

Resources for Children with Complex Medical Problems



Department of Social Work



**University of Michigan
C.S. Mott Children's Hospital**

Acknowledgements

We got information in this booklet from the following organizations. They all have useful information to plan for children with complex medical problems.

ARC

The Arc Michigan facilitates a statewide network of local chapters assisting persons with developmental disabilities and their families through education, training, technical assistance and advocacy.

<http://www.arcmi.org/>

800-292-7851 or 517-487-5426

Michigan Department of Health and Human Services (MDHHS)

MDHHS is the department of the state government whose goal is to protect, preserve, and promote the health and safety of the people of Michigan. MDHHS looks out for the needs of vulnerable and under-served populations. Services are administered throughout the State of Michigan through multiple agencies, including the Department of Health and Human Services, the Department of Public Health, Community Mental Health Agencies and local school districts.

<http://www.michigan.gov/MDHHS/>

517-373-3740

Michigan Protection and Advocacy Service (MPAS)

MPAS promotes, expands and protects rights of people with disabilities through information and advocacy. MPAS tries to answer questions you may have relating to disability. They have experience in the following areas:

discrimination in education, employment, housing, and public places; abuse and neglect; Social Security benefits; Medicaid, Medicare and other insurance; housing; Vocational Rehabilitation; HIV/AIDS issues; and other topics.

<http://www.mpas.org/>

800-288-5923 (Toll Free) or (517)487-1755

Pediatric Advocacy Clinic (PAC)

The PAC focuses on improving health outcomes for low-income children. Developed by clinical faculty in the University of Michigan Law School, the PAC provides legal advocacy training and support to pediatric providers at the University of Michigan Ypsilanti Health Center, the pediatric social work team at University of Michigan C.S. Mott Children's Hospital, the Corner Health Center, and the Washtenaw County Department of Public Health Maternal Infant Health Program.

<http://www.law.umich.edu/clinical/pediatricadvocacyclinic>

Please ask your social worker if you would like a referral to the PAC.

Social Security Administration (SSA)

The SSA administers income to disabled Americans.

<http://ssa.gov/>

800-772-1213

U.S. Department of Housing and Urban Development (HUD)

HUD directs housing programs for low-income and disabled Americans including: FHA first-time homebuyers program, Housing Choice Vouchers, Section 202, Project-based Section 8, and Public Housing programs.

<http://HUD.GOV/>

800-955-2232

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Introduction

“Disability is a natural part of the human existence and in no way diminishes the right of persons with developmental disabilities to live independently, enjoy self-determination, make choices, contribute to society, and experience full integration and inclusion in the economic, political, social, cultural, and educational mainstream of American society.”

- The Developmental Disabilities Assistance and Bill of Rights Act Amendment of 1993

Raising a child with special needs can be hard. The Pediatric Social Workers at Mott Children’s Hospital want you and your child to get the help you need. This book has basic information that you need about government and community agencies that help disabled children. Most of our patients are from Michigan, so most of the resources described are in Michigan. There is information about some national programs.

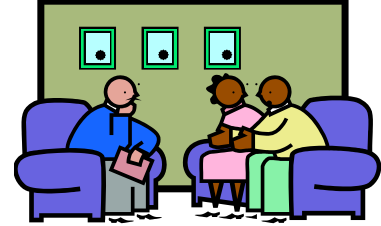
No two children are the same. This is even clearer when children have multiple disabilities. Each child with disabilities has different abilities, interests, family background, and personalities. Your child has unique strengths and needs. Equipment, materials, and strategies that work well with one child may not help another.

As a parent of a disabled child, you may find yourself caught up in all the labels that doctors use to describe your child. It may be hard to keep up with the number of doctors your child has and the number of appointments you need to keep. It may be confusing that having special needs and special doctors doesn’t automatically lead to having services in place for your child.

Parents are the foundation for caring for a disabled child. But no parent or family can do it all, especially when caring for a child with multiple impairments. Whole communities (families, schools, employers, health care providers, agencies) must work together to provide the best life for the child. This manual will serve as a guide for services for children with multiple impairments.

