhmin.org 616-247-7861 Grand Rapids	MOKA moka.org/residential-homes 800-644-2434 Muskegon, Ottawa, Kent, and Allegan counties
Dwelling Place dwellingplacegr.org/support-services 616-454-0928 Grand Rapids	Pine Rest pinerest.org/services/residential-services/pine-rest-christian-homes 616-281-0061 Grand Rapids
Gracious Grounds graciousgrounds.org 616-414-9209 Grand Haven	Thresholds threshnet.org/how-we-can-help/residential 616-455-0960 Grand Rapids

Network 180 maintains a directory of West Michigan AFC homes on their website at network180.org.

- **Transitioning Caregivers**

Providing Care as an Aging Caregiver

- **MI-OCEAN (Michigan Older Caregivers of Emerging Adults with Autism and other Neurodevelopmental Disabilities)** (ddi.wayne.edu/miocean or 313-577-6368) is a statewide project aimed at addressing the needs and health concerns of aging caregivers (age 55+) of adults with intellectual and developmental disabilities. The project uses a family support model to identify and address various issues that may negatively impact the health and well-being of aging caregivers and those that depend on them. Learn more at ddi.wayne.edu/miocean.
- **The Arc of Kalamazoo** (communityadvocates.org or 269-342-9801) offers a program called After I'm Gone that is intended to assist families in the Kalamazoo area in planning for the future of a loved one with a disability. To learn more, visit communityadvocates.org/after-im-gone or contact 269-342-9801.
- The **NDSC Family Care Toolkit** allows caregivers to record and keep all important information in one place relevant to the care for a person with Down syndrome. The toolkit is divided into 6 sections – Home, Family, Daily Living, Medical, Resources, and Emergency – which includes everything from how to use remotes to emergency medical consent forms. Download the kit at ndsccenter.org/programs-resources/family-care-toolkit.

- Published by NDSS (National Down Syndrome Society), the **Aging and Down Syndrome: A Health & Well-Being Guidebook** provides an overview of the medical and psychosocial needs that are unique to individuals with Down syndrome as they age. Download the guidebook online at ndss.org. Physical copies are available at DSAWM.

Transitioning Care to a Sibling

- The **NDSC Adult Sibling Program** provides support to siblings caring for loved ones with Down syndrome. NDSC offers many workshops at their Annual Convention for adult siblings and caregivers. Additionally, their **Adult Siblings Toolkit** is available to download for free and designed to jump-start conversations with parents about becoming more involved in their brother or sister's life. Siblings can use this information to be effective advocates and perhaps, caregivers, after their parents are no longer able. Learn more at ndsccenter.org/programs-resources/adult-siblings.

Medical

• **Alzheimer's Disease**

Individuals with Down syndrome are at an elevated risk for developing Alzheimer's disease as they age. Fortunately, many resources exist to support families and caregivers of individuals experiencing both Down syndrome and Alzheimer's Disease.

- **NDSS' Alzheimer's Disease & Down Syndrome: A Practical Guidebook** for Caregivers provides a concise, but informative overview of the relationship between Down syndrome and Alzheimer's Disease, as well as provides guidance and resources for caregivers. The publication is available for digital download from the NDSS website at ndss.org.
- DSAWM and the Alzheimer's Association partner to host a monthly support group for parents and caregivers of individuals with Down syndrome over the age of 30. **Aging with Down Syndrome** participants share experiences and discuss the process of caring for loved ones growing older with Down syndrome. View upcoming dates on our website calendar at dsawm.org/calendar.

For more information about the programs and services offered by the **Alzheimer's Association Greater Michigan** chapter, visit alz.org/gmc or call 800-272-3900.

• **Communicating with Your Physician**

Published by NDSS, the **Aging and Down Syndrome: A Health & Well-Being Guidebook** provides an overview of the medical and psychosocial needs that are unique to individuals with Down syndrome as they age. Download the guidebook online at ndss.org. Physical copies are available at DSAWM.

Boston's MassGeneral Hospital For Children (massgeneral.org/children or 888-644-3248) created a Talking to the Doctor Workbook for individuals with Down syndrome that focuses on sharing feelings and asking questions. They also offer remote second opinions to patients and health care providers in the United States. Similarly, **Children's Hospital of Philadelphia** (chop.edu or 800-879-2467) offers a Toolkit for Transitioning to Adult

Medical Care for individuals with Down syndrome. View both the workbook and toolkit at dsawm.org/school-age-resources.

LuMind IDSC (lumindidsc.org or 781-825-1300) has also launched the first-of-its-kind DSC2U, an “online toolkit that provides customized, expert-driven information for people with Down syndrome from age 1 through adulthood. Immediately upon completion of the form, caregivers receive two personalized documents: one for themselves and one to share with their primary healthcare provider. Both documents contain detailed, customized suggestions, follow-up questions, and conversation prompts that are designed to optimize time with a primary care provider and offer caregivers the vocabulary and tools they need to advocate for their loved one.” Learn more at lumindidsc.org.

For support when speaking with dental providers, take a look at **Dentably’s Dental Care Guidance for Caregivers of Patients with Down syndrome** at emergencydentistsusa.com/down-syndrome-and-dental-care.

- ***Finding a Provider***

Looking for a medical provider? The Preferred Medical Provider List is maintained by **Down Syndrome Head Start** and lists doctors, dentists, and other providers recommended by Michigan families experiencing Down syndrome. This list can be viewed at dsawm.org/school-age-resources. **Please note that Down Syndrome Head Start’s website has been down as of November 2018. This list has not been updated since 2017. If you are looking for more up-to-date information, we recommend reaching out on the **Michigan Parents of Children with Down Syndrome Facebook group** at facebook.com/groups/DownSyndromeMichigan.

Looking for a dentist? The **Special Care Dentistry Association (SCDA)** (scdaonline.org) is a unique international organization of oral health professionals and other individuals who are dedicated to promoting oral health and well-being for people with special needs. A list of Michigan dentists belonging to SCDA can be found on their site. The **Michigan Parents group on Facebook** is also a good resource for finding dental recommendations.

- ***Paying for Healthcare Expenses***

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Sibling Resources

Siblings play an important role in the lives of people with Down syndrome. During childhood, siblings provide friendship and companionship. In older adulthood, many siblings will become the primary guardian or caregiver for their sibling with Down syndrome. Throughout this unique journey, resources are available to support and provide guidance to siblings, their families, and the loved ones for whom they care.

Community Supports

For Younger Siblings

- **Grand Rapids Area Sibshops** provide an opportunity for school-age children and teens to meet other children who understand the unique experience of having a sibling with special needs, share their experiences and feelings, and learn more about their sibling's special needs. Learn more and register to participate at siblingsupport.org/sibshops/find-a-sibshop-near-you or follow the Grand Rapids Area Sibshops Facebook page at [@siblingsgroup](https://www.facebook.com/siblingsgroup).
- **Sibling Support Project** is the first national program dedicated to the life-long and ever-changing concerns of millions of brothers and sisters of people with special health, developmental, and mental health concerns. Learn more at siblingsupport.org.
- **Siblings Learn About Down Syndrome** is a website offering resources to create workshops for siblings of those with Down syndrome. Materials include age-based activities covering a wide range of topics from handling behavior challenges and the benefits of having a sibling with Down syndrome to being a policy advocate. Activities include Human BINGO, Down syndrome Jeopardy, Sensitivity games and more. Learn more at siblingslearnaboutdownsyndrome.com.
- **Eyes Different Than Mine** is a children's book by local author and sibling Erin Johnson about the unique relationship between neurodiverse siblings. Purchase the book at erinrhodesjohnson.com/book.

For Adult Siblings/Caregivers

- The **NDSC Adult Sibling Program** offers many workshops at their Annual Convention for adult siblings and caregivers. Additionally, their **Adult Siblings Toolkit** is available to download for free and designed to jump-start conversations with parents about becoming more involved in their brother or sister's life. Siblings can use this information to be effective advocates and perhaps, caregivers, after their parents are no longer able. Learn more and download the toolkit at ndsccenter.org/programs-resources/adult-siblings.

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For more information about caring for an aging person with Down syndrome, visit the Aging Resources page of our website at dsawm.org/aging-resources.

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Elvis and the 21st Chromosome

by Erin Doyle Toburen, Cascade

Elvis arrived in blue suede shoes, aviators, and a jumpsuit shortly before the end of my freshman year of college. Already the parents of four children – ages 10 through 18 – the thought of an infant was a decade removed from my parents' mind when they found themselves unexpectedly expecting. On that April morning when the baby arrived, my father called me to announce the baby's arrival.



It was a boy, he said, his name is Liam, but – but – he arrived with an extra chromosome. He arrived smaller than his older two brothers had, but little did we know, his entrance would rock our world. As a college Freshman, I drove six hours home from Steubenville, Ohio, with my college roommate to meet my brother in the NICU. His short visit in the NICU due to a heart murmur for only five days after birth gave us our first glimpse into this beautiful life we had now been given.

A few weeks after returning to college, I sat in a meeting with my sorority sisters where our sorority mother in her mid-thirties brought her adult sister with her. Her sister, born with Down syndrome, was vibrant and beautiful. I bawled. I had not yet grieved over the lost expectation of a sibling born without an extra chromosome. Ashamed because I knew my sorority sisters knew why I was bawling only increased my flood of tears. Our sorority mother soon became my personal mentor, sharing with me who her sister was, how her sister influenced her life, and how her sister was not defined by the fact she was born with Down syndrome. Sixteen years later, I am still grateful to my sorority mother.

“Down syndrome” slowly settled itself into our family’s vernacular and questions swirled. “Down syndrome” – would he go to college? “Down syndrome” – would he be able to talk? “Down syndrome” – would he be able to walk? “Down syndrome” – what does that even mean? “Down syndrome” – what would be his life’s trajectory?

Like everything else in life that is considered outside the everyday “normal,” people began asking questions they should not and voicing opinions they should not. When we mentioned that our youngest brother was born with Down syndrome, people sometimes made the trite (albeit well-meaning) comments such as: “God only sends children like “that” to “special” families, so you must have a special family” or even the suggestion that people born with Down syndrome could be healed “from” Down syndrome, perhaps suggesting my brother could be “healed.” Such well-meaning comments failed to see the reality in which my brother lives. They did not see the three-month struggle my mother went through before he would latch while nursing. They did not see how Celiac’s Disease, a common condition in people born with Down syndrome, impacts his daily life. Most importantly, such comments failed to account for the fact that Down syndrome never defined him, rather Liam would define his own life and influence those around him.

Liam would help influence some of most important decisions in my life. As a college intern for the U.S. State Department, I dreamed of one day becoming a foreign service officer. The adventure, travel, and importance of the diplomatic mission called to me, but Liam called stronger. I knew if I chose a career in the foreign service, I would spend much of my life away from Liam so I chose

law school to keep me stateside. I chose Saint Louis University, because it was only a day's drive from Liam.

My career eventually brought me back home to West Michigan where I practice in-house international corporate law and live five miles from Liam. Living so close to Liam has given me front-row seats to witness the symphony Liam has composed with his life. His symphony crescendos with his gregarious personality, pauses at his thoughtfulness and is driven by his incredible work ethic and Elvis. Oh, so much, Elvis.

When Liam was thirteen, he began watching reruns of Full House like it was his full-time job. His favorite character soon became Uncle Jesse. Liam talked of nothing but Uncle Jesse for months. He would recite entire story lines and facts about Uncle Jesse to anyone who was willing to listen to his two-hour monologues (Thank you, Carl!). Uncle Jesse was suave. Uncle Jesse liked music. Uncle Jesse loved Elvis.

One thing led to another and Liam soon forgot Uncle Jesse. Liam only talked about Elvis. Elvis's horse, Elvis's history, the nuances of the Elvis-Priscilla relationship, and Graceland. If you wanted to listen to music around Liam, it had to be Elvis, and, for the first and only time in his eyes, Liam thought I, his older sister, was cool because I wore aviator sunglasses like Elvis.

Like the Full House era, our family hoped Elvis was simply a phase. My dad complained about Elvis every time someone mentioned him. My parents spent their honeymoon driving through the Upper Peninsula of Michigan in August of 1977 when Elvis died and the only thing one could hear on the radio was Elvis music. Unlike the Full House era, Elvis was a new way of life.

When Liam's quest for all-things Elvis could not be satiated by historical facts or the Sirius-XM Elvis station being played 24-hours a day, Liam decided he wanted to become a real-life Elvis Tribute Artist ("ETA"), and an ETA he has become. For the past several years, Liam has taken dance and music lessons to improve his voice and stage presence. He practices every day – sometimes for hours – at our farm on his music. He entertains his seven nieces and nephews with his music and dancing to make sure they get to see him realize his dream someday. He beams with pride when my three-year-old daughter insists on calling him "Uncle Elvis."



His inspiration for his hard work and drive has been the ETAs he has met over the past several years at the various events my parents traveled around the country taking him to see. The first of these was Elvis Tribute Artist Jake Slater my mother and Liam met while vacationing in Northern Michigan.

Thanks to Mr. Slater and the other ETAs who have inspired him Liam began performing to large audiences in 2019. Last April, Mr. Slater performed at Liam's sixteenth birthday party and let Liam sing alongside him in front of over a hundred people. In July, Liam attended the Graceland Performing Arts Camp at Graceland where he met other Elvis fans for the second summer in a row and made friends across the country. Then in October, Liam made his YouTube.com debut when he performed "Peace in the Valley" at the 27th Annual Elvis Annual Fantasy Festival in Portage, Indiana. The proceeds from the event benefited the Porter County Special Olympics. Liam has since performed at company Christmas parties, represented Elvis fashion at the National Association for Down syndrome Fashion Show in Chicago, and sang at a wedding.

Thanks to Elvis, Liam keeps in shape so as not to hinder his chances of someday competing to become an Ultimate Elvis Tribute Artist. Thanks to Elvis, Liam tells us that he loves performing because he likes to make people happy and make the world a brighter place. Thanks to Elvis, Liam constantly reminds us that our chromosomes do not define us. Thanks to Elvis, Liam is determining his own life's trajectory. Thanks to Elvis, Liam has found his voice.

My Sister Chloe

by Peyton Brill, Grand Haven

Down syndrome is something that many people struggle to understand. I've spent the last 11 years learning about it from my younger sister Chloe and there's still so much more to learn. Over time, I have noticed how Chloe is constantly treated differently by others. I want to follow her and shield her wherever she goes, but that is just not possible. I have also become accustomed to mixed reactions from people when they learn that Chloe has Down syndrome. One of the hardest reactions to respond to is when people say "oh, I'm sorry..." as though Down syndrome is a burden. Fortunately, having Chloe in my life has taught me the importance of patience. Having patience keeps me from becoming angry at other people's lack of knowledge and instead helps me to teach them about what Down syndrome really means.



When Chloe was about five, we went to Crazy Bounce and she was ecstatic, like a kid in a candy store. The slides were steep and slippery, but she was determined to get to the top. Years later, I still vividly remember Chloe working her way up the giant tiger slide. Ignorant teenagers began sprinting up behind us. One boy began making rude remarks about Chloe and her speed. I asked him to stop, but he in turn decided to shake the slide. As much as I wanted to go teach that kid a lesson, I just turned towards Chloe and followed her the rest of the way up. People with Down syndrome are often known for their unconditional love and so often I wonder how they manage it given the way they are so often mistreated. If the boy who made fun of Chloe had fallen, she would have been the first to run up and give him a hug, no matter how he had treated her, because that is just who she is.

Inclusion is getting better, but there is still a long way to go. Part of the reason I love camping with my family is because we can escape the small-town bubble where we spend so much of our time. Traveling with someone who has Down syndrome is thought by many to be a hassle. I will be the first to admit that sometimes the stimulation of visiting new places and trying new things can be a bit much for anyone, especially someone with special needs. When my family first got a camper, we had no clue how things were going to go, but there is no way to tell unless you try. For Chloe, our motor home has become a second home. It's a place that she is familiar with and where she can return to if trying new things gets overwhelming. We have gone on all sorts of trips and Chloe has met many new friends. So many of the people we meet along the way are kind and open-minded. Kids from the campground will run up to our site looking for Chloe and they'll all run off together to play. Nobody is born with the biases that are so often directed towards individuals with special needs. Seeing Chloe with all the accepting people we've met while traveling helps me to see that even though there are those who may try to break her down, there are a lot of people who will always support and stand up for her.

Throughout my life, I have been blessed to meet friends from my community with Down syndrome and they are honestly some of the most down-to-earth people I have ever met. At my school we have a program called POPS which stands for Power of Peer Support. The focus of the club is increasing inclusion in the school. Even simple lunches together can create great memories and show the value in small moments of acceptance, especially because people with special needs are so often left out. I have seen so many friendships form through this club and learned a lot about people who I did not know that well. Keeping a club going at school can be difficult. Many

people are focused on more popular activities and are scared to try something new. Receiving messages from parents of students with special needs about how much POPS means to them and their child has pushed me to reach out and grow the club and inclusion in the school.

Recently, I ran an event called Buddy Games. During the event, individuals with special needs were paired with a buddy who stayed by their side and encouraged them as they practiced basic soccer skills like passing, dribbling, and shooting. Afterwards, a scrimmage game was held for everyone to participate in. Over 40 people participated and many of the volunteer buddies were students from Grand Haven High School. The event was totally eye-opening. Seeing inclusion on the field was just a small step towards eliminating some of the biases that people have about those with special needs. The smiles on everyone's faces were ear-to-ear and you could feel the unconditional love. Chloe often asks to participate on school teams, but those teams tend to progress quickly and, while she is just as capable as everyone else, sometimes she needs the pace to be modified. Buddy Games was not only an opportunity that allowed Chloe and others to play on a sports team that fit their needs, but it also gave everyone who came the ability to learn about others who they perceive to be unable.

The hardest part of having a sibling with special needs is seeing the way others put her down. Learning to let Chloe work through this challenge on her own is difficult and I constantly find myself stepping in to guard her. Chloe is strong though. There are days when she completely amazes me in how she carries herself so independently and, through it all, with love.

Change for the Better

by Chloe Peters, Forest Hills

I was always considered the princess of the family. Surrounded by two big brothers, habitually I was spoiled and always obtained what I wanted. Photographs of me splashed the walls of our house. The world revolved around my needs. I only realized I received the most attention from my parents when it was suddenly stolen from me in November of 2009. My family transitioned from a family of five to a family of six. The newest addition was yet another boy, so the princess label remained with me, but the label did not bring the attentive spotlight it always held.



My newest brother, Cale, was considered “different” to most people. At my age, I was unaware that most babies did not spend the first month of their life in the hospital. Like me, Cale was given a label. However, his label was something I had never heard before: Down syndrome. I feared the word “different.” It was always attached to a negative connotation, but I quickly learned that I did not have to treat Cale any differently. Over time, the picture frames on the walls contained pictures of my little brother instead of me. I respected the change because in exchange I changed myself for the better. I learned to love others no matter if they are “different” or not.

Sometimes, even a princess needs to experience change. Change pushed me to experience and learn new things. Cale taught me to respect everyone. I learned life is not all about me. Cale opened my eyes to see that you get more out of life if you encourage and love others for who they are. Little did I know the affectionate eight-year old I know now would have the greatest impact on my life. I am thankful for losing my spotlight, for I learned far more watching the light shine upon my little brother.



DS-ASD Dual Diagnosis Resources

Autism spectrum disorder is a neurological disorder that affects the brain's development of social and communication skills. As research of developmental disabilities advances, studies are now showing that people with Down syndrome are more likely to have autism than their neurotypical peers. When a person is diagnosed with both Down syndrome and autism, that person is often referred to as having a dual diagnosis or DS-ASD.

Getting & Understanding a Diagnosis

Research into DS-ASD is a relatively new field of study and, as result, many people with Down syndrome and autism remain undiagnosed with the latter. The more information is shared and relationship between Down syndrome and autism is understood, the sooner an individual with DS-ASD can be diagnosed after autistic characteristics first begin to present. Once an individual receives a dual diagnosis, additional resources for support, such as ABA (Applied Behavior Analysis) therapy, are often made available to families.

The **NDSS Down Syndrome and Autism pamphlet** offers a concise overview of what to do if you suspect your child may have a dual diagnosis and the behaviors that may indicate ASD (see below). The pamphlet can be viewed at ndss.org. Comprehensive information is also available from the **Down Syndrome-Autism Connection** (ds-asd-connection.org or 720-757-7007), the only nonprofit organization dedicated solely to DS-ASD in the United States. Additional reading can be found at the websites for the **National Down Syndrome Society** (ndss.org) and **Down Syndrome Resource Foundation** (dsrf.org).

Behaviors to Notice

- **Before 3 Years Old**
 - Repetitive motor behaviors
 - Fascination with and staring at lights, ceiling fans, or fingers
 - Episodic eye movements
 - Extreme food refusal
 - Unusual play with toys or other objects
 - Receptive language impairment
 - Little or no meaningful spoken language, gestures, or signs
- **3 Years and Older**
 - History of developmental regression
 - Hyper or hypo-activity, short attention, impulsivity, and poor organization
 - Unusual vocalizations
 - Unusual sensory responsiveness

- Difficulty with changes in routine or familiar surroundings
- Extreme anxiety, fearfulness, or agitation
- Sleep disturbances
- Disruptive behaviors
- **3 Years and Older**
 - Significant lack of social response or relatedness with family or friends
 - Lack of interest or ability to develop relationships with peers
 - Antisocial, anxious, or fearful in the presence of people they don't know
 - Intensified stereotypic and repetitive motor behaviors
 - Obsession or fascination with inanimate objects
 - Lack of ability or interest in creative play
 - Manipulation of objects in rigid ways
 - Intensified sensitivity to certain types of sensory input
 - Frequent tantrums and outbursts, as well as verbal or physical aggression
 - Great difficulty in adjusting to transitions
 - Dropping to the ground and refusing to move

If you believe your child should be evaluated for ASD, the West Michigan providers listed below are available to provide testing and a diagnosis to families.

BRAINS brainspotential.com 616-365-8920 Grand Rapids	Mary Free Bed Kids – Autism Spectrum Disorder Program maryfreebed.com/conditions/autism 616-840-8807 Grand Rapids, Traverse City, Bay City
Helen DeVos Behavioral Health Clinic – Spectrum Health spectrumhealth.org/services/helen-devos-childrens-hospital/behavioral-medicine-and-psychiatry 866-989-7999 Grand Rapids	Pine Rest Christian Mental Health Services pinerest.org 800-678-5500 Grand Rapids
Horizons Developmental Resource Center https://www.horizonsdrc.com/ 616-698-0306 Caledonia	WMed Pediatric Autism Center med.wmich.edu/node/701 269-337-6077 Kalamazoo

Blue Cross Blue Shield maintains a list of approved **autism evaluation centers (AAECs)** across the state that may be helpful in identifying an evaluation site outside of West Michigan. The list can be viewed on their website at bcbsm.com.

Additional information about diagnosis can be found at the website for the Autism Alliance of Michigan at autismallianceofmichigan.org/diagnosis or by calling 877-463-2266.

Community Supports

Ds-ASD Support

- **Down Syndrome-Autism Connection** (ds-asd-connection.org or 720-757-7007) provides education and support to individuals facing the unique challenges caused by co-occurring Down syndrome and autism.
- **Ds-ASD Listserv** is managed by the Down Syndrome Network of Montgomery County for the purpose of providing friends, relatives, and caregivers of people with dual diagnoses with a place where they can connect to share information. To join the Listserv, email dsasd+subscribe@groups.io.
- **DSDN Dual Diagnosis – Down syndrome and Autism** (facebook.com/groups/DSDNDUALDIAGNOSISAUTISMANDDS) is a Facebook group for parents of children diagnosed with Down syndrome and Autism created by the Down Syndrome Diagnosis Network.

Autism Support

- **Autism Society of Michigan** (autism-mi.org or 517-882-2800) is committed to empowering individuals with autism and their families by offering educational resources and materials, workshops, seminars and other services.
- **Autism Alliance of Michigan** (autismallianceofmichigan.org or 877-463-2266) leads efforts to raise expectations and expand opportunities for people touched by autism across the lifespan.
- **Autism Support of Kent County** (autismsupportofkentcounty.org or 616-752-8577) works to provide services that make it possible for individuals with autism to lead healthier and more productive lives.
- **Autism Support of West Shore** (asws.org or 616-395-3222) advocates and supports meaningful participation in all aspects of life for individuals with Autism Spectrum Disorder and their families in West Michigan.
- **Hope Network Center for Autism** (hopenetwork.org/autism or 844-969-0252) a multi-disciplinary team of experts specialized in treating learners on the autism spectrum as young as 18-months-old.

Michigan Alliance for Families shares additional resources on their website specific to residents with autism in the state of Michigan at michiganallianceforfamilies.org/autism-spectrum-disorder.

