Resource Directory





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.



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 <u>dsawm.org/programs</u>.



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.



Rapid Runners

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.



Shape Up

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.



Skill Building Series

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.



Water Ski Clinic

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.



Weekly Update

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.



Access! GR

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.



Holiday Party

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.



Member Picnic

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.



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

Transitioning Into Older Adulthood

Day Programming

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

o Arts

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

o 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
Kentwood Parks and Recreation	
Adaptive Recreation	West Michigan Miracle League
kentwood.us/city services/city department	<u>wmml.org</u>
s/parks and recreation/adaptive.php	616-481-0481
616-656-5270	Rockford
Kentwood	

Animals/Nature

Fellinlove Farm	Growing Roots (ages 16+)
<u>fellinlovefarm.com</u>	wegrowroots.org
616-283-7555	616-516-6777
Holland	Wayland

Social Recreation

Compassionate Heart Ministries Club 404 compheart.org/clubs 616-834-0501 Zeeland	Just Like Home justlikehomeionia.com 616-523-4310 lonia
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 (<u>network180.org</u> or 616-336-3909) maintains a directory of accredited AFC (adult foster care) homes in West Michigan on their website at <u>network180.com</u>.
- 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 (<u>oasiscommunity.info</u>) 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 (<u>communityadvocates.org</u> 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 <u>communityadvocates.org/after-im-gone</u> or contact 269-342-9801.
- Disability Network Lakeshore (<u>dnlakeshore.org</u> or 616-396-5326) is available to assist lakeshore area residents in transitioning into assisted and independent living

facilities. Visit <u>dnlakeshore.org/nursing-home-transition</u> 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 (<u>communityadvocates.org</u> 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 ndscenter.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 <u>alz.org/gmc</u> 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 (<u>lumindidsc.org</u> 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 <u>lumindidsc.org</u>.

For support when speaking with dental providers, take a look at **Dentably's Dental Care Guidance for Caregivers of Patients with Down syndrome** at

<u>emergencydentistsusa.com/down-syndrome-and-dental-care</u>.

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 <u>dsawm.org/school-age-resources</u>. **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

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 <u>dakc.us/family-support</u> or calling 616-949-1100, or by contacting your local **Arc** office. Visit The Arc's website at <u>thearc.org</u> and use the Find a Chapter button to search for your local Arc office.

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 (<u>familyhopefoundation.org</u> 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 (<u>lorisvoice.org</u>) 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 <u>mi211.org</u>.

National Assistance Programs

- AMBUCS (ambucs.org) provides AmTrykes, therapeutic tricycles for children and adults with disabilities, including children with low muscle tone
- Apraxia Kids (<u>apraxia-kids.org</u>) provides speech tablets and protective cases to children with a diagnosis of apraxia of speech to aid in communication
- Cerner Charitable Foundation (<u>cernercharitablefoundation.org</u>) provides financial assistance for medical care, medical devices, vehicle modification, and travel for those 18 and younger with a disability
- Different Needz Foundation (<u>differentneedzfoundation.org</u>) 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 (<u>lifelinepilots.org</u>) provides free medical and compassion flights to patients in the Midwest with financial need
- Maggie Welby Foundation (<u>maggiewelby.org</u>) provides scholarships to children in kindergarten thru 12th grade whose families demonstrate financial need
- McLindon Family Foundation (<u>mclindonfamilyfoundation.org</u>) provides adaptive bicycles for children with special needs
- Microsoft (<u>microsoft.com</u>) 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 (<u>modestneeds.org</u>) provides short-term financial help for families in crisis situations
- Montana Melin Foundation (<u>montanamelinfoundation.com</u>) provides financial assistance to the families of children with Down Syndrome that are facing medical hardships
- My Gym Foundation (<u>mygymfoundation.org</u>) provides grants for the purchase of medical and therapy equipment for children with special needs under 18 years old

- NDSS (<u>ndss.org</u>) provides scholarships to individuals with Down syndrome in the areas of post-secondary education, entrepreneurship, and self-advocacy
- Needy Meds (<u>needymeds.org</u>) provides discounted and free medication programs and other services for low income families
- Parker Lee Project (<u>theparkerleeproject.org</u>) provides medical supplies and equipment to children at no cost, including enteral supplies, formula, and incontinence supplies
- Project Angel Fares (<u>projectangelfares.com</u>) 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 (<u>rubysrainbow.org</u>) provides scholarships to individuals with Down syndrome who are pursuing post-secondary education, enrichment, or vocational classes
- Small Steps in Speech (<u>smallstepsinspeech.org</u>) grants funds for speech and language disorder therapies for people aged 3-22 years old
- Special Kids Photography of America (<u>specialkidsphotography.com</u>) provides grants for family pictures
- Stepping Stones for Stella (<u>steppingstonesforstella.org</u>) provides buggies for children with special needs to enjoy outdoors to its fullest
- UnitedHealthcare Children's Foundation (<u>uhccf.org</u>) offers grants for kids 16 years old or younger for services health insurance does not cover
- Wheelchairs 4 Kids (<u>wheelchairs4kids.org</u>) 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 Aging Resources, visit our website at dsawm.org/aging-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!