When to ask for Social Work

There is a Social Worker in most inpatient areas and outpatient clinics at Mott Children's Hospital. Social Workers can help you in many different ways.



For Practical Concerns...

- ✓ You would like to know where you can get information about your child's diagnosis.
- ✓ You're having a hard time understanding your insurance coverage, or are having financial troubles because of the cost of treatment.
- ✓ You have questions about transportation to medical appointments or a hotel for when your child is in the hospital.
- ✓ You have questions about services to help you care for your child at home.
- ✓ You are having a hard time setting up the help your child needs at school.

For Support...

- ✓ Your child or someone in the family is having a hard time coping with the illness or treatment.
- ✓ Your child's school isn't doing what is needed to help your child succeed.
- ✓ Your child refuses to take his/her medication and you are worried he/she will get sick because of this.
- ✓ Your child is depressed or anxious and you think he/she needs a counselor.
- ✓ Your family is having a hard time with your child's disabilities or changes in the family routine.

How do I ask for a Social Worker?

You can ask for a Social Worker when your child is in the hospital or at an outpatient appointment. You can also call the Guest Assistance Program at 800-888-9825 or 734-764-6893.



Eligibility for Services

There are three types of programs available for persons with disabilities:

- Income programs
- Insurance programs
- Service/care programs

Most government and community programs for children with disabilities have both diagnosis/disability and income requirements for eligibility. We encourage you to contact any of the programs described in this booklet to ask if your child meets their eligibility requirements.

In the State of Michigan, there are two main agencies that provide assistance programs - the Department of Health and Human Services and the Michigan Department of Community Health. These agencies have offices in every county.

Department of Health and Human Services (MDHHS)

The DHHS provides assistance programs in the following areas: Cash assistance, food assistance (SNAP), child support, child care, medical insurance (Medicaid and MICHild), in-home supports and emergency services. There are income and asset eligibility requirements for each of their programs.

Applications will ask questions about age, household income, citizenship, residency, and health issues. Please go to your local DHHS office or their website to obtain more specific information.

<http://www.michigan.gov/dhhs/>

There are two main program areas for disabled children through the MDHHS.

Children's Special Health Care Insurance (CSHCS) - a program that pays for the medical care of children with certain chronic illnesses. CSHCS is provided through the Public Health Department. Eligibility for CSHCS is based upon the child's specific health problem and need for specialty care. There may be a cost based upon family size and income.

<http://www.michigan.gov/cshcs>

Community Mental Health Service Program (CMHSP) - which provides in-home services for children who qualify. CMHSP programs are through county

Community Mental Health programs. Program eligibility is based upon the child having a developmental disability (DD). Severity of DD is also considered. The Michigan Mental Health Code (MCL 330.1100) considers **either physical and/or mental issues in developmental disability**.

According to the law DD means either of the following:

- (a) In a person older than 5 years, a severe, chronic condition that meets all of the following requirements:
- Is caused by a mental or physical disability or a both mental and physical disabilities.
 - The disability starts before they turn 22 years old.
 - The disability is likely to continue until the end of the person's life.
 - The person's functioning is limited in 3 or more of the following areas of major life activity:
 - Self-care
 - Speaking and understanding what people say
 - Learning
 - Walking on his/her own
 - Making decisions on his/her own
 - Ability to live on his/her own
 - Being able to make money by working at a job
 - The person needs special medical care and other services organized by other people to be cared for and stay safe. These services are specific to his/her needs and are needed for the rest of his/her life.
- (b) If the child is younger than age 5, he/she must have a substantial developmental delay or a specific congenital or acquired condition will most likely result in the definitions described in the section above if services are not provided.

www.michigan.gov/mdhhs



Income Programs

There are government programs that provide income to children based upon their level of disability and parent income.

Supplemental Security Income (SSI)

Supplemental Security Income (SSI) is a program of the Social Security Administration. This is a program through the Federal Government and is available in every state. SSI provides need-based income for persons who meet the requirements.

To be eligible for SSI benefits, your child must be either blind or disabled.