For more information about DS-ASD Dual Diagnosis, visit the DS-ASD Dual Diagnosis Resources page of our website at dsawm.org/dual-diagnosis-resources.

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Two Punches on the Disability Card

by Amy Wigger, Hudsonville

Your son is autistic. I let out a sigh of relief, at the same time feeling like someone had knocked the wind out of me with so few words again.

Three years before, almost to the day, another medical professional looked me in the eye and said five words, your son has Down syndrome. I was prepared for that diagnosis, even without a prenatal diagnosis. I had literal dreams about our third born child having Down syndrome, had mother's intuition, and I believe a divine message somehow letting me know that Owen would be born with Down syndrome. So while the rest of our family and friends felt the world shift completely from under their feet, I was standing tall and strong. I prided myself on the way I gracefully handled this diagnosis that no one else expected and Owen soon began to thrive.



Owen began to say words around age 2. Simple words like mom and dad or cookie rolled off his tongue. Again, we were so impressed and excited. Life marched on.

Around age 2 and a half, we noticed Owen was getting lost in his own world more times than not. He was attracted to lights and anything he could hold in his hands and shake simultaneously. I would later be informed at his autism testing that this was in fact him flapping, a characteristic of autism. He was becoming more and more angry and his words had all disappeared, really before I noticed, they were gone. He didn't try to sing along with songs anymore and the light we used to see in his eyes was almost gone.

As parents we began to wonder what we were doing wrong. We hadn't changed any routines or the way we interacted with Owen. His environment was consistent, and we kept basically the same daily schedule. We were at a loss. We were frustrated and sad, mostly because we wanted to help Owen, but we had no idea how. I was watching other kids with Down syndrome surpass Owen's developmental milestones. Their temperament was drastically different than Owen's. I quit going to playdates, not just with typical kids, but with families who had kids with Down syndrome. We had to be failing him somewhere. Why was our child the only one not moving forward?

Owen's teaching team were the ones who told us that they thought it would be beneficial for Owen to be screened for autism. I was confused and sad, but all of a sudden a bit hopeful as well. Maybe we weren't terrible parents, maybe there was more going on.

His screening took place at our local Children's hospital. It took about 4 hours and part of us wondered if we would go and they would dismiss his behavior as "low functioning" Down syndrome. We had heard from other families who had gone through testing 5-10 years before that it wasn't an uncommon phrase when they inquired about a dual diagnosis. At the end of the appointment, we heard the words, he has autism. They would of course have to write up the report and file all the paperwork, but we had our disability punch card punched again.

It took me longer to accept this diagnosis. It didn't feel fair that Owen would get another diagnosis. One that would complicate his life further. One that may limit him further. I allowed myself to stay

in that place. I still allow myself to feel those feelings, to mourn that our son no longer “just” has Down syndrome. These days we see autism characteristics come through into our daily lives more dominantly than Owen’s Down syndrome characteristics.



As a parent I still feel like I don’t quite fit at either party. I don’t totally fit in with the Down syndrome crowd and the same goes for the autism community. Owen doesn’t fit in either box either. I’ve decided that I may not be the only parent feeling this way. My goal is to be as transparent about our dual diagnosis life as possible, while still respecting our son’s autonomy. I also want to share our story to encourage any parent who is feeling what we were feeling that you are not alone. That statistics are showing that more and more people with Down syndrome also have autism. And if you suspect your loved one does, it’s always worth looking into.

We also see light again. Owen began ABA therapy and has been attending what may be an actual utopia of therapy centers for 5 years. He is fully included in a general education setting where his school welcomes his behavior techs with open arms. The team he has works together to make sure everyone is on the same page, and we are all working together to meet Owen’s needs so he can thrive. He also is gaining some verbal language back and successfully uses a device to communicate with those around him.

We still have difficult days, sometimes difficult seasons. We are all learning and growing and figuring out how to support Owen and one another as we move down this road. But we have hope again. The light is back in Owen’s eyes. He is a wonderful son, brother, and friend. He makes us laugh every day. He is blazing his own path and we could not be more proud of him.

Down Syndrome & Autism

Down syndrome and autism are both equal opportunity conditions— meaning that anyone, anywhere, regardless of race, creed or socio-economic status, can have a child with either condition. It is believed that up to 18%¹ (some research suggests up to 39%²) of individuals with Down syndrome also have autism spectrum disorder. Both Down syndrome and autism can be challenging disabilities separately, without the combination, however when combined the challenges are multiplied and can be quite complex.

Behaviors to Notice

Before 3 years old:

- Repetitive motor behaviors
- Fascination with and staring at lights, ceiling fans, or fingers
- Episodic eye movements
- Extreme food refusal
- Unusual play with toys or other objects
- Receptive language impairment
- Little or no meaningful spoken language, gestures or signs

3 years and older:

- History of developmental regression
- Hyper or hypo-activity, short attention, impulsivity and poor organization
- Unusual vocalizations
- Unusual sensory responsiveness
- Difficulty with changes in routine or familiar surroundings
- Extreme anxiety, fearfulness or agitation
- Sleep disturbances
- Disruptive behaviors



Teens and Adults:

- Significant lack of social response or relatedness with family or friends
- Lack of interest or ability to develop relationships with peers
- Antisocial, anxious, or fearful in the presence of people they don't know
- Intensified stereotypic and repetitive motor behaviors
- Obsession or fascination with inanimate objects
- Lack of ability or interest in creative play
- Manipulation of objects in rigid ways
- Intensified sensitivity to certain types of sensory input
- Frequent tantrums and outbursts, as well as verbal or physical aggression
- Great difficulty in adjusting to transitions
- Dropping to the ground and refusing to move

Please note that many of these behaviors are normal for children with Down syndrome at certain points of development. Also, a child with Down syndrome may experience relatively normal development but then regress by developing these behaviors between the ages of three and seven. When one or two of these behaviors become predictable, extreme, or resistant to change, your child may benefit from a thorough evaluation for autism spectrum disorder performed by a professional who is experienced in working with children with Down syndrome.

¹ JFK Partners, University of Colorado Denver, <http://jfkpartners.org>.

² When Down Syndrome and Autism Intersect, A Guide to DS-ASD for Parents and Professionals, P.1, Woodbine House, 2013.

Down Syndrome & Autism, continued

What to do if you suspect ASD

If you feel an evaluation is in order, observe closely, take notes, and arm yourself with current information. Some parents have been persistent and in time they finally get the answers to their questions. When seeking an evaluation, be sure to ask if the provider has experience with evaluating autism in a person/child with Down syndrome. Many families seek an appointment with an AUCD center (Association of University Centers on Disabilities), a developmental pediatrician, a neuropsychologist, Children's Hospital in their area, or their local Down syndrome clinic -- and others have been able to obtain an educational diagnosis of autism from their school system.

It's also important to do the following to take care of yourself as a care giver:

- Increase your circle of support, ask for help from family, friends, support staff from school, church family, etc.
- Pursue a Personal Care Attendant (PCA) or respite services
- Those who find themselves struggling with their emotions regarding the second diagnosis may benefit from working with a professional counselor such as a grief, marriage, or family counselor, psychologist, or a spiritual leader
- Join the Down Syndrome-Autism Connection
 - Facebook Support Page
 - Monthly on-line chat support group

Benefits of Knowing

Many parents have expressed that once their child received the additional diagnosis of autism, it became the most important issue. A lot of parents and professionals will tell you that the autism almost always "trumps" the Down syndrome, with difficult behaviors and educational challenges being the main issues in their lives.

A formal diagnosis could:

- Help get needed school and community services that are tailored to children with autism
- Explain why a child with Down syndrome and autism develops and acts differently
- Help parents and extended family members to better understand, support and guide their child

While parents of children with DS-ASD may sometimes feel alone, there are expanding efforts to make support and help available. There is growing awareness of the needs of those with DS-ASD, and efforts are underway in different parts of the country to meet those needs.

There are many reasons to remain hopeful about the future. As more is learned about the intersection of Down syndrome and autism, better health and education strategies will likely become clearer, paving the way for brighter futures to come!

Resources

- **"When Down Syndrome and Autism Intersect"**
by Margaret Froehlke and Robin Zaborek
- **The Down Syndrome Autism Connection**
(www.ds-asd-connection.org)
- **Autism Speaks** (www.autismspeaks.org)
- **Autism Society** (www.autism-society.org)
- **Kennedy Krieger Institute** (www.kennedykrieger.org)
- **The Association of University Centers on Disabilities**
(www.aucd.org/directory)
- **Children's Hospital Association's Directory**
(www.childrenshospitals.org)
- **JFK Partners** (www.jfkpartners.org)

Diversity Resources

Down syndrome affects individuals of all backgrounds. As a result, our community is vastly diverse and a collective of many unique histories, cultures, identities, and lived experiences. DSAWM is committed to improving our focus on diversity, inclusion, and equity here in the West Michigan Down syndrome community. The directory below is intended to inform families about local resources available to the many diverse communities that make up West Michigan.

DSAWM Programs and Services for Diverse & Multicultural Families

Learn more about each program by visiting dsawm.org/programs. Para información en español, vaya a, dsawm.org/espanol.

	<p>21 Shades Support Group</p> <p>21 Shades is a support group for families of color and multicultural families who are part of the Down syndrome community. Gatherings and opportunities to connect are offered frequently for families to share their experiences and discuss topics relevant to the intersection of Down syndrome and race. To learn more and get connected, visit dsawm.org/21shades, join the DSAWM 21 Shades Facebook group at facebook.com/groups/dsawm21shades, or contact us at director@dsawm.org or 616-956-3488.</p>
	<p>La Posada</p> <p>La Posada is an annual Christmastime festival hosted by DSAWM's Spanish-speaking families. The event invites families to bring a traditional passing dish and come together to celebrate the season of giving with delicious food, fun activities, and good company. Visit our calendar at dsawm.org/calendar for upcoming dates.</p>
	<p>Facebook Support Groups</p> <p>DSAWM hosts two Facebook groups that are open to diverse West Michigan families. DSAWM 21 Shades (facebook.com/groups/dsawm21shades) is open to all families of color and multicultural families who are raising or love a person with Down syndrome in West Michigan. DSAWM Familias Hispanas y Latinas (facebook.com/groups/dsawmespanol) is open to all Hispanic and Latino families raising or loving a person with Down syndrome in West Michigan.</p>

Community Supports

Families of Color

- **Resources Specific to Down Syndrome**

- **A Friend Like Anian** is a children's book by author and mother Meeka Caldwell who, after noticing she couldn't find any children's books representing African Americans with Down Syndrome, wrote this book—the first in a series—based on her son. Learn more about the book at gigisplayhouse.org.
- **African American/Black People Who Have Children with Down Syndrome Facebook Group** (facebook.com/groups/parentsofafricanamwithds) is for African American/Black people who have children with Down syndrome and parents/legal guardians of African American/Black children with Down syndrome.
- **African American Conference on Disabilities** (azdisabilitylaw.org/african-american-conference-on-disabilities) is an annual conference that addresses the intersection between race and disabilities and examines avenues for self-advocacy to ensure the effective provision of services, resources, and enforcement of civil rights in the African American and disability communities. The conference is held every February.
- **Black Families Down Syndrome Network** (facebook.com/groups/bfdsn.dsdn) is a subgroup of the Down Syndrome Diagnosis Network for black/mixed families expecting or raising a black/mixed child with Down syndrome to connect with other families.
- **The Colors of Down Syndrome Facebook Group** (facebook.com/groups/thecolorsofdownsyndrome) is for parents and caregivers of racially/ethnically diverse individuals with Down syndrome.
- **DSDN Asian Families Facebook Group** (facebook.com/groups/dsdnasianfamilies) is for Asian/mixed families expecting or raising an Asian/mixed child with Down syndrome to connect to other families.
- **Rockin' Moms en Español – DSDN Facebook Group** (facebook.com/groups/dsdnenespanol) is for Spanish-speaking moms of children with Down syndrome.
- **Sankofa** is a UC Davis support group to meet the unique needs of parents of Black children with autism and other developmental disabilities. Learn more at health.ucdavis.edu/mindinstitute/resources/family_resource_centers.html.
- **Yo Soy Yo** is a children's book by author and DSAWM mom Katelyn Herrygers about embracing who you are, translated into Spanish with the support of DSAWM's Spanish-speaking community. Learn more at katelynshae.net.

- **Local Resources Specific to Families of Color**

- **BL²END Business Leaders Linked to Encourage New Directions** (grblend.org) provides the means to empower African Americans and other minorities to achieve economic self-reliance, parity and civil rights.

- **CAIR-MI (Council on American-Islamic Relations)** (cairmichigan.org) advocates for a better understanding of Islam in Michigan by building bridges of understanding and respect.
- **Grand Rapids African American Health Institute** (graahi.com or 616-331-5831) seeks to ensure that all people have optimal health care and benefit from health systems without race being an impediment.
- **Hispanic Center of West Michigan** (hispanic-center.org or 616-742-0200) provides unmet social services to the Hispanic Community in Greater West Michigan.
- **Latin Americans United for Progress** (laup.org) empowers Latinos to participate in creating a better community for all.
- **Urban Core Collective** (urbancorecollective.org) uplifts historically marginalized communities to a place of greater self sufficiency by unifying communities of color in order to reduce the effects of systemic racism.
- **Urban League of West Michigan** (grurbanleague.org or 616-245-2207) provides the means to empower African Americans and other minorities to achieve economic self-reliance, parity and civil rights.
- **West Michigan Asian American Association** (wm-aaa.org or 616-481-6194) seeks to build a collaborative, active, and committed Asian American community in West Michigan with a focus on healthcare, education, and civic engagement.

Hello West Michigan maintains a directory of local multicultural organizations, listed by city/county at hellowestmichigan.com. West Michigan residents are also encouraged to visit the **ExperienceGR** website to learn more about the history of diversity in Grand Rapids at experiencegr.com.

LGBTQIA+ Families

- **Resources Specific to Down Syndrome**
 - **Parenting as an LGBTQIA Parent** is an online support group for LGBTQIA parents raising children with Down syndrome. To join, email support@dsdiagnosisnetwork.org and include the subject line "I would like to be added to the LGBTQIA parenting group."
- **Local Resources Specific to LGBTQIA+ Families**
 - **Grand Rapids Pride Center** (grpride.org or 616-458-3511) empowers our LGBTQ community through supportive services and awareness.
 - **OutFront Kalamazoo** (outfrontkzoo.org or 269-349-7490) creates a just, inclusive, equitable, and supportive environment in Southwest Michigan for people of all sexual orientations and gender identities and expressions.
 - **Out On The Lakeshore** (outonthelakeshore.org or 616-994-8090) provides a constant source of support and understanding to the LGBTQ community of the greater Holland area.

- **OutPro** (grandrapids.org/talent-development/outpro) is an LGBTQ+ professionals group that can serve as both a resource to employers and employees, as well as an affinity group for the LGBTQ+ community.

Adoptive Families

- **Resources Specific to Down Syndrome**
 - **National Down Syndrome Adoption Network** (ndsan.org or 513-709-1751) works to ensure that every child born with Down syndrome has the opportunity to grow up in a loving family.
 - **DSDN Adoption & Ds Facebook Group** (facebook.com/groups/DSDNadoption) is for adoptive families looking to find support in others who have adopted children with Down syndrome.
- **Local Resources Specific to Adoptive Families**
 - **Adoptive Family Support Network** (dabsj.org/what-we-do/adoption/post-adoption-support) is a service of D.A. Blodgett – St. John's that gives adoptive parents access to a community of people who can provide answers and share experiences.
 - **Bethany Christian Services** (bethany.org or 800-238-4269) is one of the leading West Michigan organizations that supports families along their adoption journey.
 - **Michigan Adoption Resource Exchange** (<https://www.mare.org> or 800-589-6273) is a statewide information and referral service for families interested in adopting children from foster care, and for adoption workers looking for homes for these children.

D.A. Blodgett also maintains a directory of local support groups for adoptive families across the state organized by county on their website at dabsj.org.

The Down Syndrome Diagnosis Network maintains a directory of online support groups for families in a variety of topic areas at dsdiagnosisnetwork.org/subgroups.

For more information about Diversity Resources, visit our website at dsawm.org/diversity-resources.

Follow us!



[@dsawestmi](https://www.facebook.com/dsawestmi)



[@dsawm](https://www.instagram.com/dsawm)



[@dsawm](https://twitter.com/dsawm)



Additional Local & National Down Syndrome Resources

DSAWM is proud to be one of the many organizations across the globe committed to providing services and advocating for individuals with Down syndrome.

Down Syndrome Community Supports

Local & Statewide

Michigan Down Syndrome Associations

Upper Peninsula Down Syndrome Association facebook.com/UPDSA Marquette	Down Syndrome Guild of Southeast Michigan dsgsemi.org 248-556-5341 Royal Oak
Down Syndrome Association of Northwest Michigan dsupnorth.org 231-357-8383 Traverse City	Michiana Down Syndrome michianadownsyndrome.org 574-334-7734 Mishawaka (Indiana)
Capital Area Down Syndrome Association cadsa.org 517-333-6655 Lansing	

Down Syndrome Support Across the State

Gigi's Playhouse Detroit gigisplayhouse.org/detroit 248-557-9899 Detroit	Families Exploring Down Syndrome familiesexploringdownsyndrome.org Sterling Heights
Down Syndrome Support Team downsyndromesupportteam.org 313-608-7374 Saline	

National

- **Down Syndrome Diagnosis Network** (dsdiagnosisnetwork.org or 612-460-0765) connects, supports, and provides accurate information to parents – and the medical professionals who serve them – from the time of diagnosis through age 3, while fostering the opportunity for lifelong connections.
- **Down Syndrome Medical Interest Group – USA** (dsmig-usa.org) is a group of health professionals committed to promoting the optimal health care and wellness of individuals with DS across the lifespan.
- **Global Down Syndrome Foundation** (globaldownsyndrome.org or 303-321-6277) is dedicated to significantly improving the lives of people with Down syndrome through Research, Medical Care, Education and Advocacy.
- **LuMind ISD** (lumindidsc.org or 781-825-1300) accelerates research to increase availability of therapeutic, diagnostic, and medical care options and empowers families through education, connections, and support.
- **National Down Syndrome Society** (ndss.org or 800-221-4602) is the leading human rights organization for all individuals with Down syndrome.
- **National Down Syndrome Congress** (ndsccenter.org or 800-232-6372) is the leading national resource of support and information for anyone touched by or seeking to learn about Down syndrome.

Special Olympics Michigan Unified Sports & Inclusion Center

In early 2021, DSAWM moved into the first-of-its-kind Special Olympics Michigan Unified Sports & Inclusion Center. The new center, located at 160 68th Street Southwest in Grand Rapids, is a 17-acre campus that features sports fields, expanded space for programming, administrative offices, and educational and wellness spaces. It is also home to a number of West Michigan disability service providers and organizations, making it a resource hub for people with intellectual and developmental disabilities and their families.

SOMI Unified Sports & Inclusion Center Partners

- **Autism Support of Kent County** (autismsupportofkentcounty.org or 616-752-8577) works to provide services that make it possible for individuals with autism to lead healthier and more productive lives.
- **Brody's Be Café** (brodysbecafe.com) is a coffee shop that employs individuals with intellectual and developmental delays along with other special needs.
- **Deaf and Hard of Hearing Services** (deafhhs.org or 616-828-0186 [video telephone]) provides equal communication access, education, and advocacy to the Deaf, DeafBlind, and Hard of Hearing in pursuit of all life's opportunities.
- **Disability Advocates of Kent County** (dakc.us or 616-949-1100) works alongside persons with disabilities as they seek to lead self-directed lives and advocates for accessible and welcoming communities.

- **Mental Health Foundation of West Michigan/be nice** (benice.org or 616-389-8601) equips individuals with knowledge to recognize, understand, accept, and take action when it comes to mental health.
- **MOKA** (moka.org or 800-644-2434) creates opportunities for independence and acceptance in our communities by supporting children and adults with developmental and intellectual disabilities in making choices, building relationships, sharing places, developing skills, enhancing reputations and contributing back.
- **Special Olympics Michigan** (somi.org or 989-774-3911) provides year-round sports training and athletic competition for children and adults with intellectual disabilities.
- **Thresholds** (threshnet.org or 616-455-0960) serves Kent County residents who have developmental disabilities in living as productively and independently as possible.

Disability Community Supports

Grand Rapids

Disability Advocates of Kent County dakc.us 616-949-1100 Grand Rapids	The Arc of Kent County arckent.org 616-459-3339 Grand Rapids
--	---

Muskegon/Lakeshore

Disability Network Lakeshore dnlakeshore.org 616-396-5326 Holland	The Arc of Muskegon arcmuskegon.org 231-777-2066 Muskegon
Disability Network West Michigan disabilitynetworkwm.org 231-722-0088 Muskegon	

Kalamazoo/Southwest Michigan

Disability Network Southwest Michigan dnswm.org 269-345-1516 (Kalamazoo), 269-985-0111 (St. Joseph)	The Arc Community Advocates communityadvocates.org 269-342-9801 Kalamazoo
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South Central Michigan

disAbility Connections disabilityconnect.org 517-782-6054 Jackson	Disability Network Capital Area dncap.org 517-999-2760 Lansing
Disability Network Mid-Michigan dnmm.org 989-835-4041 Midland	The Arc of Mid-Michigan arcmidmichigan.org Owosso

Southeast Michigan

Ann Arbor Center for Independent Living annarborcil.org 734-971-0277 Ann Arbor, Livingston, Monroe	The Arc of Detroit arc-detroit.org 313-831-0202 Detroit
Disability Network Wayne County dnwayne.org 313-923-1655 Detroit, Livonia	Washtenaw Association for Community Advocacy washtenawaca.org 734-662-1256 Ann Arbor
Disability Network Eastern Michigan dnemichigan.org 586-268-4160 (Troy), 810-987-9337 (Port Huron), 810-648-2555 (Sandusky)	The Mon-Arc of Monroe monarcofmonroe.org 734-241-5881 Monroe
Disability Network of the Thumb bwcil.org 810-987-9337 Port Huron	The Arc of Oakland County thearcoakland.org 248-16-19002 Troy
The Disability Network disnetwork.org 810-742-1800 Flint	The Arc of St. Clair County thearcsccl.org 810-989-9144 Port Huron

Northern Michigan

Disability Network Northern Michigan disabilitynetwork.org 231-922-0903 Traverse City	The Arc of Manistee thearc.org/chapter/arc-manistee 231-723-6205 Manistee
--	--

The Arc of Central Michigan arcofcentralmi.org 989-773-8765 Mt. Pleasant	The Arc of Ogemaw County thearc.org/chapter/arc-ogemaw-county 989-329-0174 Lupton
The Arc of Midland thearcofmidland.org 989-631-4439 Midland	

Upper Peninsula

Disability Network of the Upper Peninsula upsail.org 906-228-5744 Marquette	The Arc of Gogebic County thearc.org/chapter/arc-gogebic-county 906-663-4461 Bessemer
S.P.E.A.K.S Education thearc.org/chapter/s-p-e-a-k-s-education-inc 906-259-0330 Sault Ste Marie	

For a complete list of all Arc organizations in the state, visit thearc.org/chapter/the-arc-michigan.

For more information and resources, visit our website at dsawm.org/resources.

Follow us!



[@dsawestmi](https://www.facebook.com/dsawestmi)



[@dsawm](https://www.instagram.com/dsawm)



[@dsawm](https://twitter.com/dsawm)

GETTING TO KNOW ME



This booklet is designed to help you welcome your new student. To find additional resources regarding Down syndrome, please contact the Down Syndrome Association of West Michigan (DSAWM) at director@dsawm.org or 616-956-3488.

We are pleased to share our **Getting to Know Me** booklet with you. This booklet includes a lot of information about our child, _____, and our family. We hope that this information will help you get to know our child and some of his or her interests, strengths, and skills.

We have high expectations for our child, just as other parents do for their children. We hope that he or she will follow school rules, perform to the best of his or her ability, and be a contributing member of the class. Quality teaching and positive peer role models will help our child be successful.



If you have any questions, please contact us at one of the following numbers:

Home: (____) _____

Work: (____) _____

Cell: (____) _____

The best time to reach us is _____.

We look forward to working with you this year. Please let us know how we can help make this a great school year for our child, his or her classmates and schoolmates, and you.

Sincerely,

My Parents' Dreams for Me



When our child was born, we worried about: _____

Our hopes for this year are: _____

Our lifetime goals for our child are: _____

Here are some ways we think you can help our child be successful: _____

HERE IS MY FAMILY



My name is: _____ I like to be called: _____

My birthday is: _____ I was born in: _____ (City)

My Mom's name is: _____

My Dad's name is: _____

I have _____ brothers. Their names are: _____

I have _____ sisters. Their names are: _____

We have _____ pet(s).