- Your child may be eligible for SSI disability benefits beginning as early as the date of birth.
- Your child may be eligible for SSI disability benefits until age 18.
- When your child turns age 18, impairments are evaluated based on the definition of disability for adults.
- A child with a visual impairment may be eligible for SSI blindness benefits if the impairment meets the definition of blindness.

Criteria for a disabled or blind child:

- If under 18, your child must have a medically determined **physical** or **mental** disability(ies) which result in obvious and severe functional limitations.
- The condition(s) must have lasted or be expected to last for a continuous period of at least 12 months or be expected to result in death.
- If your child is blind, he or she must have a central visual acuity of 20/200 or worse.

Income Eligibility:

If a child is under age 18, not married, and lives at home with parent(s) who do not receive SSI benefits, a part of the parents' income and resources is counted.

A part of a stepparent's income and resources may also count if your child lives with both a biological or adoptive parent and a stepparent. This process is called "deeming." Deductions are made from deemed income for parents and

for other children living in the home. After the deductions are subtracted, the remaining amount is used to decide if your child meets the SSI income and resource requirements for a monthly benefit.

<http://ssa.gov/>

800-772-1213

Compassionate Allowances:

Social Security has a duty to provide benefits quickly when medical conditions are so serious that they obviously meet disability standards. Compassionate allowances allow Social Security to approve the most obviously disabled people for allowances based on objective medical information that can be obtained quickly.

To learn more, go to:

<https://www.ssa.gov/compassionateallowances/>

State Disability Assistance (SDA)

The SDA program provides cash assistance to people who are disabled for at least 90 days. Your child may be considered disabled for purposes of SDA if he/she is:

- Attending school and approved for special education services
- Approved for disability-based Medicaid
- Living in a substance abuse treatment center, adult foster care, home for the aged, or county infirmary
- Diagnosed with AIDS
- An active Michigan Rehabilitation Services (MRS) client
- A person with disability that meets Social Security's definition of disability (even if not expected to last 12 months)
- A refugee or asylee cut off SSI because of time limits

If you have income, the SDA payment will be reduced. Different rates apply to couples and people in special living arrangements.

Repay Agreements

People often apply for SDA to help make ends meet while their application for SSI or Social Security is pending. In these cases, that person is required to sign a paper that allows the Michigan Department of Human Services to keep any SSI necessary to pay itself back for any SDA received while the SSI application was pending.

Asset Limits

DHHS recently changed its policy regarding how and when it computes an applicant's assets for purposes of SDA. DHHS policy now allows SDA eligibility if assets drop below \$3000 any time in month of application.

Information can be obtained online at:

<http://www.michigan.gov/mdhhs/0,5885,7-339-9254---F,00.html>

Family Support Subsidy (FSS)

The FSS is available in Michigan for families that have less than \$60,000 annual income and who have a child under age 18 whose school has determined them to have:

- Cognitive impairment (CI)
- Severe multiple impairment (SXI) or
- Autism spectrum disorder

Children with CI must be in the severe range of functioning as decided by the local or intermediate school district. Children with autism must be receiving special education services in a program designed for students with autism, severe cognitive impairment or severe multiple impairments. Many children with severe disabilities cannot eat, walk, dress, or talk on their own. They often have both mental and physical impairments and need round-the-clock care. Families with children with severe disabilities have many expenses other families do not.

The Family Support Subsidy might be useful for the purchase of items needed to care for your child. Items include: special equipment, special foods, diapers, transportation costs, in-home care, respite care, family counseling, general household expenses, family recreation, and home remodeling to provide for special needs.

Families can be headed by birth parents, adoptive parents, or legal guardians. Foster parents are not eligible.

How can I apply for FSS?

You can get an application for FSS at your local office of Michigan's Community Mental Health Services Program (CMHSP). Your local CMHSP determines eligibility for this subsidy program. CMHSPs are listed in most telephone books and online at:

https://www.michigan.gov/mdhhs/0,5885,7-339-71550_2941_4868_7145-14670--,00.html

If you cannot get the number, call the family support subsidy office in Lansing: 517-241-5773 (TTY: 517-373-3573)

Earned Income Tax Credit (EITC)

The Earned Income Tax Credit (EITC) is a refundable federal tax credit for eligible low- and moderate-income individuals and families who work. The EITC reduces the amount of tax you owe. It may give you a refund from the Internal Revenue Service (IRS).