Pet's Name

Breed

Other family members or friends that I want you to know about are: _____

MY LEARNING STYLE



Three things that motivate me are: _____

My strengths are: _____

These are details about how I communicate: _____

These are ways to communicate with me so I'll better understand you: _____

Ways to help me transition more easily are: _____

THINGS I LIKE



These are some of my favorite things:

Activity: _____ Character: _____

Animal: _____ Color: _____

Book: _____ Game: _____

Food: _____ Drink: _____

When I'm inside I like to: _____

When I go outside, I like to: _____

After school I like to: _____

On the weekends I like to: _____

MY FEELINGS

Things that make me feel happy are: _____



Things that make me feel better are: _____

When I get upset, I may say or do: _____

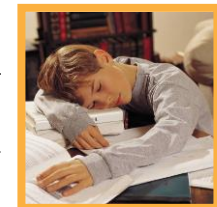
Things that might upset me or make me sad are: _____



I respond positively when: _____

I might be mischievous when: _____

When I'm tired or not feeling well I may: _____



Things I may be a little afraid of are: _____

It's hard for me to: _____

PLACES I LIKE TO GO

These are places I enjoy at school: _____



These are places that I like to go with my family: _____

These are places that I like to go with my friends: _____



My favorite place to go in my neighborhood is: _____

These are the fun things I did this summer: _____



HEALTH CONSIDERATIONS

Here are some things that you may
need to know about my health:



Surgeries: _____

Current Medication(s): _____

Recurring Illnesses: _____

Allergies: _____

I wear glasses: Yes _____ No _____ I need help cleaning my glasses: Yes _____ No _____

I have a hearing loss: Yes _____ No _____ Affected Ear(s) _____

Degree of Loss _____

If I get injured, I may need penicillin to protect myself from Bacterial Endocarditis (result of heart surgery). Please call my parents ASAP! Yes _____ No _____

I have had an ATL X-ray: Yes _____ No _____ Date _____

Results of X-ray _____

I have the following sensory needs: _____

Other things you may need to know about my health are: _____

THINGS I DO TO HELP AT HOME



THINGS I CAN DO FOR MYSELF



THINGS I MAY NEED HELP WITH AT SCHOOL



Dressing _____ Zippers _____ Coats _____ Shoelaces _____ Shoes/Boots _____

Toileting (including getting my pants on correctly) _____

Eating (including cutting my food and helping me clean up) _____

Other _____

PARENT ATTACHMENT

(Other Things We Would Like You
to Know About Our Child)

[illegible]

FAMILY PHOTOGRAPHS



**160 68th St. SW, Ste. 110
Grand Rapids, MI 49548**

**616-956-3488
www.dsawm.org**

*With grateful acknowledgement to the Down Syndrome Association of
Greater Cincinnati (DSAGC) for the concept and content of this booklet*



Supporting the Student with Down Syndrome in Your Classroom



Educator Manual

Educator Manual

Table of Contents

Introduction..... 1

 About the Down Syndrome Association of West Michigan (DSAWM).....1

 About Down Syndrome.....2

 Myths and Truths about Down Syndrome.....3

 People First Language4

Inclusion 6

 What is Inclusion?6

 Conditions for Successful Inclusion.....6

 Practical Tips to Achieve Inclusion7

Students with Down Syndrome and the General Education Classroom..... 9

 Health Conditions Associated with Down Syndrome9

 Modifying the Curriculum for Students with Down Syndrome 12

 Reading 16

 Math..... 20

 Communication..... 24

Sensory Processing 29

 Sensory Processing..... 29

 Characteristics of Sensory Processing Disorder (SPD) 30

 SPD and the General Education Classroom 31

Facilitating Friendships and Social Learning..... 33

 Promoting Social Inclusion..... 33

 Classroom Strategies..... 33

 Buddy Programs..... 38

Extracurricular Activities 39

 Special Olympics 39

 VIP Soccer..... 39

 Challenger Little League..... 40

Positive Behavior Supports 41

 Causes of Inappropriate Behavior..... 41

 Options for Behavior Management 42

Appendices 44

 Bibliography 44

 Additional Reading..... 45

 Websites 48

Acknowledgements 49

Introduction

About the Down Syndrome Association of West Michigan (DSAWM)

The DSAWM is a 501(c)(3) nonprofit organization that is committed to spreading awareness and educating its membership and the general public about all issues associated with Down syndrome. We are an affiliate of the National Down Syndrome Society and National Down Syndrome Congress.



The mission of the Down Syndrome Association of West Michigan is to be a resource and advocacy organization promoting public awareness and supporting lifelong opportunities for individuals with Down syndrome and their families.

DSAWM PRIORITY AREAS

Programming and Social Events

The DSAWM develops therapeutic, social, and recreational programs and services that enrich the lives of individuals with Down syndrome and their families, including the following:

- ✓ For Newborns, Infants and Toddlers with Down Syndrome and Their Families
 - Parent to Parent Mentoring Program
 - Baby Sign Language Program
 - OT Playgroups
- ✓ For School-Age Children with Down Syndrome and Their Families
 - Adaptive Water Ski Clinic
 - Buddy Up Tennis Program
 - iCan Bike Camp
- ✓ For Teenagers and Young Adults with Down Syndrome
 - Cooking Capers Class
 - Shape Up Fitness Class
 - Work Skills Program
- ✓ For Parents and/or Caregivers of Children with Down Syndrome
 - Parent to Parent Mentoring Program
 - Moms' and Dads' Night Out Social Gatherings
 - Aging with Down Syndrome Support Group
- ✓ Social Events
 - World Down Syndrome Day Dance
 - Summer Picnic
 - Holiday Party

Education

The DSAWM works to ensure that individuals with Down syndrome receive a quality education that will help prepare them for further education, employment and/or independent living, by providing parents/caregivers and educators with information, resources and support, including the following:

- | | |
|--|------------------------------|
| ✓ DSAWM Lending Library | ✓ Teacher Information Packet |
| ✓ <i>DSA Press</i> Tri-Annual Newsletter | ✓ Workshops and Conferences |

Family Support

The DSAWM provides social, emotional, and financial support to caregivers of individuals with Down syndrome, by way of the following:

- ✓ Parent to Parent Mentoring Program
- ✓ Guide for New & Expectant Parents
- ✓ Hospital Meal Voucher Assistance Program
- ✓ Parent Support and Social Gatherings
- ✓ Member Assistance Funds
 - Financial Assistance
 - Adoption Assistance
 - Respite Assistance

Awareness

The DSAWM works to increase public awareness, acceptance, and understanding of the abilities of individuals with Down syndrome through the following:

- ✓ Step Up for Down Syndrome Awareness Walk
- ✓ Presentations to Classrooms, Community Groups, etc.
- ✓ Promoting Possibilities Medical Outreach Program

For more information on the Down Syndrome Association of West Michigan, please visit our website at www.dsawm.org.

About Down Syndrome

IS IT “DOWN’S” OR “DOWN” SYNDROME?

Down syndrome is named after Dr. John Langdon Down, an English physician who first described the characteristic features of Trisomy 21 in 1866. People now use the term “Down syndrome” as opposed to “Down’s syndrome” because Dr. Down did not have Down syndrome, nor did he own Down syndrome.

WHAT IS DOWN SYNDROME?

Down syndrome is primarily caused by an error in cell division called nondisjunction, which causes a person’s cells to have forty-seven, instead of forty-six, chromosomes. In Down syndrome, there are three – not two – copies of the number 21 chromosome, resulting in the medical diagnosis of Trisomy 21. This extra genetic material causes changes in the orderly development of the body and brain, as well as the physical characteristics and delayed physical, intellectual and language development associated with Down syndrome. The cause of nondisjunction is currently unknown.

MORE ALIKE THAN DIFFERENT

People with Down syndrome are more like their typically developing peers than they are different. There is great diversity within the population in terms of personality, intelligence, appearance, humor, learning styles, compassion, compliance and attitude. Although persons with Down syndrome may share traits and similarities in appearance, they look more like their family members than they do one another. They have a full range of emotions and attitudes, are creative and imaginative in play, and grow up to live independent lives with varying degrees of support and accommodations. Individuals with Down syndrome establish friendships, pursue interests and are included in community activities.

Children with Down syndrome benefit from the same care, attention, and inclusion in community life that help every student to grow. As with all children, quality education in neighborhood schools, preschools, and at home provides important opportunities for developing strong academic and social skills.

FACTS ABOUT DOWN SYNDROME

- ✓ Down syndrome is the most common chromosomal abnormality in humans.
- ✓ Down syndrome occurs in every 600-800 live births and is not related to race, nationality, religion, or socioeconomic status.
- ✓ While the age of the mother can be a factor in whether a child will have Down syndrome, eighty percent of people with Down syndrome are born to parents under the age of thirty-five.
- ✓ Down syndrome occurs in males and females evenly.

- ✓ Nothing that a parent did or did not do during a pregnancy causes a baby to have Down syndrome.

THE FUTURE FOR CHILDREN WITH DOWN SYNDROME

Individuals with Down syndrome have more opportunities than ever before. As young people with Down syndrome show what they can accomplish with the support of their families, friends, and communities, and as they are integrated into mainstream programs, more and more doors open for others.

We have seen a TV series starring a talented actor with Down syndrome. Two young men have authored a book, *Count Us in: Growing up with Down Syndrome*, and have impressed audiences around the country at book signings and on talk shows. *Honor Thy Son*, a fast-paced mystery by Lou Shaw, features two characters with Down syndrome who are faithfully portrayed as multidimensional young adults. A young man with Down syndrome was the winner of the 1996 Best Actor honor at the Cannes Film Festival.

Along with these shining examples, thousands of people with Down syndrome across the world are quietly going about their lives without fame or fanfare. They transform their communities just by being there. They have dreams and the determination to reach their goals. They learn in regular classrooms in their neighborhood schools with the children who will one day be their coworkers, neighbors, and adult friends. Young adults hold diverse and meaningful jobs, maintain their own households, and make significant contributions to their communities every day.

References

- 📖 "Down Syndrome Facts." National Association for Down Syndrome
http://www.nads.org/docs/DS_Facts.pdf (accessed June 4, 2007)
- 📖 "Information Topics." National Down Syndrome Society
http://www.ndss.org/index.php?option=com_content&task=view&id=1812&Itemid=95 (accessed June 4, 2007)
- 📖 "Down Syndrome." National Down Syndrome Congress
<http://www.ndsccenter.org/resources/dsBrochure.pdf> (accessed June 4, 2007)

Myths and Truths about Down Syndrome

For individuals with Down syndrome, success as adults in the community and workplace requires the opportunity to continue to grow and learn in the classroom along with those who will later be their coworkers and neighbors. Thus, it is important to dispel the myths associated with Down syndrome and recognize that the social, emotional, and educational needs of children who have Down syndrome are mostly the same as those of other children.

MYTH: PEOPLE WITH DOWN SYNDROME HAVE SEVERE MENTAL RETARDATION

Standard IQ tests score students with Down syndrome in the mild to moderate range of cognitive impairment; however, these tests do not measure many important areas of intelligence, and you will often be surprised by their memory, insight, creativity and cleverness. The high rates of learning disabilities in students with Down syndrome often mask an array of abilities and talents. Educators and researchers are still discovering the full potential of people with Down syndrome.

See www.craigblackburn.org for a shining example of a young adult with Down syndrome who graduated high school with a regular diploma and now travels around the country as a self advocate. Jason Kingsley, one of the authors of *Count Us In*, also graduated with a regular diploma and passed all his New York State Regents Competency exams.

MYTH: ADULTS WITH DOWN SYNDROME ARE UNEMPLOYABLE

Businesses are seeking young adults with Down syndrome for a variety of positions. They are employed in small- and medium-sized offices, by banks, corporations, nursing homes, hotels and restaurants. They work in the music and entertainment industries, in clerical positions, and in the computer industry. People with Down syndrome bring to their jobs enthusiasm, reliability and dedication.

MYTH: PEOPLE WITH DOWN SYNDROME ARE ALWAYS HAPPY

People with Down syndrome have feelings just like everyone else in the population. They respond to positive expressions of friendship and are hurt and upset by inconsiderate behavior.

MYTH: ADULTS WITH DOWN SYNDROME ARE UNABLE TO FORM CLOSE RELATIONSHIPS LEADING TO MARRIAGE

People with Down syndrome date, socialize and form ongoing relationships. Some are beginning to marry. In fact, the Best Documentary winner at the 2010 Tribeca Film Festival was *Monica and David*, a film exploring the marriage of two adults with Down syndrome.

MYTH: INDIVIDUALS WITH DOWN SYNDROME ARE STUBBORN

A student with Down syndrome may not be able to tell you how she feels. This can lead to the false perception that she is “stubborn.” Behavior is communication. Consider all the circumstances. Is your student experiencing sensory or communication difficulties?

MYTH: BEHAVIOR PROBLEMS AND DEPRESSION ARE JUST PART OF HAVING DOWN SYNDROME

Often, medical or mental health problems go untreated due to the assumption that it is typical of this genetic condition. Complete examinations by appropriate health care professionals should always be pursued.

MYTH: CHILDREN WITH DOWN SYNDROME “PLATEAU”

Learning is a lifelong experience for people with Down syndrome, as it is for everyone. Individuals with Down syndrome learn at a slower pace, but nonetheless continue to learn.

MYTH: THERE ARE NO EFFECTIVE TREATMENTS FOR DOWN SYNDROME

Researchers are making great strides in identifying the genes on chromosome 21 that cause the characteristics of Down syndrome. Scientists now feel strongly that it will be possible to improve, correct or prevent many of the problems associated with Down syndrome in the future. Particularly encouraging is the establishment of the Stanford Center for Research and Treatment of Down Syndrome, whose mission is to conduct research and develop treatments related to the cognitive disabilities related to Down syndrome.


MYTH: CHILDREN WITH DOWN SYNDROME WILL NEVER GROW UP TO BE INDEPENDENT

Parents of individuals with Down syndrome and society-at-large are coming to understand the abilities and aspirations of persons with Down syndrome to participate in all aspects of community life: education, recreation, employment, socialization, and family life.

MYTH: HAVING A SIBLING WITH DOWN SYNDROME WILL BE A HARDSHIP FOR YOUR “TYPICAL” CHILD(REN)

Most families report that their “typical” kids are more compassionate, patient, and tolerant of all people because of their experiences having a sibling with Down syndrome. The sibling relationship is generally a typical one — full of love, occasional arguments and just being together.

References

-  “Down Syndrome Myths and Truths.” National Down Syndrome Society
http://www.ndss.org/index.php?option=com_content&task=category§ionid=23&id=58&Itemid=234
(accessed October 10, 2007)

People First Language

It is estimated that one in five Americans has a disability. Oftentimes, society makes assumptions, based on a person’s diagnosis, about how a student should be educated, what his potential is, where and how he will live and what “services” he needs. Negative stereotypes and the inappropriate use of medical diagnoses have led people across the country to advocate for “People First Language.”

IN YOUR LANGUAGE (BOTH WRITTEN AND ORAL), PUT THE PERSON BEFORE THE DISABILITY

- ✓ Use “My student with Down syndrome” rather than “my Downs student” or “he’s Downs.”

- ✓ Say “My student receives special ed services” rather than “he’s a special ed student.”
- ✓ Encourage all students to think of students with Down syndrome as people first.

RECOGNIZE THAT WORDS CAN CREATE BARRIERS

- ✓ Avoid terms with obvious negative connotations, such as “retarded.”
- ✓ “Developmentally delayed” is preferable to potentially offensive words like “mentally retarded,” “disabled,” or “handicapped.”
- ✓ If you aren’t sure how to refer to the student’s condition, ask the parent.
- ✓ Try to describe people without disabilities as “typically-developing” rather than “normal.”

USE EMOTIONALLY NEUTRAL EXPRESSIONS

- ✓ A person “has” Down syndrome, rather than “suffers from,” “is a victim of” or “afflicted by.”
- ✓ Say “My student has Down syndrome” rather than “my student suffers from Down syndrome.”

AVOID USE OF STEREOTYPES

- ✓ Try not to use the clichés that are so common when describing an individual with Down syndrome.
- ✓ Avoid saying “They are so loving/happy all the time.” Individuals with Down syndrome experience a wide range of emotions and are not all alike.
- ✓ Recognize that a student is “a student with Down syndrome,” and an adult is “an adult with Down syndrome.”

USE EXAMPLES OF WHAT CHILDREN NEED RATHER THAN LABELING THEM AS HAVING “PROBLEMS”

- ✓ Use “Billy needs . . .” rather than “Billy has problems or special needs.”

AVOID USE OF TERMS “MILD” OR “SEVERE”

- ✓ A person either has Down syndrome or does not. While there are varying degrees of abilities, using “mild” or “severe” can be insulting to parents or other families who overhear.

References

- 📖 “Public Awareness Language Guidelines.” National Down Syndrome Congress
<http://www.ndsccenter.org/resources/package4.php> (accessed June 4, 2007)
- 📖 Snow, Kathie. “People First Language.” Disability is Natural
<http://www.disabilityisnatural.com/peoplefirstlanguage.htm> (accessed June 4, 2007)

Inclusion

What is Inclusion?

Inclusion is a philosophy of education based on a belief in every person's inherent right to fully participate in society. It implies acceptance of differences and access to the educational experiences that are fundamental to every student's development.

When effectively implemented, research has demonstrated that inclusion offers academic and social benefits for all students – both those who have special needs and those who do not. Friendships develop, typically-developing students are more appreciative of differences and students with disabilities are more motivated. True acceptance of diversity ultimately develops within the school environment and is then carried into the home, workplace, and community.

THE EDUCATIONAL CHALLENGES INCLUSION STUDY

In a 1996 study conducted on behalf of the National Down Syndrome Society (NDSS), parents of children with Down syndrome described multiple benefits of successful inclusion experiences, including higher self-esteem, independence in daily living skills, greater academic achievement, positive social interactions and improved speech and communication.

They reported that the following factors had the most significant relationship to successful inclusion experiences:

- ✓ Teacher preparation
- ✓ Format of the curriculum (lesson plans and materials)
- ✓ Classroom management and curricular style of the teacher
- ✓ Collaboration between special and general education
- ✓ Parental confidence in professionals
- ✓ Attitude of professionals (open-mindedness, enthusiasm and confidence were cited as helpful character traits for successful inclusion)
- ✓ Contact, encouragement from and friendships with peers

Schools that are successful in integrating students with Down syndrome have the following attributes:

- ✓ Effective leadership from a head teacher who is committed to meeting the needs of all pupils
- ✓ Confidence amongst staff in dealing with students' individual needs
- ✓ A sense of optimism that all pupils can succeed
- ✓ Arrangements for supporting individual members of staff
- ✓ A commitment to provide a broad and balanced range of curriculum for all students
- ✓ A systematic procedure for monitoring and reviewing progress

References

- 📖 Wolpert, Gloria. "The Educational Challenges Inclusion Study." National Down Syndrome Society.
http://www.ndss.org/index.php?option=com_content&task=view&id=1955&Itemid=208 (accessed June 27, 2007)

Conditions for Successful Inclusion

Students with Down syndrome benefit from education in the general education classroom setting when schools implement "best practices," such as the following:

- ✓ View special education as a collection of supports and services, rather than as a place
- ✓ Remove barriers that are created by dual systems (general and special education) and provide access to the resources and expertise of both
- ✓ Maintain respectful attitudes toward students and their families
- ✓ Encourage meaningful participation from parents as equal members of the IEP team
- ✓ Have high expectations of all students
- ✓ Provide access to the same academic curriculum, with or without adaptations, as students without disabilities

- ✓ Proactively use positive behavior support strategies
- ✓ Provide access to and training for assistive technology
- ✓ Facilitate and support peer relationships and interactions using deliberate strategies
- ✓ Plan and implement transition
- ✓ Emphasize staff development and training
- ✓ Foster a strong sense of community among students, staff and parents

Parents also can, and should, contribute to their student's success in inclusive settings by way of the following:

- ✓ Maintain the same expectations of behavior for students with Down syndrome as for any other student
- ✓ Teach students with Down syndrome how to behave and interact with others in a socially acceptable way, e.g., taking turns and sharing
- ✓ Teach appropriate reactions and responses in the school environment, e.g., greeting and asking for help
- ✓ Foster independence and cooperation
- ✓ Teach self-help and practical skills
- ✓ Develop an effective home-school communication system
- ✓ Be involved in school activities
- ✓ Do additional activities at home to reinforce what the student is learning at school

References

- 📖 "Position Statement on Inclusive Education for Students with Down Syndrome." National Down Syndrome Congress.
<http://www.ndsccenter.org/resources/position5.php> (accessed June 27, 2007)
- 📖 "What is Inclusive Education?" Down Syndrome South Africa.
<http://www.downsyndrome.org.za/main.aspx?artid=25> (accessed June 6, 2007)

Practical Tips to Achieve Inclusion

LONG TERM GOALS

Parents should tell the IEP team that they want to prepare their child to live and work as independently as possible. This means being able to function and behave appropriately in a world of typical peers. The goals on the student's IEP should reflect the skills necessary to achieve this — both academic and nonacademic.

Parents should acknowledge their high, but reasonable, expectations and inform the IEP team that they will support them in any way possible. It is critical that the IEP team sees the student's future through both the parents' and the student's eyes.

DRAFTING IEP GOALS FOR INCLUSIVE SETTINGS

The goals for the student drive placement decisions at IEP meetings. As long as the student can make progress toward her goals in an inclusive environment, the team should not consider a more restrictive placement. It is important that these goals be appropriate for the general education classroom. For example, if the student's IEP includes a goal that specifically requires trips into the community, it cannot be met in an inclusive environment; if her goal is to learn to handle money in real-life situations, the goal can be written in a way that uses the cafeteria or the school store, rather than the mall or McDonald's.

It also helps to have social goals that involve interactions with typical peers, which cannot be worked on in segregated settings. The goals should not be restricted to "small group settings." Even though small groups can be arranged in the general education classroom, the term "small group setting" is often considered to be synonymous with a special education class.


PLANNING MATRIX

A chart should be used to show how the student's goals can be worked on in the different parts of a typical school day. For example, the schedule may indicate that the student will work on money at lunchtime, communication and reading skills throughout the day and one-to-one correspondence during math — by handing out dittos (assignment sheets) to each classmate. By demonstrating to the IEP team and school personnel that including a student with special needs in the general education classroom just takes a little creativity and flexibility, the concept of inclusion becomes less threatening.

SUPPLEMENTARY AIDS AND SERVICES

All the supports and services that the student and teacher will need should be reflected in the IEP. Examples include curriculum modifications; assistive technology; augmentative communication; paraprofessional support; a behavior plan; staff training; staff collaboration time; psychological support; and occupational, speech and physical therapy. The student's need for these supports is not grounds for a more restrictive placement unless they cannot be provided at the school. It is not enough for the school to say it does not have these services; efforts must be made to bring the services to the school, through traveling staff or some other means.

References

-  This Section was reprinted with permission from the NDSS publication "Practical Tips to Achieve Inclusion." National Down Syndrome Society. http://www.ndss.org/index.php?option=com_content&task=view&id=1940&Itemid=236 (accessed October 10, 2007)

Students with Down Syndrome and the General Education Classroom

Health Conditions Associated with Down Syndrome

One factor that teachers must consider is the effect that chronic health problems have on learning. By the time they reach school-age, many young children with Down syndrome have had multiple surgical procedures. Although they seem resilient, chronic health issues can take their toll. General health may be poor, students may have problems with eating or sleeping, or they may suffer from chronic ear or sinus infections.

In general, the following reminders and practices will promote improved classroom success:

- ✓ Be aware of physical characteristics and health conditions that may affect classroom success. It is important to note that behaviors you witness in the classroom may have a medical or health basis. Speak with the student's parents to identify previous health conditions and ongoing medications, as these can affect ability to listen and follow directions. Recognize that unusual behaviors or situational responses may signal an illness which the child is unable to communicate.
- ✓ Ask parents to alert you to changes in their child's health or sleeping patterns, as these factors can detract from their ability to solve problems. Schedule the most challenging academic areas in the morning. Tiredness at the end of the school day can significantly increase the time required to process information or directions and cause frustration and perceived behavior problems.
- ✓ Students with Down syndrome may require additional recovery time from illness; consider alternative activities and additional periods of rest in these cases. Recognize that non-routine activities (field trips, parties, etc.) can be physically or emotionally draining for students with Down syndrome. Avoid situations that set up a student for failure.

The following are some of the physical characteristics and health conditions that may affect the classroom success of students with Down syndrome:

MUSCLE HYPOTONIA

Hypotonia is a medical term used to describe decreased muscle tone (the amount of resistance to movement in a muscle). Symptoms of hypotonia include problems with mobility and posture, breathing and speech difficulties, lethargy, ligament and joint laxity, and poor reflexes.

To understand the physical demands that low muscle tone places on children with Down syndrome, imagine cooking dinner while wearing socks on your hands. Students with Down syndrome can get frustrated when their abilities to complete tasks are hindered by low muscle tone. Muscle development can require repetitive training.

- ✓ Allow extra time for a student with Down syndrome to complete tasks.
- ✓ Provide increased opportunities for practice.
- ✓ Work with physical therapists to identify and improve specific muscle development needs.
- ✓ To support fine motor development, use wrist and finger strengthening activities. Multisensory activities and materials work well. Provide opportunities to practice self-help skills such as using buttons and zippers.

SPEECH INTELLIGIBILITY

Speech intelligibility refers to the ability to be understood when speaking orally. This can be difficult for students with Down syndrome because of low muscle tone, jaw movement difficulties and motor planning difficulties.

To understand how your student with Down syndrome may feel, imagine communicating your needs while your mouth is full.

- ✓ Upon evaluation, many students with Down syndrome exhibit great differences between receptive (understanding) and expressive (spoken language production) language abilities. For this reason, their intelligence is often underestimated.
- ✓ Recognize that situational factors can impact communication and classroom performance, e.g., an impatient listener, anxiety, perceived pressure, embarrassment or lack of confidence.
- ✓ Use simple questions (5Ws and H), and allow extra response time. If your student uses American Sign Language (ASL), learn basic signs and teach them to the class.
- ✓ Peer group acceptance may hinge on the ability to communicate intelligibly. Goals for the classroom should include teaching the student with Down syndrome to communicate, in addition to teaching peers how to engage in meaningful interactions.
- ✓ Work with your district's therapists to assist students with Down syndrome:
 - Speech therapists can design a speech remediation component to the IEP.
 - Occupational therapists can work on postural control required for speech.
 - Audiologists measure a child's ability to hear.
 - Aides can provide one-to-one instruction for articulation skills.
- ✓ Students may exhibit an increase in stuttering when under stress. Attempt to ease stress by increasing the comfort level of the classroom.

MEMORY

Most students with Down syndrome will have short term or working memory difficulties. This makes it harder for them to access, understand and process information at the speed of other students, but it does not prevent them from learning the same information. Individual motivation is the key to learning!

Present information in a clear, ordered manner. Explain the links between information to build a system of knowledge.

- ✓ Allow more time to learn.
- ✓ Allow more practice to apply knowledge.

COMPACT STRUCTURE OF EAR, NOSE AND THROAT

Students with Down syndrome typically have compact bone and soft tissue structure of the ear, nose, and throat. This increases their susceptibility to, and the severity of, upper respiratory and sinus infections. It may also increase sensitivity to loud sounds or vibrations. A child with Down syndrome may cover his ears or avoid activities that create loud noises. Be aware of the activity noise levels in and around your classroom. If appropriate, headphones can limit auditory distractions.

SLEEP APNEA

Recent studies indicate that as many as forty-five percent of individuals with Down syndrome may suffer from sleep apnea. This is the term used when someone stops breathing for very short periods of time, usually ten to twenty seconds, during sleep. Sleep apnea can cause memory loss and intellectual impairment and may make a student more tired and lethargic. Alternatively, it may result in hyperactivity (which is often inaccurately interpreted as an attention deficit disorder). If you recognize these issues in a student with Down syndrome, explore sleep patterns (including snoring) with parents. Medical interventions can improve your student's quality of life and school performance.

HEARING, VISION AND THYROID PROBLEMS

It is estimated that sixty-five to eighty percent of children with Down syndrome have conductive hearing loss, and that fifty percent have vision problems. There is also a higher rate of hypothyroidism, which can cause sluggishness, weight gain and mental impairment.

Perform an annual hearing and vision screening. Note that hearing loss may fluctuate when fluid is present or when a student is experiencing ear pain. A student may not be "ignoring" your instructions, but may not be able to hear you. Inform parents of your observations. When left untreated, these problems can significantly affect a student's ability to succeed academically and socially.

The following tips and tactics are recommended to improve the listening environment:

- ✓ Place the student at the front of the class.

- ✓ Speak directly to the student and supplement with signs, gestures, or expressions.
- ✓ Use visual aids, e.g., write on the board.
- ✓ Rephrase and repeat questions or instructions often.

The following tips and tactics are recommended to support visual skills:

- ✓ Place the student at the front of the class.
- ✓ Use larger font.
- ✓ Use visual aids, e.g., signs on floors or walls.

HEART CONDITIONS

Forty to forty-five percent of children with Down syndrome have congenital heart disease. Many of these children will have to undergo cardiac surgery and can participate in classroom activities without restrictions. If a student has had or is scheduled to have surgery, ask the parents if it is appropriate to teach his or her classmates about the condition.

References

- 📖 Bird, Gillian, et al. "Accessing the Curriculum: Strategies for Differentiation for Pupils with Down Syndrome." (The Down Syndrome Educational Trust, UK. 2000)
- 📖 Bird, Gillian and S. Buckley. "Meeting the Educational Needs of Pupils with Down Syndrome in Mainstream Secondary Schools." Down Syndrome News and Update 1, no. 4 (1999): pp. 159174. via The Down Syndrome Educational Trust, <http://www.downsyndrome.org/practice/148/?page=1>
- 📖 Leshin, Len, M.D. FAAP. Obstructive Sleep Apnea and Down Syndrome. (1997) <http://www.dshealth.com/apnea.htm>
- 📖 Peoples, Susan J. Understanding How Children with Down Syndrome and Other Developmental Delays Learn. Fort Wayne: Special Offspring Publishing, 2003

Modifying the Curriculum for Students with Down Syndrome

Individuals with Down syndrome have varying degrees of abilities, skills, behavior, and physical development. Their learning deficits result from different learning styles rather than learning impediments. As a general rule, students with Down syndrome need activities that are more highly structured and sequenced, small amounts of information presented at a time and a good reward system. Teachers can use some of the tips and tactics below in their classrooms to maximize the classroom experience.


AREA	LEARNING STYLE	TIPS AND TACTICS
Classroom Information and Curriculum	<ul style="list-style-type: none"> Students with Down syndrome are visual learners. 	<ul style="list-style-type: none"> Use teaching methods that involve cues and objects. Pair pictures with spoken words. Present information visually, e.g., overhead projector, posters, pocket charts, chalkboard.
	<ul style="list-style-type: none"> They may suffer some degree of hearing loss and have fewer short-term memory channels. 	<ul style="list-style-type: none"> Use simple directions. Break down directions into small steps.
	<ul style="list-style-type: none"> They are not proficient in auditory processing and auditory memory. They have some difficulty retaining directions or information that is only processed verbally. 	<ul style="list-style-type: none"> Allow adequate response time.
	<ul style="list-style-type: none"> They need time to process new skills they have learned before moving on to others. They have a slower rate of learning in comparison to their peers. 	<ul style="list-style-type: none"> Assign fewer problems to a page. Give students more freedom to choose their work activities. Foster independence and self-reliance by balancing developmental and chronological needs as higher academic expectations are set in the classroom. When presenting independent work, try to divide it into small segments, e.g., fold a test in half. Allow extra time to complete tasks. Reduce length of assignments.
Teacher Arrangement and Instructional Methods	<ul style="list-style-type: none"> Students with Down syndrome work best with one-on-one or small group instruction. 	<ul style="list-style-type: none"> Avoid large group and whole class instruction, as they are least effective.
	<ul style="list-style-type: none"> Working with teaching assistants or aides can be effective. 	<ul style="list-style-type: none"> While aides can be effective, some parents caution that they can isolate a student and discourage peer interaction. Provide lesson plans to assistants in advance to give them more confidence with the lesson and allow them time to develop their own ideas for suitable practical materials and resources.
	<ul style="list-style-type: none"> Computer-assisted instruction can be effective because it is interactive, self-paced and nonthreatening. 	<ul style="list-style-type: none"> Be aware that some students may lack the fine motor coordination to use a keyboard and mouse effectively. Assistive and/or adaptive equipment, such as specialized key guards or an alternative keyboard, can be used.
	<ul style="list-style-type: none"> Peer tutors are sometimes effective. 	<ul style="list-style-type: none"> Students may work harder to be independent and accepted by their peers.
	<ul style="list-style-type: none"> Communication with parents is necessary for success. 	<ul style="list-style-type: none"> Use daily notebooks to communicate with parents.

AREA	LEARNING STYLE	TIPS AND TACTICS
Materials Used	<ul style="list-style-type: none"> Concrete or “hands-on” materials are most effective for students with Down syndrome. 	<ul style="list-style-type: none"> Workbooks are not generally effective. Paper and pencil tasks, the computer and textbooks are sometimes effective in the upper grades. Manipulatives are useful. Use “hands-on” materials in creative ways, e.g., throw a soft ball at a student if you want him or her to answer a question. Assist students with exercise before writing, e.g. push palms together, push hard on the desktop, squeeze and relax fists. Have a variety of multilevel reading books in your class. Homework is effective: (a) to inform parents about what child is doing in school and (b) to provide extra practice with basic concepts.
Transitions		<ul style="list-style-type: none"> Change of location and subject teachers can be refreshing for students with Down syndrome. Breaks between classes can allow for valuable social interaction with peers, as well as exercise. When students are ready, or upon request, they should be allowed to change classes independently, meet aides at arranged classrooms and spend lunch and break times with their peers. If students need assistance, it is preferable to use peer support rather than adult staff support during these times.
Attention	<ul style="list-style-type: none"> The building block of all learning is attention. Researchers have developed a two-stage theory of attention: <ul style="list-style-type: none"> → Stage 1: Ability to attend to a task → Stage 2: Ability to identify relevant stimulus to the problem Students with Down syndrome may have a hard time paying attention to tasks, but once Stage 1 is mastered, they are able to learn the task and learn well. 	<ul style="list-style-type: none"> The goal in early childhood is at least a 15-20 minute attention span. Attention can be trained. Minimize distractions. When choosing stimuli or objects, ensure that they have clear and obvious dimensions that vary on as few dimensions as possible, e.g., color, size, texture. Use prompts, cues, and lighting to capture the student’s attention. Try using differently colored or textured backgrounds for work. Minimize or remove distractions by placing fewer pictures on the wall or problems on a page. Pay attention to seating. Avoid seating students with Down syndrome near a window, door, or high traffic area. Give immediate feedback or praise to ensure that students associate rewards with their efforts.
Sensory/Motor Difficulties	<ul style="list-style-type: none"> Students with Down syndrome may have difficulty processing information from many sources at once, doing more than one thing at a time or responding quickly to some situations. 	<ul style="list-style-type: none"> Focus on one sense at a time or completing one task at a time. Look at the student to give directions; look away while he is processing the request. A student may not be able to sit on the floor without back support; use a chair, pillow, or prop. Ensure the student is seated at a desk that is the right size, with the feet supported, elbows at a 45-degree angle from the desktop and the back supported. Uneven surfaces may be difficult to navigate. Allow the student to practice walking on these surfaces.

AREA	LEARNING STYLE	TIPS AND TACTICS
Memory	<ul style="list-style-type: none"> Individuals with Down syndrome have poor memory ability for three reasons: <ol style="list-style-type: none"> They are at a disadvantage for adequate short-term memory due to language delays. They have a limited repertoire of memory strategies. They tend to be “inactive” learners when it comes to memory. 	<ul style="list-style-type: none"> Use labeling or verbal associations. Break information down into small clusters and sequence ideas. Make tasks interesting and meaningful for the student. Teach rehearsal strategies. Provide opportunities to practice in different contexts and use multisensory approaches (hands-on activities tend to work best). Show patterns and teach memory tricks. Repetition is the key to learning!
Concept Attainment	<ul style="list-style-type: none"> Students with Down syndrome may function at a mental stage below their chronological age. Once you figure out what mental stage a student is at, you can determine how to adapt your lessons to meet his needs and play to his strengths. “Concept attainment” describes the difference between mental stage and chronological age. A 1997 study identified four developmental stages for the acquisition of cognitive skills (at right). 	<ul style="list-style-type: none"> Figure out a student’s mental stage rather than focusing on chronological age: <ol style="list-style-type: none"> Sensorimotor – The environment is experienced via sensory and motor encounters. The student learns to distinguish himself from the world. Preoperational – Concepts are absorbed via language and thought. The student remembers past events and forms future expectations. Concrete Operations – Objects are ordered and classified through logic. The student needs to manipulate objects to solve problems or learn cause and affect relationships. Formal Operations – Abstract reasoning develops. The student can link concepts, mentally use symbols, hypothesize and predict consequences or events. If a student functions in the concrete operation stage, use objects and other items to help with conceptual tasks, such as math (tokens, rods, etc.). These will help students solve problems and maintain interest. Learning is sequential. Break down tasks into steps. Students build on what they know. Before teaching new concepts, ensure that they have the requisite background knowledge to be successful. Repetition is the key to learning!
Mediation Strategies and Paired Associates	<ul style="list-style-type: none"> “Serial learning” describes the concept of getting from concept A to conclusion C (“If I touch the stove, I’ll get burned”). “Paired associates” is the ability to link concepts, ideas, and words. “Mediation strategies” are prompts or cues (the “B”). Using the example above, A to B would be “The stove is hot,” and B to C would be “if I touch something hot, it burns my hand.” Students with Down syndrome typically need more assistance with abstract concepts, but can be taught to break down and combine concepts through use of mediation strategies. 	<ul style="list-style-type: none"> Introduce a mediator to break down concepts that are too abstract for your student to grasp. Use materials that are familiar and meaningful. Break down relationships to basic concepts or categories (size, shape, color). Sequence activities from simple to complex. Increase response time. Verbalize and repeat the “B” — the link between concepts. Repetition is the key to learning!

AREA	LEARNING STYLE	TIPS AND TACTICS
Transfer of Learning (Generalization)	<ul style="list-style-type: none"> • “Transfer of Learning” refers to the ability to apply old knowledge or skills in a different situation or environment, e.g., ability to do math at school but not at the grocery store. • Teachers also report that students with Down syndrome seem to forget learned skills from one day to the next, as previous learning is often not transferred to future experiences. 	<ul style="list-style-type: none"> • Teach and practice new concepts and skills in several different environments and utilize different materials and people. Point out similarities and/or differences. • Materials should be meaningful to the student. • Use verbal explanations as well as hands-on activities. • Repetition is the key to learning!
Motivation	<ul style="list-style-type: none"> • Students with Down syndrome may need more encouragement and positive feedback than other students. • By the time they get to your class, they likely have experienced multiple delays, negative responses from adults or other children and frequent criticism or correction. • They may have developed coping mechanisms such as passive behavior, avoidance or learned helplessness (giving up and waiting for someone else to answer for them). They may also depend on external cues (“external locus of control”). 	<ul style="list-style-type: none"> • Assign well-explained tasks that are suitable for the student’s mental stage. • Materials should be meaningful and familiar. • Allow students to help develop rules or the lesson design. • Use positive language. Rather than saying “That’s wrong,” say, “Try another way.” • Encourage peer buddies and social rewards. • Reward independence. • Help students maintain motivation and develop an internally-based reward system by gradually fading out your cues and rewards.

References

-  Wolpert, Gloria. “The Educational Challenges Inclusion Study.” National Down Syndrome Society. http://www.ndss.org/index.php?option=com_content&task=view&id=1955&Itemid=208 (accessed June 27, 2007)

Reading

Reading is important for all students. It provides students with means to obtain information and gain enjoyment, and it facilitates social relationships (Downing, 2005). For many students with Down syndrome, reading is strength. Research demonstrates that teaching reading to students with Down syndrome enhances and facilitates language development because typically they are visual learners. As their reading ability increases, so does articulation and vocabulary. Since reading is language made visual, it is the ideal means of helping a student with Down syndrome with expressive language, which is normally a deficit area for students with Down syndrome (Kotlinski & Kotlinski, 2002).

The ability to read and the praise it elicits from others correlates with higher self-esteem and independent performance. Reading is also beneficial for the development of functional skills required for personal development, community life, a career and recreation. Teachers should strive to incorporate effective reading instruction for both practical and functional skills into the reading curriculum (DeutschSmith, 2006).

READING READINESS

There are several skills that can prepare students for success in reading:

SKILL	STRATEGIES FOR CLASSROOM OR HOME
Attending Skills – the ability to behave appropriately in a given situation, e.g., sitting at a desk or in a circle, looking at the teacher	<ul style="list-style-type: none">• Minimize distractions.• Teach and practice the required skills.• Seat students with Down syndrome near the teacher.
Visual Discrimination – the ability to differentiate between objects based on a set of criteria, e.g., color, shape, size <ul style="list-style-type: none">• Students must also be able to grasp the concepts of same and different.	<ul style="list-style-type: none">• Simplify choices.• Use meaningful visual aids, e.g., photos of items that interest the student.• Progressively make problems more difficult as the student is ready.
Memory – the ability to recall sounds and words, and imitate them spontaneously or upon request <ul style="list-style-type: none">• Students with Down syndrome tend to learn more slowly than their typically-developing peers.• They may forget previously learned skills.	<ul style="list-style-type: none">• Expose a student to music and beat from an early age.• Encourage singing, clapping, and dancing.• Repeat finger plays, nursery rhymes and songs for help with retention and recollection of vocabulary.• Seek creative and active ways to build a student’s vocabulary of meaningful words.• Use visual and sensory cues, e.g., pair actions with words, finger cuing and pacing.• Use tactile approaches, e.g., sandpaper words or drawing in finger paints or sand.• Repeat instructions or break down into smaller steps,• Review and practice learned skills.
Auditory Discrimination – the ability to identify and distinguish between different sounds	<ul style="list-style-type: none">• Teach good listening skills.• Use tactile and visual cues.• Use spelling to reinforce auditory discrimination.

Likewise, a teacher’s expectations, skill, methods and flexibility contribute to a student’s overall success with reading. It is important to recognize that opportunities for reading instruction in the general education classroom are unlimited. Reading instruction and activities can be incorporated into other subjects such as math, social studies or science.

Classroom Strategies:

- ✓ Use materials and activities that reflect the student’s interests and are age-appropriate, i.e., as students age, materials should reflect their growth and development.
- ✓ Develop a planning matrix that identifies a student’s reading opportunities during the school day.
- ✓ Incorporate visual and tactile cues.

- ✓ Give students opportunities for practice.
- ✓ Review “learned” concepts frequently to encourage retention.
- ✓ Maintain high expectations for your student(s) with Down syndrome.

EARLY READING AND LITERACY DEVELOPMENT

Language is the building block of any effective reading program. However, students with Down syndrome display significant delays in speech and language attainment relative to their nonverbal mental ability (Rondal & Buckley, 2003). Hearing loss, auditory processing and short-term memory difficulties can affect speech and cause language delays. Therefore, it is difficult for students with Down syndrome to learn language from listening to verbal communication.

Reading allows students with Down syndrome to view language visually. Printed text provides students with Down syndrome a permanent transitory signal. As a result, students are allowed more time to process information and more opportunities to learn. When introduced to reading as early as two to three years of age, children with Down syndrome show significantly advanced speech, language, literacy and memory skills in childhood and teenage years (Rondal & Buckley, 2003). Therefore, it is particularly important to start reading instruction for students with Down syndrome as early as preschool.

Early Intervention Strategies for the Classroom and the Home:

- ✓ Expose children to books and word games at an early age.
- ✓ Encourage parents to read to children regularly as part of the daily family routine.
- ✓ Teach children listening and attending skills. Some prerequisite skills include the ability to do the following:
 - Sit quietly and listen to a book.
 - Point to pictures.
 - Request a book or read independently.
 - Hold a book right side up and read from left to right.
 - “Finger track.”
 - Predict what will happen next.
 - Paraphrase what the book is about.

TEACHING SIGHT WORDS (LOGOGRAPHIC READING)

Reading instruction for students with Down syndrome should typically begin with sight word or automatic recognition activities. Research shows that preschool students with Down syndrome are able to learn sight words at the same pace as preschool children without any disabilities (Appleton, Buckley, & MacDonald, 2002). Students with Down syndrome can learn to sight read before becoming competent verbal communicators. Those with limited verbal ability are able to expand both their receptive and expressive language skills by learning to read (Sue Buckley, 1996, 1997).

Sight word instruction involves teaching the association between a word and the thing or idea that the word represents, e.g., pairing the “apple” with a picture of an apple. Sight word instruction should be meaningful and useful to the student. Start with words and concepts that the student already understands. Gradually incorporate sight words into sentences and encourage students to repeat words and sentences.

Classroom Strategies

- ✓ Over time, have the student combine previously learned words to form short phrases of two to three words.
- ✓ Create books with students based on the sight words and sentences they are learning and give them frequent opportunities to read the books (Copeland & Calhoon, 2007).
- ✓ Play games using the sight words.
- ✓ Practice in natural settings is essential. Traditionally, sight word instruction occurs in a decontextualized way, such as through flashcards. However, students should be given ample opportunities to practice sight word recognition in natural settings. Label items in the classroom and review the words with the whole class on a daily basis.
- ✓ Create sentence strips or Velcro cards and have students’ progress from copying a sentence structure to creating their own sentences in response to a photo or picture.
- ✓ Emphasize and provide practice with connecting words, e.g., “and,” “or,” “but.”
- ✓ Use repetitive sentence patterns to help students match words to pictures, as well as sequence, predict and expand on their sight words, e.g., “I like...” and “May I have...”

METHODS FOR TEACHING SIGHT WORDS

Pair Pictures and Words	<ul style="list-style-type: none"> Pairing pictures with words is the most popular sight word instructional technique among educators. However, there is evidence that students may subsequently associate the spoken word with the picture rather than with the printed word (Copeland & Calhoun, 2007). With “stimulus fading,” a picture is paired with a word on a flashcard. The picture is slowly faded from the flashcard, leaving only the word. Once students can pair pictures, move on to matching words. Start with two to four words that are familiar to and meaningful for the student, e.g., family names. Make two sets of identical cards and have the student match the words. Use pictures on the back of the cards and fade them over time.
Match, Select and Name	<ul style="list-style-type: none"> Step 1: Matching words together Step 2: Selecting words upon request, e.g., “Give me ‘Dog.’” Step 3: Naming, e.g., hold up a card and ask, “What does this say?” Start with two to four words that are meaningful for the student and gradually add words over time.
Copy, Cover and Compare	<ul style="list-style-type: none"> “Copy, cover and compare” is another method used in the development of reading and writing skills. A student is given a paper arranged in three sections. Section one contains the sight word. In section two, the word is printed in dashes. The last section is left blank. After the student has stated the sight word, she traces the sight word using the dashes in section two. As the student traces the sight word, she states the letters in the sight word as well as the sight word. Once she has completed sections one and two, the letters should be covered with another piece of paper. In section three, the student must write the word from memory, again stating the sight word and the letters in the sight word. Finally, the cover is removed so the teacher and student may compare work.
Response Prompts	<ul style="list-style-type: none"> “Response prompts” refers to any assistance a teacher gives a student that increases the likelihood that the student will respond correctly (Copeland & Calhoun, 2007). “Progressive time delay” is one method of response prompts. A student is given a cue to stimulate a response. The student is then given a prompt to solicit the correct answer. Gradually the prompt is delayed until, with practice, the student no longer needs a prompt to solicit the correct answer.

READING COMPREHENSION

As a student’s sight word bank grows, it is important to introduce comprehension strategies. These will reinforce learning and ensure that the student understands the meaning behind the words he is reading.

Classroom Strategies:

- ✓ Take frequent breaks to determine the students’ comprehension level, e.g., ask questions (5Ws and 1H), request a summary of the story, predict what will happen next, clarify any text you think they may not understand.
- ✓ Encourage students to ask questions when they do not understand.
- ✓ For older students, use cue cards so that they can self-check their level of comprehension. This will also reinforce self-help skills.

TEACHING PHONICS (ALPHABETIC READING)

Phonics is the relationship between letter and sound. Acquiring and applying basic phonic knowledge can be helpful to students when they encounter unfamiliar words (Copeland & Calhoun, 2007). Phonics can be difficult for students with Down syndrome because they generally exhibit auditory memory deficits, and many have trouble hearing and discriminating between sounds. Many students with Down syndrome exhibit increased phonological awareness when they reach the word reading skills of a typically-developing seven- to eight-year-old, or once the student has a sight vocabulary of approximately fifty words.

There are two basic approaches to teaching phonics: implicit/analytic phonics and explicit/synthetic phonics. Implicit/analytic phonics focuses on analyzing letters and sounds within familiar words. Students look at the whole word, then analyze the sounds of each letter in the word. Explicit/synthetic phonics focuses on teaching isolated letter and sound relationships. Once the student has learned the letters and sounds, she is taught to blend sounds in order to decode words.

Classroom Strategies:

- ✓ Provide opportunities for daily practice.
- ✓ Use visual cues, e.g., an alphabet line, finger cuing; and tactile cues, e.g., popping lips, to teach students to “feel” how sounds are made.
- ✓ Encourage practice in a mirror.
- ✓ Use sensory-related cues, e.g., “What shape is my mouth making?” “What sound do you hear with your ears?”

Older students should be given daily opportunities to write. Reading and writing are interrelated. Writing allows a student to record his thoughts and read the written text several times. Participation in writing activities allows the students to develop a deeper understanding of literacy and the use of print (Copeland, 2007). Writing does not necessarily mean that the student has to handwrite the words; he may use words, symbols and pictures.

EVALUATE STUDENT PROGRESS

Evaluation of a student’s progress is essential and should focus on areas of success and need for change. Standardized methods of assessment may not be effective for students with Down syndrome; thus, teachers should seek alternative assessment procedures, such as teacher-student conferences, observation of the student in the classroom or a review of past work. One type of alternative assessment procedure is to keep a portfolio of the student’s progress and work during the school year.

Have high expectations for student development. Link a student’s evaluation to core curriculum standards that have been accommodated to the student’s abilities. Ensure that modifications are not so oversimplified that the original goals of the core curriculum standard(s) are lost.

Finally, make reading fun. The aim is to engage the student in intellectual stimuli that promote the development of language, speech, communication, and literacy skills and provide a lifetime of enjoyment.

References

- 📖 Appleton, Michele et al. “The Early Reading Skills of Preschoolers with Down Syndrome and their Typically Developing Peers Findings from Recent Research.” *Down Syndrome News and Update* 2, no. 1 (2002): pp. 910. via The Down Syndrome Educational Trust, <http://www.downsyndrome.org/updates/157/?page=1>
- 📖 Buckley, Sue. “Literacy and Language.” In *Speech and Language Intervention in Down Syndrome*. ed. Jean A. Rondal & S. Buckley, pp.132153. London: Whurr Publishing Ltd., 2003
- 📖 Copeland, Susan R. “Written Communication.” In *Effective Literacy Instruction: For Students with Moderate or Severe Disabilities*. ed. Susan R. Copeland & Elizabeth B. Keefe, 109126. Baltimore: Paul H. Brooks Publishing Co., 2007
- 📖 Copeland, Susan R. & Elizabeth B. Keefe. “Word Recognition Instruction.” In *Effective Literacy Instruction: For Students with Moderate or Severe Disabilities*. ed. Susan R. Copeland & Elizabeth B. Keefe, 4162. Baltimore: Paul H. Brooks Publishing Co., 2007
- 📖 Downing, June E. *Teaching Literacy to Students with Significant Disabilities*. pp. 1120. Thousand Oaks: Corwin Press, 2005
- 📖 Deutsch-Smith, Deborah. *Introduction to Special Education: Teaching in an Age of Opportunity*. 5th ed. (Boston: Pearson Education Inc., 2006), 185221
- 📖 Kotlinski, Joe & S. Kotlinski. “Teaching Reading to Develop Language.” *Down Syndrome News and Update* 2, no. 1 (2002): 56. via The Down Syndrome Educational Trust, <http://www.downsyndrome.org/practice/154/?page=1>
- 📖 Laws, Glynis et al. “The Influence of Reading Instruction on Language and Memory Development in Children with Down’s Syndrome.” *Down Syndrome Research and Practice* 3, no. 2 (1995): 5964. via The Down Syndrome Educational Trust, <http://www.downsyndrome.org/reports/52/?page=1>
- 📖 Tien, Barbara. *Effective Teaching Strategies for Successful Inclusion: A Focus on Down Syndrome. A Resource Guide for Educators and Parents*. (The PREP Program, 1999)
- 📖 UK Down Syndrome Education Consortium. “Education Support Pack.” (Down’s Syndrome Association: A Registered Charity, 2000). http://www.downs-syndrome.org.uk/pdfs/DSA_Special_Schools.pdf (accessed June to October 2007)

Math

Math skills are essential for day-to-day independent living. Unfortunately, reform in mathematics education has been slow to address the needs of students with disabilities (Mastropieri & Scruggs, 2002). Traditionally, the mathematics curriculum for students with disabilities was developed using a functional curriculum approach which focuses on “life skills” (DeutschSmith, 2006). Students were taught mathematics through basic skills required for “personal maintenance and development, homemaking and community life, work and career, recreational activities, and travel within the community.” For instance, mathematics instruction would include topics such as telling time, making change, money skills and cooking measurements. However, many educators utilizing this approach tend to simplify the importance of the underlying math concept being taught. For instance, instead of a student learning how to use basic operations like addition, subtraction, multiplication and division, the lesson often turns into instruction on how to bake a cake.

Students with Down syndrome can learn mathematic concepts. In fact, learning mathematic concepts will motivate students with Down syndrome to apply these skills to different situations not demonstrated in the classroom; further, teachers must provide students opportunities to practice these skills in different settings to promote the transfer of learning/generalization.

It is important to recognize that deficits in learning math often reflect a lack of teaching, rather than a lack of ability to master mathematic concepts.

MATHEMATIC ASSESSMENT

Standardized assessment tests do not always provide educators with information regarding specific skills students have or have not mastered, nor do they specify which techniques are most effective for the student. Educators must take the extra step to evaluate student performance by analyzing each student on an individual basis:

- ✓ Is the instructional format still optimal?
- ✓ Is the student mastering the skills at an appropriate rate?
- ✓ Is the student retaining previously mastered skills?
- ✓ Is the student applying mathematic concepts to other areas in the general curriculum?

Once the necessary information is gathered, an educator can develop an effective individual education plan for math instruction that addresses the student’s needs. Plans should build on students’ strengths and develop strategies for them to overcome or compensate for areas of weakness.

DIFFICULTIES AND STRENGTHS IN MATHEMATICS FOR STUDENTS WITH DOWN SYNDROME

Students with Down syndrome can learn mathematics at any age. They are helped most by teaching methods which incorporate research-based methods for addressing their strengths, e.g., social understanding and interactions, visual processing and visual memory, use of gestures to communicate; and weaknesses, e.g., motor skill delays, speech and language delays, auditory processing and working memory difficulties.

The difficulties and strengths listed below have been observed in many students with Down syndrome, though not in all. It is important to note that many of the students who displayed difficulties were able to overcome or compensate for them with proper instruction (Martinez, 2002).

STRENGTHS	CLASSROOM STRATEGIES
Visual Processing – Students with Down syndrome can better solve problems and follow procedures if information is presented visually.	<ul style="list-style-type: none">• Teach students to sketch out problems and write the arithmetic for the solution afterwards.• Draw a graph/chart/picture.• Act problems out.• Make a step-by-step video.• Use number lines.

STRENGTHS	CLASSROOM STRATEGIES
Practice Makes Perfect – Practice leads to retention, and more practice (over-learning) leads to automatization. At this point, skills require less conscious effort, and working memory is freed up for mental processing during tasks.	<ul style="list-style-type: none"> • Review and repetition are crucial to success. • Build on prior knowledge. Review learned concepts at the beginning of each math lesson. • Practicing concepts improves memory retrieval and the amount of effort needed to complete a task. • Practice skills in different contexts and with varied materials. • Use a planning matrix to determine opportunities for teaching mathematical concepts outside of “math class.” • Practice should be fun, varied in content and relevant to real life.
Accommodations	<ul style="list-style-type: none"> • Assign fewer problems. • Allow more time. • Minimize noise and distractions. • Use the student’s real word interests and experiences. • Utilize hands-on learning, e.g., manipulatives or common classroom items. • Use number lines to count number sequences. • Use classroom modeling, e.g., show the student what the completed project will look like, and make deliberate mistakes so you can model problem-solving strategies. • Encourage peer teaching.
Junior High and High School	<ul style="list-style-type: none"> • Teach real world, independent living skills, e.g., using currency, banking, and budgeting, telling time, shopping, cooking. • Work on memorization of important numbers, e.g., bank card passwords, phone numbers, locker combinations. • Students with Down syndrome can be taught when and how to use technology for mathematics, i.e., computers, calculators.
Manipulatives	<ul style="list-style-type: none"> • Aides can create manipulatives and encourage students to verbalize steps as they are working (this will help with math vocabulary and sequencing). • Examples of manipulatives include games, e.g., Candyland, Chutes and Ladders, Monopoly, dice, cards; felt boards; personalized books; numicon plates and materials; and sorting containers, e.g., boxes, jars, bowls. • Skills that can be taught with manipulatives include the following: <ul style="list-style-type: none"> → Sorting and classification, e.g., solving puzzles of increasing complexity; matching objects and pictures; sorting by color, shape, size or function; sorting by opposites or exclusion → Sequencing and patterns, e.g., beads or stacking cups; sequencing cards that teach first, next, last; pictures that tell a story or describe past events when arranged properly

WEAKNESSES	CLASSROOM STRATEGIES
Memory – Students with Down syndrome often have difficulty with their short-term memory spans and organization, in addition to long-term memory. They may display difficulty with rote memorization of mathematical concepts, e.g. math vocabulary multiplication tables, counting backward, sequencing steps of problem solving. Also, they may display inconsistencies in learned concepts, i.e., “forgetting” skills they displayed the day before.	<ul style="list-style-type: none"> • Start each math lesson with a review of concepts covered in the previous lesson. Use direct teacher questioning to solicit responses from students. When appropriate, offer corrective feedback based on the student’s performance. Practicing concepts improves memory retrieval and amount of effort to complete task (Nye & Bird, 1996).

WEAKNESSES	CLASSROOM STRATEGIES
<p>Information Processing – Because of difficulties processing and recalling information, timed drills can be difficult for students with Down syndrome.</p>	<ul style="list-style-type: none"> • Assign fewer items and allow additional time. • Repeat group instructions. • Use visual aids. • Practice math vocabulary and steps, and review concepts often. • When presenting new material, first clarify the goals and main objective (Mastropieri & Scruggs, 2002).
<p>Abstract Thinking – Concrete learning is generally a strength for students with Down syndrome, but abstract thinking skills, e.g., subtraction, the decimal system, complex calculations, values of digits, are more difficult. Many students exhibit difficulties with sequencing and problem-solving.</p>	<ul style="list-style-type: none"> • Use purposeful activities that move beyond imitation and copying. Teach students what numbers actually represent. • Provide varied opportunities to distinguish differences in size, shape and quantity. • Students with Down syndrome perform well when they are given a visual illustration of the mathematical procedure. Teach them to sketch out the problem first and write the arithmetic solution on the sketch afterwards.
<p>Vocabulary – There are many terms that students must have in their vocabulary for success in mathematics, e.g., sizes, weights, units of measurement, numbers, fractions, times, money, shapes.</p>	<ul style="list-style-type: none"> • Students with Down syndrome must first acquire math vocabulary. • Teach the sequence of number words through a variety of methods, e.g., matching, sorting activities, memorization, peer tutoring. • The number sequence may not be learned with comprehension at first, but will develop over time as the student performs more number activities. Though initially some students will always start the count string at “one,” you can help them use the sequence more effectively by starting counts at other numbers. • Consider counting in sign language as a multi-sensory approach. • Do not assume that your student with Down syndrome understands the vocabulary for number work. You must develop vocabulary and related concepts when they are needed. Teach them to read the word at the same time the concept is learned. Related concepts can help them to develop greater understanding. • Use visual aids to teach math vocabulary/concepts, e.g., pictures, objects, gestures. • Use a hierarchy for teaching math vocabulary. For example, using the chart below, first teach the concept, e.g., size, weight. Then teach the vocabulary, e.g., big, small, heavy, more than.
<p>Fine Motor Skills – Because of hypotonia (decreased muscle tone) and motor-planning difficulties, printing numerals can be frustrating and fatiguing, and turn a math lesson (understanding and processing math concepts) into a handwriting lesson.</p>	<ul style="list-style-type: none"> • Ensure that math instruction time is used to master math concepts. • Allow students with Down syndrome to circle correct answers or use stamps, number cards or tiles. • Assign fewer items and allow additional time. • Use computers for older students.
<p>Motivation – There is no bigger detriment to motivation than repeated failures when performing tasks perceived as too difficult. Remember that even the brightest of typically-developing students will lose her motivation and stop trying if she is overcorrected.</p>	<ul style="list-style-type: none"> • Focus on the process rather than the end result or grade, i.e., “Wow! You did three problems correctly! Let’s go work on another one!” rather than “You failed.” • Apply mathematical concepts in various subject areas. • Repeat teaching concepts using different materials and methods. • Use teaching materials that reflect the students’ interests.

PRACTICAL ACTIVITIES TO DEVELOP THESE PRINCIPLES SHOULD BE DEvised PROGRESSING ALONG THE FOLLOWING SEQUENCE* (REPRINTED WITH PERMISSION)

1. Sort and matchlike objects by color, size, and shape.
2. Write counting objects from one to ten.
3. Count up to ten objects in a row.
4. Associate numerals with the written words, spoken words and appropriate amounts.
5. Select up to five objects from a set of ten.
6. Match numerals one through five.
7. Select numerals one through five on request.
8. Sequence numerals one through five in correct order.
9. Sequence amounts one through five in correct order.
10. Identify and select the correct numeral on request.
11. Label amounts one through five with the correct numeral.
12. Copy numerals one through five on request.
13. Repeat items (v)(xii) using numerals one through ten.
14. Count left to right using one-to-one correspondence.
15. Organize materials so they can be counted accurately.
16. Perform one-digit addition, e.g., 3+4.
17. Count objects to twenty.
18. Perform one-digit subtraction, e.g., 4-2.

*Reprinted from UK Down Syndrome Education Consortium. "Education Support Pack." (Down's Syndrome Association: A Registered Charity, 2000). http://www.downs-syndrome.org.uk/pdfs/DSA_Special_Schools.pdf (accessed June to October 2007).

References

- DeutschSmith, Deborah. Introduction to Special Education: Teaching in an Age of Opportunity. 5th ed. (Boston: Pearson Education Inc., 2006), 185221
- Martinez, Elisabetta M. "Learning Mathematics at School . . . and Later On." Down Syndrome News and Update 2, no. 1 (2002): 1923. via The Down Syndrome Educational Trust, <http://www.downsyndrome.org/practice/160/?page=1>
- Mastropieri, Margo A. & Thomas E. Scruggs. Effective Instruction for Special Education. 3rd ed. Austin: Proed An International Publisher, 2002
- Nye, Joanna & Gillian Bird. "Developing Number and Math Skills." DownsEd New 6, no. 2 (1996): pp. 17. via The Down Syndrome Education Trust, <http://www.he.net/~altonweb/cs/downsyndrome/index.htm?page=mathskills.html>
- Tien, Barbara. Effective Teaching Strategies for Successful Inclusion: A Focus on Down Syndrome. A Resource Guide for Educators and Parents. (The PREP Program, 1999)
- Vincent, Marth. Teaching Math to Students with Down and Significant Cognitive Disabilities

Communication

Effective communication has a tremendous impact on the development of students with Down syndrome. It affects their ability to become contributing members of the classroom and the community. Students feel good when others value whom they are and what they have to say. Ability and fluency in oral communication “will to a large extent determine their opportunities and options in . . . society” (DeutschSmith, 2006). Unfortunately, for many individuals with Down syndrome, the inability to communicate with others can have a devastating effect on social and personal skills.

Research indicates that the language comprehension skills in individuals with Down syndrome are almost always better than their language production; in other words, they understand messages conveyed to them, but cannot produce messages of equal complexity. Educators can help students with Down syndrome communicate by providing appropriate motivation, keeping expectations high and letting students with Down syndrome realize that all communication is valuable. “Once this basic premise is in place, specific intervention and support can produce excellent results” (Downing, 1999).

ASSESSMENT AND PLANNING

Goals must be achievable, measurable and meaningful. Prior to setting goals, however, you must first develop an understanding of the student’s communication skills, including how successfully the student interacts in class, on the playground and in public. A teacher must first assess the communication skills by matching language and speech of the student to comprehension ability. Students with Down syndrome do not respond well to standardized tests, which fail to provide educators with practical information that can be used for intervention purposes (Downing, 1999).

General educators should observe a student’s responses to directions, commands, questions, and social interactions. Educators should also document situations during which the student used specific forms of communication. In addition, the teacher can ask parents for examples of speech heard at home and instructions the student can understand or ask the student’s aide to track speech and ability to follow instructions during the school day.

Consider the following questions in determining a student’s communication skills:

- ✓ What medium is the student using to communicate, i.e., oral speech, symbols, gestures, writing, etc?
- ✓ Does the student have opportunities to initiate communication with others?
- ✓ How do others respond to the student?
- ✓ Can the student maintain conversations with others?

TOTAL COMMUNICATION

“Total Communication” refers to the use of all means necessary to convey your meaning. This includes cuing, pacing, sign language, visual aids (written words) or augmentative communication devices to supplement speech. Most students will fade out the use of cues over time as they master sound and word production.

TOTAL COMMUNICATION METHOD	TOTAL COMMUNICATION METHOD CLASSROOM TIPS
Finger Cuing	<ul style="list-style-type: none">• Finger Cuing is the term used when the teacher or therapist taps his or her own mouth when speaking. This alerts the student to watch the speaker’s mouth as he or she models the sounds or words. It is used primarily to evoke sounds or words.• Students will first use finger cues to talk and fade out the technique as they gain confidence to use speech spontaneously.

TOTAL COMMUNICATION METHOD	TOTAL COMMUNICATION METHOD CLASSROOM TIPS
Finger Pacing	<ul style="list-style-type: none"> Finger Pacing refers to holding up one finger at a time to model the sequence of sounds, syllables, or words. This alerts a student to articulate or slow down. It is used primarily to teach sound and word sequencing. Through repetition, a student will memorize the correct sequences and gain confidence to use in conversation. Students may use finger pacing to help them articulate multi-syllable words or long sentences.
Gestures	<ul style="list-style-type: none"> Some commonly understood gestures are waving, pointing or the “okay” symbol. A student can pair these gestures with speech to help ensure he is understood.
Sign Language	<ul style="list-style-type: none"> Sign language builds receptive language and early communication in a visual way and can be used as a transitional communication system until the child can communicate through speech. Signs should be accompanied by the verbal word, so that when the student masters the oral words, the sign can be faded out.
Reading	<ul style="list-style-type: none"> As discussed in the chapter on reading, students with Down syndrome are visual learners. Reading positively impacts language development and is often a catalyst for increased intelligibility and sentence length. Reading provides a visual cue to articulate, pace and use longer sentences. Reading can improve word retrieval, auditory memory and sequencing (by providing repetition necessary to memorize and recall word order and the grammatical structures that will lengthen their sentences in speech), rate of speech and ability to follow instructions.
Music	<ul style="list-style-type: none"> Music can be invaluable to speech production. Not only is it a powerful motivator for many students with Down syndrome, but it enhances a student’s ability to focus on auditory stimuli (which is normally a weakness). The intonation, beat, and rhythm of music provide cues for retrieval, sequencing, and memory. When students repeatedly sing the songs they enjoy, they are practicing and enhancing their receptive and expressive vocabulary! For younger students, use music during opening and closing circles and during daily routines (“clean-up”). Older students can use chants or cheers or practice songs for seasonal performances. Several useful classroom strategies are the following: <ul style="list-style-type: none"> → Sing slowly and enunciate or emphasize key words. → Pair words with actions or visual cues, e.g., pictures, stuffed animals. → Choose songs with meaningful vocabulary. → Encourage pacing by clapping or tapping to the beat. → Talk about the meaning of the song. → Use cues, e.g., mouth or omit key vocabulary words. → Use music creatively for transition times or to give instructions.

IN THE CLASSROOM

You can teach students with Down syndrome strategies to make communication less work and more fun. The goal of most parents is for their child with Down syndrome to be able to talk to and befriend classmates; ask for help; be a part of classroom discussions and activities; make presentations; and communicate needs, feelings, and ideas.

The initial goal for your classroom should be to motivate the student with Down syndrome to talk spontaneously. This can be difficult at first, because they typically take longer to adjust to changes and learn routines. It is common for them to be reserved in group settings. If they do not feel confident about their speech, they may tend to “shut down.”

Focus on effort rather than results. Praise and positive reinforcements are powerful tools for students with Down syndrome. You can tell when a student is demonstrating effort if she does any combination of the following:

- ✓ Initiates and maintains eye contact
- ✓ Willingly faces the speaker

- ✓ Watches the speaker's face intently
- ✓ Imitates the speaker's words/phrases spontaneously
- ✓ Displays pride when praised by others, e.g., smiles, claps

Students with Down syndrome need more time, practice, consistency, and reinforcement to learn communication skills. Group acceptance is a big motivator for all students. Teachers can facilitate this relationship for students with Down syndrome by fostering tolerance and understanding in the classroom, as well as refusing to allow teasing or mimicking.

Ensure that aides and assistants allow students with Down syndrome to converse with their classmates. Teachers can also provide public speaking opportunities, give the student "speaking" jobs, view the student with Down syndrome as capable and provide ample opportunity for buddy activities.

Positive and specific reinforcement is key, since praise is more powerful when it is a reminder of what a student has accomplished, e.g., "I like the way you ____" is more meaningful than "good talking." Remember to make communication activities fun!







GOAL	CLASSROOM TECHNIQUES AND STRATEGIES
Initiate and Maintain Eye Contact	<ul style="list-style-type: none"> • Model the behavior you want to see by getting down to the student's level and initiating eye contact. • Use prompts or cues, e.g., "Look at me," or "Chin up." • Use visual aids, e.g., hold the object of conversation up to your own face. • Wait for the student to cease other activity and give a visual cue, e.g., point to your eyes.
Attend to Speaker's Face and Respond to Visual or Auditory Cues	<ul style="list-style-type: none"> • Model the behavior you want to see, and teach the class a "listening position," e.g., hands on lap, chin up; or "listening technique," e.g., "Stop, look, listen" paired with visual gestures. • Initiate eye contact with the student and wait for eye contact in return. • Use visual aids or strategies at transition times, e.g., flicker lights. • Make accommodations, e.g., consider seating the student near the speaker. • Repeat instructions.
Watch and Imitate the Actions and Words of Others	<ul style="list-style-type: none"> • Model the behavior you want to see. • Use classroom peer "Buddies," and remind students with Down syndrome to follow their Buddy's lead, i.e., "Look at your friend. What do you need to do?" • Reinforce spontaneous imitations with praise. • Use action songs and finger plays. • Encourage the student to ask you for clarification. • Repeat. • Use cues. When using visual aids, have the student self-check his work, e.g., "Did you cover all the steps?" When giving directions, prompt the student to repeat or paraphrase what you said.
Acknowledge Others and Initiate Greeting and Farewell Routines	<ul style="list-style-type: none"> • Model the behavior you want to see by establishing the words and routines you will use in your daily greeting routine, and use them consistently, e.g., shake hands or give a high five and say, "Hey! How are you today?" • Work with other school personnel to encourage a consistent appropriate greeting, i.e., if you teach your student to greet others by giving a high five, you don't want other staff to greet her by hugging. • Teach students the names of their classmates using various methods, e.g., photo books of classmates.

GOALS	CLASSROOM TECHNIQUES AND STRATEGIES
Take Turns During Conversation	<ul style="list-style-type: none"> • Model the behavior you want to see, and teach turn-taking behaviors in small groups, e.g. “My turn,” “Wait for your turn.” “Raise your hand.” • Use cues, i.e., call on the student to take turns. • Set and consistently enforce consequences for interrupting.
Increase Vocabulary in Order to Enhance Class Participation	<ul style="list-style-type: none"> • Review theme words and give parents a set to reinforce at home. • Use visual strategies, e.g. word banks, personal dictionaries, word webs. • Assign theme-related reading.
Recall Previously Learned Vocabulary When Cued	<ul style="list-style-type: none"> • Use prompts, i.e., “Tell/show me,” by sound/first part of word, or mouth the word with no sound. • Use visual cues or signs. • Use word associations, e.g., “It’s not night, it’s ____.” • Rhyme, e.g., “Sounds like cat.”
Speak Clearly and Intelligibly	<ul style="list-style-type: none"> • Remind the student to speak slowly or augment speech with signs or gestures. • Ask the student to repeat herself. • Model slow, clear speech. • Use pacing methods, e.g., finger or clapping.
Lengthen Sentences	<ul style="list-style-type: none"> • Use pacing methods, e.g., say and clap “I want to eat.” • Use cues, e.g., “Tell me more/in a sentence.” • Use prompts, e.g. “And then I _____.” • Practice and repeat. • Provide visual aids, e.g., sentence patterns.
Regulate the Volume of the Voice, and Speak Appropriately in Different Situations	<ul style="list-style-type: none"> • Model the behavior you want to see. • Teach concepts of quiet and loud, i.e., “inside” vs. “outside” voice, in a variety of different contexts, e.g., PE, recess, library. • Use cues or prompts, e.g., hold your finger to your mouth; say “Shhh...” “I can’t hear you,” or “Inside voice please.”
Speak Smoothly or Fluently	<ul style="list-style-type: none"> • Model the behavior you want to see by (1) allowing the student to finish speaking, and (2) maintaining attention and eye contact while he is speaking. • Encourage turn-taking and listening skills.
Express Emotions or Feelings	<ul style="list-style-type: none"> • Model the behavior you want to see by using “feeling” words, e.g., “You look sad. Tell me about it.” • Cue students to use words rather than expressing their feelings through actions. • Problem solve, e.g., “What upset you?” “What can you do next time?” • Use a visual aid such as a “feelings chart.”
Stay On Topic During Social Conversations	<ul style="list-style-type: none"> • Use cues, e.g., “Answer the question.” • Use redirections, i.e., “We’re on ____ now.” • Use visual cues to start conversations. • Practice and repeat a bank of social questions and appropriate social responses, e.g., “How are you doing today?” “What are you doing this weekend?” “What music do you like?”

SPEECH AND BEHAVIOR

Effective communication skills and socially appropriate behavior are interrelated. A student’s IEP goals must address behavioral expectations with regard to listening and attention because these are crucial to speech development. Students with Down syndrome can learn behavior skills when they are clearly taught and consistently enforced. It is important for educators and parents to work together on communication and behavioral concerns, as these will negatively impact a student’s learning or ability to interact socially with peers.

References

-  Downing, June E. Teaching Literacy to Students with Significant Disabilities. pp. 1120. Thousand Oaks: Corwin Press, 2005
-  DeutschSmith, Deborah. Introduction to Special Education: Teaching in an Age of Opportunity. 5th ed. (Boston: Pearson Education Inc., 2006), 149183
-  Leddy, Mark. "The Biological Bases of Speech in People with Down Syndrome." In Improving the Communication of People with Down Syndrome. ed. Jon f. Miller, Mark Leddy, & Lewis A. Leavitt, 6181. Baltimore: Paul H. Brooks Publishing Co., 1999
-  Miller, Jon F., Mark Leddy, and Lewis A. Leavitt. "Introduction: The Communication Challenges that People with Down Syndrome Face." In Improving the Communication of People with Down Syndrome. ed. Jon F. Miller, Mark Leddy, & Lewis A. Leavitt, pp. 19. Baltimore: Paul H. Brooks Publishing Co., 1999
-  Miller, Jon F. "Profiles of Language Development in Children with Down Syndrome." In Improving the Communication of People with Down Syndrome. ed. Jon F. Miller, Mark Leddy, & Lewis A. Leavitt, pp. 1141. Baltimore: Paul H. Brooks Publishing Co., 1999
-  Tien, Barbara. Effective Teaching Strategies for Successful Inclusion: A Focus on Down Syndrome. A Resource Guide for Educators and Parents

Sensory Processing

Sensory Processing

Sensory processing, also called sensory integration, refers to the normal neurological process of organizing and interpreting information from the environment (Wheble and Hong, 2006).

In our everyday lives, we obtain and process information through the senses, which include sight (vision), smell (olfactory), taste (gustatory), touch (tactile) and hearing (auditory), as well as movement (vestibular) and body position (proprioception).

The tactile, vestibular and proprioceptive senses are the lesser known of the senses; however, these senses are the most important for daily functioning. They can affect academics, attention, balance, bilateral coordination, body awareness, emotional and gravitational security, coordination, fine and gross motor skills, hand preference, self-comforting, self-esteem, social skills, speech and tactile discrimination.

Challenges in this area can lead to behavioral problems as well. Educators should be aware of Sensory Processing Disorder when examining and reacting to the classroom behavior of a student with Down syndrome.



THE TACTILE SYSTEM	THE VESTIBULAR SYSTEM	THE PROPRIOCEPTION SYSTEM
Protective Touch – The tactile system helps us to discriminate between threatening and nonthreatening touch sensations. Furthermore, the tactile system provides information about objects, e.g., texture, shape, and size.	Coordination – The vestibular system helps us coordinate the movement of our eyes, head and body (Wheble and Hong, 2006). In addition, the vestibular system controls our body's relation to gravity.	Motor Skills – “The proprioception system consists of components of muscles, joints and tendons that provide us with a subconscious awareness of our body; for example, it enables us to sit properly in a chair and to step off a curb smoothly” (Wheble and Hong, 2006).
Characteristics of a Child with a Hypo- or Hyper-reactive Tactile System: <ul style="list-style-type: none">• Withdraws from being touched• Dislikes certain textures• Prefers to wear loose clothing• Complains about or resists efforts at washing hair, brushing teeth or washing face• Often is unable to determine where something is touching their body (Rosinia, 2006)	Characteristics of a Child with a Hypo- or Hyper-reactive Vestibular System: <ul style="list-style-type: none">• Displays spinning and rocking behavior• Frequently falls and trips• Exhibits poor eye control and concentration• Shows increased emotional sensitivity (Rosinia, 2006)	Characteristics of a Child with a Hypo- or Hyper-reactive Proprioception System: <ul style="list-style-type: none">• Is often clumsy• May display hand flapping• May hold objects tightly or loosely• Hugs tightly• Walks very heavily• Seeks deep pressure by wearing heavy cloths or placing heavy objects upon the body

Characteristics of Sensory Processing Disorder (SPD)

Sensory Processing Disorder (SPD), also referred to as Sensory Integration Disorder or Dysfunction, occurs when an individual's brain inefficiently processes sensory messages from the environment. Individuals with SPD have difficulty responding to sensory experiences. A child may have a sensory input that is either unusually high or low. Children can fluctuate between the two extremes. Children with SPD usually display symptoms with frequency, i.e., several times per day; intensity, i.e., degree of reaction or avoidance; and duration, i.e., period of symptoms.

CHARACTERISTICS OF CHILDREN WITH SPD	
OVERLY SENSITIVE	UNDERSENSITIVE
Touch: <ul style="list-style-type: none">• Child avoids contact with people and objects• Reacts negatively and emotionally to touch• Is picky about personal hygiene, particularly relating to clothes• Intentionally avoids certain textures and temperatures	Touch: <ul style="list-style-type: none">• Child is unaware of being touched or bumped• May be unaware of messiness on face from food or runny nose
Movement: <ul style="list-style-type: none">• Child avoids movement• May avoid activities that are not earthbound, e.g., running, climbing, swinging	Movement: <ul style="list-style-type: none">• Child is in constant movement• Craves fast and spinning movements, e.g., child may flap arms
Body Position: <ul style="list-style-type: none">• Child is insecure with body movement	Body Position: <ul style="list-style-type: none">• Child is frequently clumsy• Displays a lack of coordination
Sights: Child lacks control of eye movement May have difficulty concentrating on objects May overreact to light.	Sights: <ul style="list-style-type: none">• Child often misses important visual cues, e.g., facial expressions, gestures, signposts, written directions
Sounds: <ul style="list-style-type: none">• Child prefers silence• Often complains about heavy noise.	Sounds: <ul style="list-style-type: none">• Child has a poor attention span• Has poor auditory comprehension

References

-  Rosinia, J. M. "Looking at Children with New Eyes: Sensory Processing and The Theory of Sensory Integration." Kid Links Unlimited, Inc. http://www.nads.org/docs/conf_handouts/Rosinia.pdf (accessed on October 06, 2007)
-  Wheble, J. and Chia S. Hong. "Apparatus for Enhancing Sensory Processing in Children." International Journal of Therapy and Rehabilitation 13, no. 4 (April 2006): 177178

SPD and the General Education Classroom

Children with SPD usually have difficulty in adapting to the general education classroom at first. However, there are several strategies a teacher can utilize to include a student with SPD in the general education classroom.

Assessment is crucial for managing sensory problems in the classroom. Standardized assessment can be used, but authentic assessment, which requires students to perform real-world tasks, is more effective. Teachers must first identify a real-world task and then identify or set the standards for correct performance of the task. Next, break down the task into subtasks. Once the teacher has identified criteria, a rubric can be created.

Example of Authentic Assessment for Sensory Processing:

SENSORY PROCESSING: PROPER HAND WASHING TECHNIQUE

Teacher's Name: _____

Student's Name: _____

CATEGORY	EXCELLENT	GOOD	POOR
Used Soap			
Rubbed Hands Together			
Duration of Rubbing Hands			
Water Use			
Paper Towel Use			

USUAL THERAPEUTIC INTERVENTION

- ✓ Identify child's sensory processing problems, e.g., registration, modulation, emotional and behavioral responses
- ✓ Develop a sensory processing team made up of relevant individuals, e.g., parents, caregivers, educational staff, school therapists
- ✓ Develop a sensory diet, i.e., a schedule of daily activities that promote sensory integration and provide useful feedback
- ✓ Use activities that calm or alert the system (see chart below)
- ✓ Utilize environmental modifications, e.g., light boxes, headphones, trampolines
- ✓ Frequently assess student's progress

MANAGING SENSORY PROBLEMS

It is beyond the scope of this manual to describe the whole management process for children with Sensory Processing Disorder. If you suspect that your student may have sensory processing difficulties, please consult the student's parents and your school's therapists.

GENERAL ACTIVITIES TO CALM & ALERT		
SENSORY SYSTEM	TO CALM	TO ALERT
Tactile	<ul style="list-style-type: none"> • Deep pressure touch • Swaddling • Rhythmic patting/stroking (massage) • Hugs (holding firmly) • Taking a bath 	<ul style="list-style-type: none"> • Light touch (especially to face, palms and stomach) • Touch that involves movement • Taking a shower
Vestibular	<ul style="list-style-type: none"> • Rhythmic movement • Slow rocking • Maintaining head or body position • Sustained movement 	<ul style="list-style-type: none"> • Non-rhythmic movement • Jiggle, bounce or jump • Upright positioning
Proprioceptive	<ul style="list-style-type: none"> • Resistive activities • Rhythmic motor activities 	<ul style="list-style-type: none"> • Resistive activities • Changeable motor activities
Visual	<ul style="list-style-type: none"> • Muted, soft or natural colors • Room dividers • Steady, consistent input 	<ul style="list-style-type: none"> • Bright colors and lights • Moving objects towards face • Focused lighting on objects • Moving objects at irregular speeds
Auditory	<ul style="list-style-type: none"> • White noises • Low-key humming • Monotone speaking or singing • Use of slow rhythms 	<ul style="list-style-type: none"> • Vary intensity, pitch, or beat • Loud music
Gustatory/Oral	<ul style="list-style-type: none"> • Sucking • Use of mild flavors • Consistent temperature and texture of food and liquids • Sustained blowing activities 	<ul style="list-style-type: none"> • Citrus, salty or sour flavors • Cold liquids • Frozen treats • Variation in temperature and texture of food • Chew before or during focused tasks

References

- 📖 Moursund, D. "Assessment in ITAssessed PBL." In Project-Bbased Learning: Using Information Technology, 2nd ed. pp. 6578. Eugene: International Society for Technology in Education, 2003
- 📖 Mueller, J. "What is Authentic Assessment?" Authentic Assessment Toolbox.
<http://jonathan.mueller.faculty.noctrl.edu/toolbox/whatisit.htm> (accessed on October 07, 2007)
- 📖 Rosinia, J. M. "Looking at Children with New Eyes: Sensory Processing and the Theory of Sensory Integration." Kid Links Unlimited, Inc. http://www.nads.org/docs/conf_handouts/Rosinia.pdf (accessed on October 06, 2007)
- 📖 Wheble, J. and Chia S. Hong. "Apparatus for Enhancing Sensory Processing in Children." International Journal of Therapy and Rehabilitation 13, no. 4 (April 2006): 177178

Facilitating Friendships and Social Learning

Promoting Social Inclusion

TIPS FOR PROMOTING SOCIAL INCLUSION

To promote social inclusion, make sure the child with Down syndrome has learned how to behave appropriately in social situations. She needs to understand rules and routines and have the ability to cooperate with peers. In group work, she must be able to participate and respond appropriately, without dominating or becoming totally passive. She needs to learn how to share and take turns.

Outside, she needs to understand the rules of playground games and what is involved in being a team member.

IN THE CLASSROOM, SUCCESSFUL INCLUSION IS PROMOTED BY ENSURING THAT THE CHILD:

- ✓ Knows the major routines of the day (a visual timetable can help here)
- ✓ Has learned the class rules
- ✓ Can participate appropriately in a small group
- ✓ Will respond to requests and instructions from the class teacher
- ✓ Can tidy her work and line up appropriately
- ✓ Cares for others in the group and is aware of their feelings

Learning appropriate social and self-help skills is a high priority for most young children with Down syndrome. However, many will need extra help and support.

Key skills should be identified and then taught in small steps. Structured approaches such as backward chaining (the child is taught initially to do just the last part of the task, and then works backwards one step at a time) can be particularly useful.

Picture or photo prompt cards can be helpful, as they show the child what it looks like to complete the task. Similarly, peers can be used as role models to demonstrate successful task completion.

Before starting on a toilet training program, make sure the child is developmentally ready. Can she retain urine for at least an hour? Does she tell people when she is wet or soiled? If not, she may not be ready.

When teaching dressing skills, make sure the student is taught at the appropriate point in the day, e.g., coming in from play or changing for PE. Give her extra time so she doesn't feel rushed. If she is really slow, use a timer, and give smiley faces for finishing before the bell rings.

Encourage lunchtime staff to help the child eat independently, but not to cut everything up or feed her unnecessarily. If she takes a packed lunch, talk to her parents about making sure that it is easy to unwrap. If she needs extra time, let her go into lunch a bit early, but don't encourage her to push to the front of an existing queue.

Reprinted with permission from UK Down Syndrome Education Consortium. "Education Support Pack." (Down's Syndrome Association: A Registered Charity, 2000). http://www.downssyndrome.org.uk/pdfs/DSA_Special_Schools.pdf (accessed June to October 2007)

Classroom Strategies

Social inclusion is a primary goal for most students with Down syndrome who are entering public school. In order to make progress in cognitive areas, it is crucial for them to interact with others in a socially acceptable way and to respond appropriately to their environment. Classmates can be role models for appropriate social behavior and are powerful motivators for learning.

Students with disabilities exhibit deficits in age-appropriate social skills (Mastropieri & Scruggs, 2002). Children of elementary-school-age who have developmental delays find it difficult to establish and maintain reciprocal friendships, e.g., many play alone rather than engage in group play. They are also less likely to initiate interactions with other children. However, research findings show that students can develop real friendships with early intervention. Developing social skills at a young age is critical. As students get older, the opportunities to form friendships with typically-developing classmates diminish.

Friendships benefit both “typically-developing” students and students with Down syndrome (Falvey, 2005). Students with Down syndrome avoid loneliness; gain support in developing social, communicative and cognitive skills; increase self-esteem with a sense of belonging and develop a support network within their school communities. Typically-developing students “seem to have more positive attitudes and a better understanding of the challenges that peers with disabilities face” (DeutschSmith, 2006).

Keep in mind that too much one-on-one support from an aide or teacher can impair the student’s ability to benefit from peer group models, learn to work cooperatively and develop social relationships with classmates.

ASSESSING SOCIAL SKILLS

Social skills are a collection of behaviors in an individual’s repertoire that enable him or her to interact successfully in the environment (Mastropieri & Scruggs, 2002). It is important to assess the social skills of all students in the classroom.

The following assessment procedures are good methods to assess students’ social skills:

- ✓ Sociometric Measures
- ✓ Teacher Ratings
- ✓ Roleplay Tests
- ✓ Naturalistic or Direct Observation

Sociometric measures assess the degree of social acceptance among students. Peer nomination, e.g., polling students to determine who they like the most or least, can help educators identify students who are not being socially accepted in the classroom. Teacher ratings provide information about strengths and weaknesses in social skills, e.g., a daily checklist of “how well” or “how frequently” a student displays appropriate social skills (Mastropieri & Scruggs, 2002). Role-playing can be used to assess a student’s ability to perform specific social skills. Naturalistic or direct observations are performed in the students’ natural settings to determine which social skills are appropriate for a specific student.

SOCIAL SKILLS INSTRUCTION

It is important to note that students with Down syndrome must be directly taught socially-appropriate behaviors, e.g., no hugging, turn-taking, sharing, classroom rules. Social skills instruction should start at an early age and be geared toward teaching students with Down syndrome how to participate appropriately in major routines of the day, e.g., circle time, lining up.

SOCIAL SKILLS INSTRUCTION	
Daily Review	<ul style="list-style-type: none"> Practice learned social skills at the start of each new lesson, e.g., if the previous lesson emphasized eye contact, the next lesson begins with a review of appropriate eye contact (Mastropieri & Scruggs, 2002). Daily review is valuable because it provides educators with opportunities to assess students’ retention.
Presentation of Material	<ul style="list-style-type: none"> Clearly outline goals and objectives. Provide students with a step-by-step overview of the lesson. Use varied examples in different contexts.
Guided Practice	<ul style="list-style-type: none"> Model, demonstrate, and question students first, and then allow time to practice exercises. Guide students through the exercise and provide immediate corrective feedback when appropriate. Group activities are perfect to utilize when developing guided practice activities for social skills.
Independent Practice	<ul style="list-style-type: none"> Create worksheets displaying scenarios with appropriate and inappropriate behavior. Students would be required to circle/match the scenario with the behavior.

Weekly/Monthly Review	<ul style="list-style-type: none"> • Provide weekly and monthly reviews of previously taught social skills. • As inappropriate and appropriate social behaviors occur throughout the day, emphasize and reinforce previously learned social skills (Mastropieri & Scruggs, 2002).
Formative Evaluation	<ul style="list-style-type: none"> • At the end of the lesson, assess students' mastery of the social skills learned. • This can be conducted as a class activity.

Strategies for Facilitating Friendships

The following techniques are strategies that facilitate student friendships and social networks:

FOSTERING INTERDEPENDENCE

Traditionally, the curriculum for students with Down syndrome has focused on direct or independent teaching. However, interdependence is essential for students with disabilities. "Interdependence is when two or more people learn and agree to function as a group, relying on each other to get through the day and accomplish what is necessary and desired by the group" (Falvey, 2005). Designing curriculum to include interdependence teaches students responsibility and trust.

Classroom Strategies:

- ✓ Arrange seats in clusters and give each member a daily assignment that is necessary for the group to accomplish its daily task(s).
- ✓ For example, one student must sharpen all the pencils, and another student must collect and turn in all the homework assignments, of students in the cluster.

ALTERNATIVE AND AUGMENTATIVE COMMUNICATION

Students must be able to communicate with their classmates and must have opportunities to make choices and decisions. Students with Down syndrome often cannot communicate effectively because of a speech or language impairment. Augmentative communication devices allow students to use an alternative source to spoken language.

Classroom Strategies:

- ✓ Create communication boards with photos.
- ✓ Utilize technology.
- ✓ Work with the speech therapist and IEP team to determine whether a student needs an augmentative communication device.

SOCIAL STORIES

"Social Stories are short, explicit descriptions of appropriate social behaviors in the form of a story" (Falvey, 2005). Social stories are a great strategy for teaching students social skills because social stories place the social skill in a real scenario to which the student can relate.

Classroom Strategies:

- ✓ Incorporate social stories into the class day, e.g., students can read them independently or on audiotape, teachers can read aloud.
- ✓ For social stories to be effective the stories must be individualized and meaningful, i.e., they should incorporate the specific needs of the student for whom the story is written.
- ✓ Use social stories to teach social skills such as how to ask for help or deal with emotions.

PEER COLLABORATIONS

Another effective strategy for facilitating friendships and social networks is peer collaborations. Peer collaborations utilize students as instructors, advocates, and decision makers in the classroom (Falvey, 2005). For this strategy to work, educators are required to provide students with active planning, support, and facilitation. The results of successful peer collaborations can be both social and academic.

Classroom Strategies:

- ✓ Use peer tutors. In comparison to adults, peer tutors use more age-appropriate vocabulary and examples, are more directive and are more familiar with potential frustrations.
- ✓ Have peers assist students with Down syndrome in making transitions between activities or classrooms.
- ✓ Peer collaborations build friendships and caring classrooms.
- ✓ The more opportunities students with disabilities have to interact and socialize with other students, the greater the possibility for friendships to occur.
- ✓ Remember that the goal of peer collaborations is for students to develop their own social networks. This is accomplished by providing students with numerous opportunities to work together teaching and making decisions.
- ✓ Help students see that individuals with disabilities have similar strengths and interests.
- ✓ Facilitate student communication outside the classroom in other school settings.
- ✓ Encourage students to join extracurricular activities. This not only fosters social networks, but provides students with ample opportunities to practice social skills in different settings.

COOPERATIVE LEARNING GROUPS

In this strategy, “students work in small mixed-ability groups for reading and content subjects, and they help each other learn and understand information” (DeutschSmith, 2006). Students engaged in cooperative learning demonstrate higher levels of reasoning, generate new ideas and solutions and transfer learned skills appropriately to different situations (Falvey, 2005). In addition, cooperative learning enhances the “social and emotional well-being of the student by promoting positive interpersonal relationships.”

Classroom Strategies:

- ✓ Rewards can be given based on a team’s results.
- ✓ Be sure to make tasks manageable for students with Down syndrome and be aware of the potential positive and negative outcomes of group dynamics. If a group “fails” because of a student with Down syndrome, his classmates could become resentful.

CIRCLES OF FRIENDS

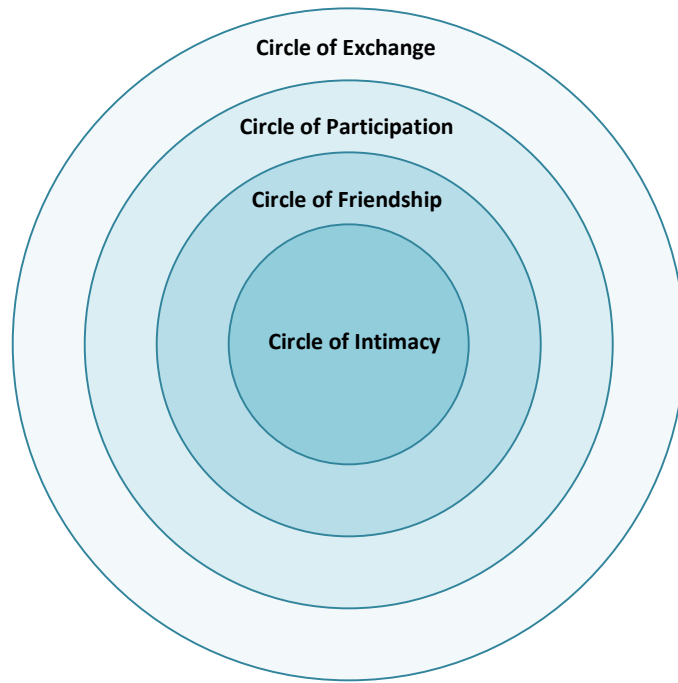
Circles of Friends is an exercise designed to bring peers together by creating a network of support and friendship for a particular student (Falvey, 2005). Students are asked to consider their own circle of friends and family, and then reflect on the circles of other students in the class.

Circles serve as a visual representation of people in students’ lives and can be useful in identifying voids in their social networks. Circles can teach students about the value of relationships and the impact that people can have in their lives.

The picture of the student’s life is represented by four concentric circles, with the student placed in the center circle. In the surrounding circles, she is asked to place people according to the nature and closeness of their relationship with her.

The circles are arranged starting with the inner circle and moving out, ending with the outermost circle.

Each circle has a different meaning: (1) circle of intimacy, (2) circle of friendship, (3) circle of participation and (4) circle of exchange (Falvey, 2005).



Circle of Intimacy	The students are asked to place themselves into the circle of intimacy. In the circle, the students are instructed to write the names of family and friends who are the closest to the student, e.g., mother, father, brother, sister, grandparent.
Circle of Friendship	In the second circle, students are instructed to write the names of best friends and people that they spend a lot of time with and/or care about, e.g., neighbors, aunt, family friend, cousins.
Circle of Participation	In the third circle, students are instructed to write the names of people they see frequently as a result of participation in school, organizations, clubs or other activities, e.g., teammates, classmates.
Circle of Exchange	In the fourth circle, students are instructed to write the names of people who are paid to provide a service for the student, e.g., teachers, therapists, counselors, social workers.

Classroom Strategies:

- ✓ Use circles to identify voids in a student's social network.
- ✓ Fill voids by creating a "circle of support" around the student.
- ✓ Once a circle of support is created, the group should meet on a regular basis to identify ways to spend time with the student and introduce her to new people.
- ✓ Remember that bringing people together to form friendships takes time, commitment, and effort.
- ✓ Provide support and encourage attendance at lunchtime or afterschool clubs.

References

- DeutschSmith, Deborah. Introduction to Special Education: Teaching in an Age of Opportunity. 5th ed. (Boston: Pearson Education Inc., 2006), pp. 130 & 204205
- Buckley, Sue. "Children's Friendships A Skill for Life." Portsmouth Down's Syndrome Trust News 3, no. 9 (1993): pp. 14
- Culatta, Richard A., James R. Tompkins, & Margaret G. Werts. Fundamentals of Special Education: What Every Teacher Needs to Know. 2nd ed. (Upper Saddle River: Merrill Prentice Hall, 2003), pp. 175176
- Falvey, Mary A. Believe in My Child with Special Needs: Helping Children Achieve Their Potential in School. (Baltimore: Paul H. Brookes Publishing Co., 2005), pp. 4663
- Mastropieri, Margo A. & Thomas E. Scruggs. Effective Instruction for Special Education. 3rd ed. Austin: Proed An International Publisher, 2002

- 📖 Randall, V. "Cooperative Learning: Abused and Overused?" The Education Digest 65, no. 2 (October 1999): pp. 2932
- 📖 UK Down Syndrome Education Consortium. "Education Support Pack." (Down's Syndrome Association: A Registered Charity, 2000). http://www.downs-syndrome.org.uk/pdfs/DSA_Special_Schools.pdf (accessed June to October 2007)

Buddy Programs

Friendships play an important role in achieving success in school, the workplace, and the community. Since many students easily make friends, it is easy to overlook this important aspect of development for children with Down syndrome.

There are many reasons to start a Best Buddies or similar Buddy program at your school:

- ✓ **Loneliness and Isolation** – Children with disabilities can frequently experience isolation and loneliness.
- ✓ **Benefits for Typically-Developing Students** – Research shows that interaction with children who have disabilities has a positive impact on typically-developing students.
- ✓ **Social Skills are Essential to Holding a Job** – To be hired for and be successful at a job, individuals must be able to interact effectively with other people, as well as perform job tasks. Social and interpersonal skills are crucial to workplace success.
- ✓ **Fostering Appreciation of Diversity** – By pairing "typically-developing" students with others who have disabilities, Buddy programs can meet immediate needs and have long-term effects by changing peoples' attitudes toward individuals with disabilities.

"Best Buddies High Schools" pairs people with intellectual disabilities in one-to-one friendships with high school students. By introducing Best Buddies into high schools, Best Buddies "crosses the invisible line that too often separates those with disabilities from those without."

Each chapter is a registered student organization within the school and is led by a chapter president who organizes, leads and maintains a chartered chapter of Best Buddies for the duration of one academic year. There are currently no Best Buddy chapters in the State of Michigan.

To learn more about Best Buddies or to start a chapter, go to www.bestbuddies.org.

e-Buddies®

e-Buddies® is an e-mail pen pal program for people ages ten and older who have intellectual disabilities and peer volunteers from across the United States and around the globe. e-Buddies® is a fun and safe way to make a new friend in a secure online setting and is available to anyone who has an e-mail address. e-Buddies® can also be a great teaching tool for a special education classroom. It can help teach social skills, as well as literacy and computer skills. Joining e-Buddies® is quick and easy. Visit www.ebuddies.org to read more and to complete the online application.



Extracurricular Activities

There are several adaptations which can be made to assist students with Down syndrome with participating in extracurricular activities such as team sports.

STRATEGIES

- ✓ Explain the rules of the game in clear, understandable language.
- ✓ Teach turn-taking.
- ✓ Partner students with Down syndrome and typically-developing Buddies in working toward an objective, or have Buddies assist students with Down syndrome with transitioning from prior classes or activities.
- ✓ Use visual cues, e.g., gestures, markings on floor.
- ✓ Be aware of noise levels and gravitational insecurities.
- ✓ Plan teams for students of all abilities!

References

-  Bird, Gillian, S. Alton & C. Mackinnon. Accessing the Curriculum Strategies for Differentiation for Pupils with Down Syndrome. (The Down Syndrome Educational Trust, UK. 2000)
-  "Down Syndrome Myths and Truths." National Down Syndrome Society.
http://www.ndss.org/index.php?option=com_content&task=category§ionid=23&id=58&Itemid=234
(accessed October 10, 2007)

Special Olympics



The mission of Special Olympics is to provide year-round sports training and athletic competition in a variety of Olympic-type sports for all children and adults with intellectual disabilities. Athletes are given continuing opportunities to develop physical fitness and athletic skill; demonstrate courage; experience joy; and participate in a sharing of gifts, skills and friendship with their families, other Special Olympics athletes, and the community. Events are year-round in area, regional and state levels. Event divisions are based on age, gender, and ability level to give athletes an equal chance to win. Each participant receives a medal or ribbon following his or her event.

Special Olympics training and competition is open to every person age eight or older who has an intellectual disability. There is no maximum age limitation for participation in Special Olympics. Children who are at least six years old may participate in age-appropriate Special Olympics training programs offered by SOMI or in specific (and age-appropriate) cultural or social activities offered during the course of a Special Olympics event.

Find information on your SOMI area chapter at 1-800-644-6404 or www.somi.org.

VIP Soccer



The AYSO Very Important Players (VIP) Program provides a quality soccer experience for children and adults whose physical or mental disabilities make it difficult to successfully participate in mainstream teams. The VIP Program is structured to integrate players into the rest of AYSO by providing a soccer season, and in some cases using "buddies" – able-bodied helpers - to assist players both on and off the field. The goals for every participating player are to have fun playing soccer, understand the fundamentals of the game, learn teamwork and fair play, increase positive self-esteem, become more physically fit and meet and be comfortable with new people.

The Kentwood AYSO (Area 767) currently offers a VIP program. Call 1-616-531-2552 for current and upcoming schedules.

Find a VIP Program in your area at www.ayso.org/special_programs/vip.aspx

Challenger Little League



The Challenger Division was established in 1989 as a separate division of Little League Baseball in order to enable boys and girls with physical and mental challenges, ages five through eighteen years or the completion of high school, to enjoy the game of baseball along with the millions of other children who participate in this sport worldwide.

Teams are set up according to abilities, rather than age, and can include as many as fifteen to twenty players. Players can participate in one of three levels: Tee-Ball, Coach-Pitch or Player Pitch. The use of "buddies" is encouraged for the Challenger players. Buddies assist the Challenger players on the field, but whenever possible encourage the players to bat and make plays themselves.

The Grandville Little League currently offers the Challenger program. Call 1-616-813-8466 or go to <http://www.eteamz.com/grandvillell/> for further information.

Find a Challenger Program in your area at:

www.littleleague.org/Learn_More/About_Our_Organization/divisions/challenger.htm

Positive Behavior Supports

In terms of behavior and personality, individuals with Down syndrome vary just as widely as their peers. Most are sociable and well-behaved.

Students with additional needs in the area of behavior rarely fall outside the range of behavior exhibited by their peers, and the school's behavior guidelines will be applicable to all students. If a student with Down syndrome routinely engages in difficult behavior, it is important to examine the underlying reasons, because often some aspect of school life does not meet her needs. Research-based knowledge regarding the ranges and types of behavior difficulties exhibited by students with Down syndrome can be informative, particularly if paired with proven behavior intervention plans. This includes using information from assessments, partnerships with parents, quality of relationships with these students, achievement in the curriculum and differentiated instruction. Research has shown that "inappropriate" behavior can serve an important function for an individual with a disability. Behavior, whether or not it is socially acceptable, frequently serves to communicate wants, needs or preferences. This is especially true for individuals who may not have an effective system of verbal communication.

BRIEF INSIGHT INTO BETTER CLASSROOM BEHAVIOR

In a 1996 NDSS Study, parents and educators provided tips on managing classroom behavior. Generally, the most effective technique for behavior management is praise. The following methods are sometimes effective for behavior management in students with Down syndrome:

- ✓ Material Rewards
- ✓ Time-outs
- ✓ Peer Pressure
- ✓ Loss of Privileges
- ✓ Contact with Parents

The following methods are generally NOT effective for behavior management in students with Down syndrome:

- ✓ Ignoring the Behavior
- ✓ Reprimands
- ✓ Punishment

References

- Wolpert, Gloria. "The Educational Challenges Inclusion Study." National Down Syndrome Society. http://www.ndss.org/index.php?option=com_content&task=view&id=1955&Itemid=208 (accessed June 27, 2007)
- Bird, Gillian and S. Buckley. "Meeting the Educational Needs of Pupils with Down Syndrome in Mainstream Secondary Schools." Down Syndrome News and Update 1, no. 4 (1999): pp. 159-174. via The Down Syndrome Educational Trust, <http://www.downsyndrome.org/practice/148/?page=1>

Causes of Inappropriate Behavior

The most common form of inappropriate behavior in all children, including those with Down syndrome, is behavior designed to gain attention. Children with Down syndrome may be particularly attention-seeking because:

- ✓ They enjoy being the center of attention and dislike being ignored.
- ✓ They are used to having adults by their sides all the time and resent the adults working with other children.
- ✓ They are used to getting special treatment and object if it is withdrawn.
- ✓ They have been successful in using attention-seeking behavior in the past to get their own way or avoid work.

Sometimes children with Down syndrome will misbehave because they are angry or frustrated.

- ✓ They may try to do the same tasks or activities as others, but find they can't cope without help.
- ✓ They may presume that the work they are being given is too difficult or uninteresting.
- ✓ They may get annoyed when other people don't take the time to understand what they are trying to say.

Sometimes children with Down syndrome may appear to misbehave when they are, in reality, just confused or uncertain about what they are supposed to do.

- ✓ They may have failed to understand instructions given to the whole class.
- ✓ They may have forgotten what they have been told.
- ✓ They may be finding it hard to learn new rules and routines and still do things in the old way.
- ✓ They may be confused by different adults giving conflicting messages.


Children with Down syndrome are often subjected to a high level of structure and supervision. As a result, they may feel the need to exert some control over their lives.

- ✓ They may refuse to cooperate with their teachers or assistant as a matter of principle.
- ✓ They may be obstinate if they feel they are given no opportunities to choose their own activities.
- ✓ They may feel under pressure and need a break.
- ✓ They may resent being regularly withdrawn from class and separated from their friends.

Finally, immaturity may lead to behaviors more appropriate of younger children.

- ✓ They may not have the concentration or memory skills of their peers.
- ✓ They may have immature play and social skills.
- ✓ Immature behavior may have been ignored or reinforced in the past.
- ✓ They may have been over supported and had little opportunity to mix freely with their peers.

REFERENCES

-  Reprinted with permission from UK Down Syndrome Education Consortium. "Education Support Pack." (Down's Syndrome Association: A Registered Charity, 2000). http://www.downs-syndrome.org.uk/pdfs/DSA_Special_Schools.pdf (accessed June to October 2007)

Options for Behavior Management

The management of behavior in students follows the progression from "external locus of control" to "internal locus of control." These are fancy phrases to describe the process of moving from adults being responsible for controlling behavior (in young students), to students becoming more and more responsible for controlling their own behavior. It is a progression through which all individuals go. Thus, when a child or student is not behaving, ask yourself, "Where is the location of control? Is it in the person or in the external source?" The goal of behavior management must be to transition from external to internal control. This is a learned activity; therefore, it can be taught.

THE BEST FORM OF BEHAVIOR MANAGEMENT IS PREVENTION.

Adults who work with children begin to know very early on when trouble is brewing. That adult has the following three options available to nip the behavior in the bud:

1. Modify the child.
2. Modify the environment.
3. Modify the interaction.

Each of these three options has strengths when it comes to behavior management, but one of the main strengths is that prevention keeps the behavior from ever becoming a problem.

SUPPOSE YOU MESSED UP ON PREVENTING A BEHAVIOR FROM ESCALATING, WHAT THEN?

The second-best method of behavior management is redirection. Redirection is accomplished by simply walking over to the child and directing him to another activity. This can be done with a hug, a smile, and a reassurance that there is something better to do. No words are used. It is not necessary to get into a great explanation about what is not acceptable to you — just physically redirect the child to a better place. Redirection requires warmth and genuineness, so it is probable that you need to be known to the child. Never underestimate the power of a hug.

MOVING ON FROM PREVENTION AND NONVERBAL REDIRECTION, THE NEXT BEHAVIOR MANAGEMENT TECHNIQUE IN THE LIST OF OPTIONS IS TO SAY “NO,” OR BETTER, “NOT” AND GIVE THE CHILD SOME WAY TO FIND A BETTER ACTIVITY

This involves the first use of speech and language with the child. However, it does not mean you stand across the room or sit on the couch and shout “NO!” It means you go over to the child, get on her level (bend down, squat down or sit on the same level) and get her attention in a very quiet way. Make sure she is looking at you, and then tell her, “No, we don’t do that; let’s do this...” You may offer the child an option, not a series of options or undirected choices, of doing something else. When a child is offered a choice, it needs to be from no more than two options. Let the child be in control and choose from the two options. It is wise on the adult’s part to stack the deck by offering choices that are known to be favorites. Play to win.

THE SOURCE OF PERSONAL POWER IS THE FEELING THAT YOU HAVE A CHOICE

Often when a child is not doing what is requested or expected, it is because he does not feel empowered to participate in what is happening. Acting out or defying is an illustrated example of a person who feels powerless. You must be smarter than the problem. Take the child to a safe place where there are no distractions and talk to him in a low voice about making good choices. The key to this, for most children, is to ask if the exhibited behavior “makes a friend.” Every person wants friends. Powerless people do not feel that they have friends; therefore, use the moment as a teachable moment to talk about making friends. “What would make a friend? Would it be sharing, would it be waiting your turn, would it be respecting the other person?” Find out what the child thinks makes a friend of another.

IT IS A RULE OF HUMAN BEHAVIOR THAT BEING AWARE OF THE BEHAVIOR CHANGES THE BEHAVIOR

This is called “reactivity,” meaning that when a student is asked to keep a record of good behavior, that behavior increases. Keeping a written record, therefore, is a very powerful management approach. Remember that “behavior that is rewarded will be repeated.” Reactivity rewards the behavior that you want. You may start (external locus of control) by keeping a chart of good behavior taped to the student’s desk and periodically going by and noting good behavior. This may also be reinforced with verbal praise like, “I really like it when you stay in your seat, listen to the lecturer, pay attention to directions, etc,” paired with a mark on the chart. Then gradually fade out the marking and get the student to practice reactivity.

USE CHARTS TO STAY ON TASK

It is possible to use the top of a desk to apply a chart that gives the schedule for the day or hour or however long the teacher selects (shorter is better). Pointing to the task or moving a marker along the chart to keep on task is another way to enhance internal control of behavior.

SELF-REWARD IS THE MOST POWERFUL BEHAVIOR MANAGEMENT APPROACH WE HAVE

Having the student say, “Good boy,” when complying with a request is another way to increase the internal locus of control. Counting the “Good boy” comments, again, gives positive reward for behaviors. Find out what he likes, wants, and desires, and have him choose his own reward for compliance. Remember, rewards move along a continuum of tangible, to intangible, to self-reward. That the student knows the rule and gives the rule to himself is the ultimate behavior management goal.

By Ed Hammer, B.A., M.S., M.Ed., LPC, LMFT, Ph.D

Appendices

Bibliography

- Appleton, Michele et al. "The Early Reading Skills of Preschoolers with Down Syndrome and their Typicallydeveloping Peers-Findings from Recent Research." Down Syndrome News and Update 2, no. 1 (2002): pp. 910. via The Down Syndrome Educational Trust, <http://www.downsyndrome.org/updates/157/?page=1>
- Bird, Gillian and S. Buckley. "Meeting the Educational Needs of Pupils with Down Syndrome in Mainstream Secondary Schools." Down Syndrome News and Update 1, no. 4 (1999): pp. 159174. via The Down Syndrome Educational Trust, <http://www.downsyndrome.org/practice/148/?page=1>
- Bird, Gillian, et al. Accessing the curriculum Strategies for differentiation for pupils with Down syndrome. (The Down Syndrome Educational Trust, UK. 2000).
- Buckley, Sue. "Children's Friendships-A Skill for Life." Portsmouth Down's Syndrome Trust News 3, no. 9 (1993): pp. 14.
- Buckley, Sue. "Literacy and Language." In Speech and Language Intervention in Down Syndrome. ed. Jean A. Rondal & S. Buckley, pp.132153. London: Whurr Publishing Ltd., 2003.
- Copeland, Susan R. "Written Communication." In Effective Literacy Instruction: For Students with Moderate or Severe Disabilities. ed. Susan R. Copeland & Elizabeth B. Keefe, pp. 4162. Baltimore: Paul H. Brooks Publishing Co., 2007.
- Copeland, Susan R. & Elizabeth B. Keefe. "Word Recognition Instruction." In Effective Literacy Instruction: For Students with Moderate or Severe Disabilities. ed. Susan R. Copeland & Elizabeth B. Keefe, pp. 4162. Baltimore: Paul H. Brooks Publishing Co., 2007.
- Culatta, Richard A., James R. Tompkins, & Margaret G. Werts. Fundamentals of Special Education: What Every Teacher Needs to Know. 2nd ed., pp. 175176. Upper Saddle River: Merrill Prentice Hall, 2003.
- "Down Syndrome." National Down Syndrome Congress. <http://www.ndscenter.org/resources/dsBrochure.pdf> (accessed June 4, 2007).
- "Down Syndrome Facts." National Association for Down Syndrome. http://www.nads.org/docs/DS_Facts.pdf (accessed June 4, 2007).
- Downing, June E. Teaching Literacy to Students with Significant Disabilities: Strategies for K12 Inclusive Classroom. Thousand Oaks: Corwin Press., 2005.
- DeutschSmith, Deborah. Introduction to Special Education: Teaching in an Age of Opportunity, IDEA 2004 Update 5th ed. Boston: Pearson Education Inc., 2006.
- Falvey, Mary A. Believe in My Child with Special Needs! Helping Children Achieve Their Potential in School. pp. 4663. Baltimore: Paul H. Brookes Publishing Co., 2005.
- "Information Topics." National Down Syndrome Society http://www.ndss.org/index.php?option=com_content&task=view&id=1812&Itemid=95 (accessed June 4, 2007)
- Kotlinski, Joe & S. Kotlinski. "Teaching Reading to Develop Language." Down Syndrome News and Update 2, no. 1 (2002): 56. via The Down Syndrome Educational Trust, <http://www.downsyndrome.org/practice/154/?page=1>
- Laws, Glynis et al. "The Influence of Reading Instruction on Language and Memory Development in Children with Down's Syndrome." Down Syndrome Research and Practice 3, no. 2 (1995): 5964. via The Down Syndrome Educational Trust, <http://www.downsyndrome.org/reports/52/?page=1>
- Leddy, Mark. "The Biological Bases of Speech in People with Down Syndrome." Improving the Communication of People with Down Syndrome. ed. Jon f. Miller, Mark Leddy, & Lewis Leavitt, 6181. Baltimore: Paul H. Brooks Publishing Co., 1999.
- Leshin, Len, M.D. FAAP. Obstructive Sleep Apnea and Down Syndrome. (1997) <http://www.dshealth.com/apnea.htm>.
- Martinez, Elisabetta M. "Learning Mathematics at School . . . and Later On." Down Syndrome News and Update 2, no. 1 (2002): 1923. via The Down Syndrome Educational Trust, <http://www.downsyndrome.org/practice/160/?page=1>
- Mastropieri, Margo A. & Thomas E. Scruggs. Effective Instruction for Special Education. 3rd ed. Austin: Proed An International Publisher, 2002.
- Miller, Jon F. "Profiles of Language Development in Children with Down Syndrome." In Improving the Communication of People with Down Syndrome. ed. Jon F. Miller, Mark Leddy, & Lewis A. Leavitt, pp. 1141. Baltimore: Paul H. Brooks Publishing Co., 1999.








- 📖 Miller, Jon F., Mark Leddy, and Lewis A. Leavitt. "Introduction: The Communication Challenges that People with Down Syndrome Face." In *Improving the Communication of People with Down Syndrome*. ed. Jon F. Miller, Mark Leddy, & Lewis Leavitt, pp. 19. Baltimore: Paul H. Brooks Publishing Co., 1999.
- 📖 Moursund, D. "Assessment in ITAssessed PBL." In *Projectbased Learning: Using Information Technology*, 2nd ed. pp. 6578. Eugene: International Society for Technology in Education, 2003.
- 📖 Mueller, J. "What is Authentic Assessment?" Authentic Assessment Toolbox. <http://jonathan.mueller.faculty.noctrl.edu/toolbox/whatisit.htm> (last accessed on October 07, 2007).
- 📖 Nye, Joanna & Gillian Bird. "Developing Number and Math Skills." *DownsEd New 6*, no. 2 (1996): pp. 17. via The Down Syndrome Education Trust, <http://www.he.net/~altonweb/cs/downsyndrome/index.htm?page=mathskills.html>
- 📖 "Position Statement on Inclusive Education for Students with Down Syndrome." National Down Syndrome Congress. <http://www.ndsccenter.org/resources/position5.php> (accessed June 27, 2007).
- 📖 "Public Awareness Language Guidelines." National Down Syndrome Congress. <http://www.ndsccenter.org/resources/package4.php> (accessed June 4, 2007).
- 📖 Randall, V. "Cooperative Learning: Abused and Overused?" *The Education Digest* 65, no. 2 (October 1999): pp. 2932.
- 📖 Randall, V. "Cooperative Learning: Abused and Overused?" *The Education Digest* 65, no. 2 (October 1999): pp. 2932.
- 📖 Rosinia, J. M. "Looking at Children with New Eyes: Sensory Processing and The Theory of Sensory Integration." Kid Links Unlimited, Inc. http://www.nads.org/docs/conf_handouts/Rosinia.pdf (last accessed on October 06, 2007).
- 📖 Snow, Kathie. "People First Language." *Disability is Natural*, <http://www.disabilityisnatural.com/peoplefirstlanguage.htm> (accessed June 4, 2007).
- 📖 Tien, Barbara. *Effective Teaching Strategies for Successful Inclusion: A Focus on Down Syndrome. A Resource Guide for Educators and Parents.* (The PREP Program, 1999).
- 📖 UK Down Syndrome Education Consortium. "Education Support Pack." (Down's Syndrome Association: A Registered Charity, 2000). http://www.downssyndrome.org.uk/pdfs/DSA_Special_Schools.pdf (accessed June to October 2007).
- 📖 "What is Inclusive Education?" Down Syndrome South Africa. <http://downsyndrome.org.za/main.aspx?artid=25> (accessed June 6, 2007).
- 📖 Wheble, J. and Chia S. Hong. "Apparatus for Enhancing Sensory Processing in Children." *International Journal of Therapy and Rehabilitation*, Vol. 13, Iss. 4, 05 Apr 2006, pp. 177181.
- 📖 Wolpert, Gloria. "Practical Tips to Achieve Inclusion." National Down Syndrome Society. http://www.ndss.org/index.php?option=com_content&task=view&id=1952&Itemid=208 (accessed June 4, 2007).
- 📖 Wolpert, Gloria. "The Educational Challenges Inclusion Study." National Down Syndrome Society. http://www.ndss.org/index.php?option=com_content&task=view&id=1955&Itemid=208 (accessed June 27, 2007).

Additional Reading



The DSAWM does not endorse the materials listed in this resource section. These titles are listed for your personal reference and further research. Any items marked with a Y are available from the DSAWM Lending Library. Members and professionals in the West Michigan area may borrow these books for up to one month, free of charge. Contact the DSAWM at info@dsawm.org or 616-956-3488 for more information.

Inclusion and Modification Of The Curriculum


- 📖 Bunch, Gary. *The Basics: Supporting Learners with Intellectual Challenge in Regular Classrooms: A Resource for Teachers*. Toronto: Inclusion Press, 2006.
 - Resource whose premise is that good teaching is good teaching for all students. Attempts to reduce teachers' anxieties and addresses making adjustments to current knowledge in order to effectively instruct all students. <http://www.inclusion.com>
- 📖 Bunch, Gary. *Inclusion: How To Essential Classroom Strategies*. Toronto: Canada. Inclusion Press, 1999.
 - Outlines proven strategies that work in real classrooms. References known research that gives authority to these strategies.
- 📖 Doyle PhD, Mary Beth. *The Paraprofessional's Guide to the Inclusive Classroom: Working as a Team*. Brookes Publishing Company, 2008. Y
 - Packed with friendly guidance, practical tips and relatable first-person stories. Reveals the best ways to provide effective, respectful services to students in inclusive classrooms.

-  Hammeken, Peggy A. Inclusion: 450 Strategies for Success – A Practice Guide for All Educators Who Teach Students with Disabilities. Peytral Publications, Inc., 2000. Y
 - Includes hundreds of teacher-tested techniques and easy-to-use strategies that will save you time and help you achieve success for all learners.
-  Janney, Rachel & Snell, Martha E. Behavioral Support: Teacher’s Guide to Inclusive Practices. Brookes Publishing Company, 2008. Y
 - Easy-to-read manual detailing new plans for implementing positive behavior support, both in the classroom and across an entire school.
-  Janney, Rachel & Snell, Martha E. Modifying Schoolwork: Teacher’s Guide to Inclusive Practices. Brookes Publishing Company, 2004. Y
 - Describes curricular, instructional and alternative adaptations. Enables educators of students from grades K–12 in deciding when and how to implement them.
-  Peoples, Susan. Understanding How Children with Down Syndrome Learn. Special Offspring Publishing, 2004. Y
 - Guide to how children with Down syndrome and other developmental delays learn and insights that expedite student progress.
-  Tien, Barbara and C. Hall. Effective Teaching Strategies for Successful Inclusion: A Focus on Down Syndrome. Calgary: PREP, 1999. Y
 - Focuses on methods to teach students with Down syndrome to maximize their inclusion. Electronic version available at <http://www.prepprog.org>.
-  Vandercook, Terri et al. Lessons for Inclusion. Toronto: Canada. Inclusion Press. 1994. Y
 - Assists teachers of elementary and middle school children in developing a classroom community in which all children feel good about themselves and work together as valued members. Specific lessons provided. <http://www.inclusion.com>
-  Voss, Kimberly S. Teaching by Design: Using Your Computer to Create Materials for Students with Learning Differences. Woodbine House, 2005. Y
 - Shows readers how to use the computer to design meaningful educational materials for children and adults with special needs.



Math

-  Horstmeier, DeAnna. Teaching Math to People with Down Syndrome and Other Hands-On Learners, Book #1. Bethesda: Woodbine House, 2004. Y
 - Guide to teaching meaningful math skills by capitalizing on visual learning styles. Covers introductory math skills, but may also help older students who struggle with math concepts.
-  Horstmeier, DeAnna. Teaching Math to People with Down Syndrome and Other Hands-On Learners, Book #2. Bethesda: Woodbine House, 2008. Y
 - Continues with the proven, practical, hands-on activities from book one – with the help of games, manipulatives, props and worksheets.


Reading

-  Oelwein, Patricia. Teaching Reading to Children with Down Syndrome: A Guide for Parents and Teachers. Bethesda: Woodbine House, 2009. Y
 - Step-by-step guide to reading. Allows parents to work with their children at home and coordinate reading lessons with teachers.

Motor Skills

-  Bruni, Maryanne. Fine Motor Skills in Children with Down Syndrome: A Guide for Parents and Professionals, Second Edition. Bethesda: Woodbine House, 2006. Y
 - Practical guide to understanding and developing fine motor skills in children with Down syndrome.
-  Winders, Patricia C. Gross Motor Skills in Children with Down Syndrome: A Guide for Parents and Professionals. Bethesda: Woodbine House, 1997. Y
 - Provides parents and professionals with essential information about motor development.

Sensory Integration

-  Kranowitz, Carol Stock. The Out of Sync Child: Recognizing and Coping with Sensory Processing Disorder. Revised Ed. New York: Pedigree Books, 2006. Y

- Provides a description of sensory integration dysfunction and includes dozens of activities with information on appropriate developmental age, equipment needed, how to prepare, what the child can do and what the benefits are. www.outofsyncchild.com

Communication

- 📖 Kumin, Libby. Early Communication Skills for Children with Down Syndrome. Bethesda: Woodbine House, 2003. Y
 - Focuses on speech and language development from birth through the stage of making three-word phrases. Covers problem areas and treatment. www.woodbinehouse.com
- 📖 Kumin, Libby. Classroom Language Skills for Children with Down Syndrome. Bethesda: Woodbine House, 2001. Y
 - Covers the language needs of children in school, from kindergarten to adolescence, and how to address those needs in the IEP and adapting school work. www.woodbinehouse.com
- 📖 Kumin, Libby. Kumin, Libby. Helping Children with Down Syndrome Communicate Better Speech and Language Skills for Ages 6-14, Bethesda: Woodbine House, 2008. Y
 - Provides parents and professionals with the information and resources they need to improve their child's communication at school home and in the wider community. www.woodbinehouse.com
- 📖 Kumin, Libby. What Did You Say? A Guide to Speech Intelligibility in People with Down Syndrome (DVD). Blueberry Shoes Productions. Y www.blueberryshoes.com
- 📖 MacDonald, James D. Communicating Partners: 30 Years of Building Responsive Relationships with Late-Talking Children. London: Jessica Kingsley Publishers, 2004. Y
 - Contains practical strategies that families can use to help their children develop positive, engaging and fun connections with others. www.jkp.com
- 📖 Miller, Jon F., Mark Leddy and Lewis A. Leavitt. Improving the Communication of People with Down Syndrome. Baltimore: Brookes Publishing. 1999.
 - Provides a framework for assessing and treating speech, language and communication problems in children and adults with Down syndrome. www.brookespublishing.com
- 📖 Schwartz, Sue. The New Language of Toys: Teaching Communication Skills to Children with Special Needs. 3rd ed. Bethesda, MD: Woodbine House, 2004. Y
 - Contains ideas to help stimulate language development in children with special needs through play. www.woodbinehouse.com
- 📖 Schermerhorn, Will. Discovery: Pathways to Better Speech for Children with Down Syndrome. Blueberry Shoes Productions (2005) (DVD). Y
 - Overview of language development in children with Down syndrome age two and up. www.blueberryshoes.com

Facilitating Friendships

- 📖 Hughes PhD, Carolyn & Carter PhD, Erik. Peer Buddy Programs for Successful Secondary School Inclusion. Brookes Publishing Company, 2008. Y
 - Guidebook showing educators exactly why and how to create a peer buddy program.
- 📖 Janney, Rachel & Snell, Martha E. Social Relationships & Peer Support. Brookes Publishing Company, 2006. Y
 - Helps educators foster meaningful friendships and relationships among students.
- 📖 Newton, Colin and D. Wilson. Creating Circles of Friends: A peer support and inclusion workbook. Nottingham: Inclusive Solutions, 2003.
 - Practical guide to creating circles of friends written by educational psychologists. Contains background, stories and reproducible handouts for use in school and other settings. www.inclusivesolutions.com

Person-centered Planning

- 📖 O'Brien, John and J. Pearpoint. Person-Centered Planning with MAPS and PATH: A Workbook for Facilitators. Nottingham: Inclusive Solutions, 2004.
 - Assists facilitators in learning and implementing PATH and MAPS processes. <http://www.inclusion.com>

Websites

National Organizations Providing Accurate and Current Information about Down Syndrome

☞ Down Syndrome Association of West Michigan	www.dsawm.org	616-956-3488
☞ National Down Syndrome Congress	www.ndsccenter.org	800-232-6372
☞ National Down Syndrome Society	www.ndss.org	800-221-4602
☞ National Association for Down Syndrome	www.nads.org	630-325-9112
☞ The Down Syndrome Educational Trust	www.downssyndrome.org.uk	

Education Research and Resources

☞ Teachers Helping Teachers	www.pacificnet.net/~mandel/SpecialEducation.html
☞ Down Syndrome Information Network	http://information.downsed.org/
☞ Universal Design For Learning	www.cast.org/
☞ Enhancing Access To General Education Curriculum	www.k8accesscenter.org/index.php
☞ "Inclusion Solutions" Newsletter for Educators	www.kcdsg.org/for_educators.php?show_child=80

Inclusion

☞ PREP Centre for Inclusion	www.prepprog.org
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Reading and Literacy

☞ The Learning Program	www.dsloc.org/learning_program.htm
☞ Special Offspring	www.specialoffspring.com
☞ Love and Learning	www.loveandlearning.com

Math

☞ The Learning Program	www.dsloc.org/learning_program.htm
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Health Issues

☞ Down Syndrome: Health Issues	www.dshealth.com
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Dear Parents,

Some of you already know our child, _____. For those of you who do not, our child has Down syndrome and is excited to be in class with your child!

We understand that you and your child may have questions about Down syndrome. Children with Down syndrome are now included in general education classrooms and are achieving great academic and social success. It is only through supportive environments that individuals with Down syndrome will meet with success beyond the school setting. We have the same expectations for our child that you do for yours – we hope our child will learn to the best of his or her ability, make lasting friendships, follow school rules, and be a contributing member of the classroom and community. Your child's positive interactions and role modeling will help our child become successful in these areas.

Research on inclusion has shown that forming friendships with children who have Down syndrome or other special needs has a positive effect on typically-developing children, such as meaningful friendships, increased appreciation and acceptance of diversity, and respect for all people. Research further shows that this can translate to greater academic outcomes for typically-developing students, as they gain additional mastery over subject areas by practicing and teaching others.

We have shared information with the classroom teacher about Down syndrome and some of the challenges our child and others with Down syndrome face. We hope this will give your child insight into the similarities of all children and help answer some of the questions he or she may have. We encourage you to talk openly with your child about these similarities in order to ensure a positive classroom environment for each and every student.

We are including information for you and hope you will contact us if your family has any questions. Children with Down syndrome have unlimited potential when given opportunities and support.

We know that you and your child will enjoy your year with _____ because _____ is a loving and dynamic child who has a lot to teach us about persistence, friendship and accepting people for who they are.

Sincerely,

For more information on Down syndrome, you can visit the Down Syndrome Association of West Michigan website at www.dsawm.org or call their office at 616-956-3488.

MYTHS AND TRUTHS ABOUT DOWN SYNDROME

Myth: Down syndrome is a rare genetic disorder caused by older parents and/or genetics.

Truth: Down syndrome is the most commonly occurring genetic condition, with approximately one in every 700 births resulting in a child with Down syndrome. There are approximately 350,000 people who have Down syndrome living in the United States today. Eighty percent of children born with Down syndrome are born to women younger than age thirty-five. However, research has shown a link between the incidence of Down syndrome and maternal age. In general, Down syndrome does not run in families, and a sibling or aunt has no greater chance of conceiving a child with Down syndrome.

Myth: People with Down syndrome have severe cognitive delays.

Truth: Most people with Down syndrome have cognitive delays that are mild to moderate; however, IQ is not an adequate measure of the abilities and talents of people with Down syndrome. People with Down syndrome have great potential if given opportunities. Thanks to laws governing public education and greater opportunities, more and more individuals with Down syndrome are graduating with their peers and attending college.

Myth: The life expectancy of people with Down syndrome is age thirty.

Truth: Thanks to advances in medical and clinical treatment and opportunities to thrive, as many as eighty percent of adults with Down syndrome reach age fifty-five, and many live longer.

Myth: Behavior problems and depression are just part of having Down syndrome

Truth: Often, medical or mental health problems go untreated due to the assumption that it is typical of having this genetic condition. Complete examinations by appropriate health care professionals should always be pursued.

Myth: Adults with Down syndrome are unable to work.

Truth: Businesses are seeking young adults with Down syndrome for a variety of positions. They are employed in small- and medium-sized offices, banks, corporations, nursing homes, hotels and restaurants. They work in the music and entertainment industries, clerical positions, and the computer industry. People with Down syndrome bring to their jobs enthusiasm, reliability and dedication.

Myth: People with Down syndrome are always happy.

Truth: People with Down syndrome have feelings just like everyone else in the population. They respond to positive expressions of friendship, and they are hurt and upset by inconsiderate behavior.

Myth: There are no effective treatments for Down syndrome.

Truth: Researchers are making great strides in identifying the genes on chromosome 21 that cause the characteristics of Down syndrome. Scientists now feel strongly that it will be possible to improve, correct or prevent many of the problems associated with Down syndrome in the future.

Myth: Having a sibling with Down syndrome will be a hardship for “typical” children.

Truth: Most families report that their “typical” kids are more compassionate, patient and tolerant of all people because of their experiences having a sibling with Down syndrome. The sibling relationship is generally a typical one — full of love, occasional arguments and just being together.

School Accommodations and Modifications

Some students with disabilities need accommodations or modifications to their educational program in order to participate in the general curriculum and to be successful in school. While the Individuals with Disabilities Education Act (IDEA) and its regulations do not define accommodations or modifications, there is some agreement as to what they mean. An accommodation as used in this document allows a student to complete the same assignment or test as other students, but with a change in the timing, formatting, setting, scheduling, response and/or presentation. This accommodation does not alter in any significant way what the test or assignment measures. Examples of accommodations include a student who is blind taking a Braille version of a test or a student taking a test alone in a quiet room.

A modification as used in this document is an adjustment to an assignment or a test that changes the standard or what the test or assignment is supposed to measure. Examples of possible modifications include a student completing work on part of a standard or a student completing an alternate assignment that is more easily achievable than the standard assignment.

Needed modifications and accommodations should be written into a student's Individualized Education Program (IEP) or Section 504 Plan. These changes should be chosen to fit the student's individual needs. It's important to include the student, if appropriate, when discussing needed accommodations and modifications. Asking the student what would be helpful is a good first step.

Here are some ideas for changes in textbooks and curriculum, the classroom environment, instruction and assignments, and possible behavior expectations that may be helpful when educating students with disabilities. When reviewing these ideas, keep in mind that any accommodations or modifications an IEP team chooses must be based on the individual needs of students, and the changes must be provided if included in the child's IEP.

Textbooks and Curriculum

Books

- ☐ Provide alternative books with similar concepts, but at an easier reading level.
- ☐ Provide audiotapes of textbooks and have the student follow the text while listening.
- ☐ Provide summaries of chapters.
- ☐ Provide interesting reading material at or slightly above the student's comfortable reading level.
- ☐ Use peer readers.
- ☐ Use marker to highlight important textbook sections.
- ☐ Use word-for-word sentence fill-ins.
- ☐ Provide two sets of textbooks, one for home and one for school.
- ☐ Use index cards to record major themes.
- ☐ Provide the student with a list of discussion questions before reading the material.
- ☐ Give page numbers to help the student find answers.
- ☐ Provide books and other written materials in alternative formats such as Braille or large print.

Curriculum

- ☐ Shorten assignments to focus on mastery of key concepts.
- ☐ Shorten spelling tests to focus on mastering the most functional words.
- ☐ Substitute alternatives for written assignments (clay models, posters, panoramas, collections, etc.).
- ☐ Specify and list exactly what the student will need to learn to pass. Review this frequently.

- ☐ Modify expectations based on student needs (e.g., “When you have read this chapter, you should be able to list three reasons for the Civil War.”).
- ☐ Give alternatives to long written reports (e.g., write several short reports, preview new audiovisual materials and write a short review, give an oral report on an assigned topic).

Classroom Environment

- ☐ Develop individualized rules for the student.
- ☐ Evaluate the classroom structure against the student’s needs (flexible structure, firm limits, etc.).
- ☐ Keep workspace clear of unrelated materials.
- ☐ Keep the classroom quiet during intense learning times.
- ☐ Reduce visual distractions in the classroom (mobiles, etc.).
- ☐ Provide a computer for written work.
- ☐ Seat the student close to the teacher or a positive role model.
- ☐ Use a study carrel. (Provide extras so that the student is not singled out.)
- ☐ Seat the student away from windows or doorways.
- ☐ Provide an unobstructed view of the chalkboard, teacher, movie screen, etc.
- ☐ Keep extra supplies of classroom materials (pencils, books) on hand.
- ☐ Use alternatives to crossword puzzles or word finds.
- ☐ Maintain adequate space between desks.

Instruction and Assignments

Directions

- ☐ Use both oral and printed directions.
- ☐ Give directions in small steps and in as few words as possible.
- ☐ Number and sequence the steps in a task.
- ☐ Have student repeat the directions for a task.
- ☐ Provide visual aids.
- ☐ Show a model of the end product of directions (e.g., a completed math problem or finished quiz).
- ☐ Stand near the student when giving directions or presenting a lesson.

Time/transitions

- ☐ Alert student several minutes before a transition from one activity to another is planned; give several reminders.
- ☐ Provide additional time to complete a task.
- ☐ Allow extra time to turn in homework without penalty.
- ☐ Provide assistance when moving about the building.

Handwriting

- ☐ Use worksheets that require minimal writing.
- ☐ Use fill-in questions with space for a brief response rather than a short essay.
- ☐ Provide a “designated notetaker” or photocopy of other student or teacher notes. (Do not require a poor notetaker or a student with no friends to arrange with another student for notes.)
- ☐ Provide a print outline with videotapes and filmstrips.
- ☐ Provide a print copy of any assignments or directions written on the blackboard.
- ☐ Omit assignments that require copying, or let the student use a tape recorder to dictate answers.

Grading

- ☐ Provide a partial grade based on individual progress or effort.
- ☐ Use daily or frequent grading averaged into a grade for the quarter.
- ☐ Weight daily work higher than tests for a student who performs poorly on tests.
- ☐ Mark the correct answers rather than the incorrect ones.
- ☐ Permit a student to rework missed problems for a better grade.
- ☐ Average grades out when assignments are reworked, or grade on corrected work.
- ☐ Use a pass-fail or an alternative grading system when the student is assessed on his or her own growth.

Tests

- ☐ Go over directions orally.
- ☐ Teach the student how to take tests (e.g., how to review, to plan time for each section).
- ☐ Provide a vocabulary list with definitions.
- ☐ Permit as much time as needed to finish tests.
- ☐ Allow tests to be taken in a room with few distractions (e.g., the library).
- ☐ Have test materials read to the student, and allow oral responses.
- ☐ Divide tests into small sections of similar questions or problems.
- ☐ Use recognition tests (true-false, multiple choice, or matching) instead of essays.
- ☐ Allow the student to complete an independent project as an alternative test.
- ☐ Give progress reports instead of grades.
- ☐ Grade spelling separately from content.
- ☐ Provide typed test materials, not tests written in cursive.
- ☐ Allow take-home or open-book tests.
- ☐ Provide possible answers for fill-in-the blank sections.
- ☐ Provide the first letter of the missing word.

Math

- ☐ Allow the student to use a calculator without penalty.
- ☐ Group similar problems together (e.g., all addition in one section).
- ☐ Provide fewer problems on a worksheet (e.g., 4 to 6 problems on a page, rather than 20 or 30).
- ☐ Require fewer problems to attain passing grades.
- ☐ Use enlarged graph paper to write problems to help the student keep numbers in columns.
- ☐ Provide a table of math facts for reference.
- ☐ Tape a number line to the student's desk.
- ☐ Read and explain story problems, or break problems into smaller steps.
- ☐ Use pictures or graphics.

Other

- ☐ Use Post-it notes to mark assignments in textbooks.
- ☐ Check progress and provide feedback often in the first few minutes of each assignment.
- ☐ Place a ruler under sentences being read for better tracking.
- ☐ Introduce an overview of long-term assignments so the student knows what is expected and when it is due.
- ☐ Break long-term assignments into small, sequential steps, with daily monitoring and frequent grading.
- ☐ Have the student practice presenting in a small group before presenting to the class.
- ☐ Hand out worksheets one at a time.
- ☐ Sequence work, with the easiest part first.
- ☐ Use blackline copies, not dittos.
- ☐ Provide study guides and study questions that directly relate to tests.
- ☐ Reinforce student for recording assignments and due dates in a notebook.
- ☐ Draw arrows on worksheets, chalkboard, or overheads to show how ideas are related, or use other graphic organizers such as flow charts.

Behavior

- ☐ Arrange a "check-in" time to organize the day.
- ☐ Pair the student with a student who is a good behavior model for class projects.
- ☐ Modify school rules that may discriminate against the student.
- ☐ Use nonverbal cues to remind the student of rule violations.
- ☐ Amend consequences for rule violations (e.g., reward a forgetful student for remembering to bring pencils to class, rather than punishing the failure to remember).
- ☐ Minimize the use of punishment; provide positive as well as negative consequences.
- ☐ Develop an individualized behavior intervention plan that is positive and consistent with the student's ability and skills.
- ☐ Increase the frequency and immediacy of reinforcement.

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- ☐ Arrange for the student to leave the classroom voluntarily and go to a designated “safe place” when under high stress.
 - ☐ Develop a system or a code word to let the student know when behavior is not appropriate.
 - ☐ Ignore behaviors that are not seriously disruptive.
 - ☐ Develop interventions for behaviors that are annoying but not deliberate (e.g., provide a small piece of foam rubber for the desk of a student who continually taps a pencil on the desktop).
 - ☐ Be aware of behavior changes that relate to medication or the length of the school day; modify expectations if appropriate.
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Positive Steps to Social Inclusion

The National Down Syndrome Society created a list of action steps to help guide parents through the ins and outs of social inclusion.



1. If you believe it is appropriate for your child to be educated to any extent in regular education classes, it is important to start inclusion as early as possible.
2. If your child may benefit from being held back a year, start him/her in kindergarten a year late. You don't want to hold your child back later, after friendships have been formed with classmates.
3. The teacher (and para-educator if applicable) should receive training or at least be aware of the importance of facilitating friendships. The best way to do this is to put a social goal on the IEP and specifically request staff training.
4. In the younger grades, talk to your child's class (and all the classes that will be at lunch or recess with your child) if there are obvious modifications/adaptations required for your child's assignments, if your child requires any special equipment, or if your child has significant communication issues. Explain Down syndrome and its effect on your child in very simple terms. Explain the need for adaptations and/or equipment as being the same as a person needing glasses or braces. Then spend time talking about all the ways your child is just like them: loves pizza, movies, sports, etc. You only need to do this for a couple of years. After that, the other students who have been in the same class with your child will start sharing this information with new students. *Everyone Counts: Teaching Acceptance & Inclusion*, the new NDSS disability awareness curriculum for grades K-6, is an excellent resource for lesson plans, activities, and discussions. For more information, contact NDSS at (800) 221-4602 or info@ndss.org.
5. Consider sending a letter to parents of your child's classmates that provides the information you shared with the students. Communicate your willingness to answer any questions they may have about this information and about inclusion. This may also help when it comes to arranging activities with classmates outside of school.
6. Ensure that a few of your child's friends or supportive acquaintances are in his/her class every year. This is especially important during transition years to middle school and high school. The students who know and are supportive of your child will model positive relationship and promote the expectation that your child will continue to be an important part of the group. The fact that your child's friends may be in "gifted" or higher level classes in middle and high school should not be an obstacle. Many of these classes have a greater focus on group discussions than the regular classes and may be the best classes in which to promote your child's communication goals. Modified materials for these classes can be found as easily as for the regular classes.
7. Ensure that your child is a full participant in all class and school activities.
 - No matter how challenging the task, there is always a part that your child can do. The teacher should be looking for the objective in the assignment that is most meaningful for your child and adapt the assignment and materials accordingly. Example: groups of students are playing a math game based on prime numbers – the adapted assignment is for your child to keep score using the calculator.

- Your child should always partner with the students for group activities. The aide or teacher can help but they shouldn't be your child's partner.
- Your child should participate in any homework or projects that will be presented to the class or hung up on the walls. If the workload needs to be reduced, cut out homework and assignments that are not shared with the class. Any work on below grade level skills should be done when students are working independently at their desks rather than during a group activity.
- Paraeducators (aides) should be seen as helpers for all the students, not just your child. They should play as small a role as possible at lunch, recess, PE, art, and music. Class work should be adapted to let your child work as independently as possible.
- To the extent possible, your child should participate in after school and weekend activities like carnivals, math night, plays, concerts, dances, clubs, and sports events.
- As the student get older the friends will naturally provide support at these events for your child instead of having an adult present, or the adult can observe from a distance. Remember how you felt when your parents hovered around. This is difficult because it can involve taking some risks. It is important to ensure that your child receives as much information as possible about risky behaviors. The school health classes do a good job at starting this dialogue.
- If your child likes sports but cannot participate on a school team, he or she can be a manager. It is easier to make friends in small cohesive groups like teams and clubs than in the classroom.
- Explore volunteer opportunities that are available to students at school, like putting up decorations or collecting canned goods.

8. Out of school activities

- Consider having your child join scouts and community sports teams to provide additional opportunities to meet with classmates outside of school. Involvement in youth groups and religious education classes sponsored by your place of worship also achieves this goal and provides social inclusion in your religious community.
- Arrange community service opportunities with other classmates.
- Provide one-on-one time with a variety of classmates outside of school. Initially, you may need to be proactive and initiate these get-togethers. This is not necessarily an issue with the other students' interest in your child. Often it is their parents who are uncomfortable because they have exaggerated ideas about your child's needs. Inviting the other parent along can help with this issue.

9. If friendships are still not developing you can explore school activities that facilitate friendships such as a peer-mentoring program. One example of this type of program is "Circle of Friends." For a fact sheet on "Circle of Friends," see <http://www.unr.edu/educ/ndsip/factsheets/circle.friends.pdf>. Another excellent resource is the "Promoting Social Success" curriculum available from Brookes Publishing (<http://www.brookespublishing.com/store/books/siperstein-6741/index.htm>).

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