The financial rules are based on your family income and number of children. There is a maximum amount that each family can receive. Married workers must file a joint tax return to qualify. The credit is available if you have biological, adopted or foster children. You can also apply for children at any age who have “total and permanent” disabilities. Adult children who have developmental disabilities may automatically qualify if their physical or mental condition prevents them from working a regular job. You must have Social Security numbers for all the children you list.

https://www.michigan.gov/mdhhs/0,5885,7-339-71547_5531_39747---,00.html

You can find information and the forms you need by calling the IRS at 1-800-829-3676 or going to this website:

<https://www.irs.gov/Credits-&-Deductions/Individuals/Earned-Income-Tax-Credit>

Taxpayer assistance is available in different Michigan cities. More information about locations can be found at:

<http://www.irs.gov/uac/Contact-My-Local-Office-in-Michigan>



Insurance Programs

Medicaid

Medicaid is health insurance available to Michigan Residents under certain income and asset limits. If the income is over the income limit, persons may incur medical expenses that equal or exceed the excess income and still qualify for this program.

If your child is already on Medicaid, you will have to reapply when he/she turns 18 years old.

If your child is not on Medicaid, he/she may be eligible at 18 years of age as the government considers only their income when they become a legal adult.

A person can have a private insurance and still be eligible for Medicaid. Young adults can remain on their parents' insurance until the age of 26. However, it may be beneficial to have Medicaid as a secondary insurance to pay medical costs not covered by the primary insurance, such as co-pays, diaper supplies, etc.

How do I apply for Medicaid?

You can apply online at: https://newmibridges.michigan.gov/s/isd-landing-page?language=en_US

- Submit the application online
- Print a letter that tells you who qualifies

You can also get help applying at your local DHS office.

MiChild

Children under age 19 whose family income is too high for Medicaid/Healthy Kids may be able to get health and dental care insurance through MiChild. To qualify, your child must:

- Be under age 19
- Have no comprehensive health insurance, including Medicaid
- Have a Social Security Number (or have applied for one)
- Live in Michigan, even for a short time

- Be a U.S. citizen or qualified immigrant
- Meet monthly family income limits

How much does MIChild cost?

There is a low monthly cost for your whole family (even if you have more than one child).

How do I apply for MIChild?

You can apply online at: https://newmibridges.michigan.gov/s/isd-landing-page?language=en_US

Fill out the online application

- Submit the application online
- Print a letter that tells you who qualifies

You can also get help applying at your local DHS office.

For questions and/or problems, or help to translate, call the Beneficiary Help Line: 800-642-3195/TTY: 1-866-501-5656.

https://www.michigan.gov/mdhhs/0,5885,7-339-71547_2943_4845_4931---,00.html

Children's Special Health Care Services (CSHCS)

CSHCS is a program that pays for the medical care of children with certain chronic illnesses. Children must have a qualifying medical condition and be less than 21 years old to be eligible. Persons 21 and over with cystic fibrosis or certain blood clotting disorders may also qualify for services. This program is for both uninsured and insured patients. It also provides supportive programs for parents. The goal of the CSHCS program is to assure that children with chronic medical conditions have access to the specialty medical care needed.

The child's medical condition, not income, determines eligibility for this program. There may be a monthly premium payment depending on family size and income. The income of young adults between the ages of 18 and 21 are considered apart from their parents.

What are the Benefits of CSHCS?

CSHCS works with you to ensure the very best care is received for your child's medical condition. CSHCS helps with:

- Paying specialty medical bills

- Coordinating services from multiple providers
- Covering co-pays or deductibles for the qualifying diagnosis
- In some cases, CSHCS can cover other insurance premiums

How does someone enroll in CSHCS?

Two forms are needed for enrollment to be completed:

1. Medical Eligibility Report Form (MERF): Your child's specialty physician must submit the MERF to the State. At Michigan Medicine, your Social Worker will help with this.
2. Patient/Parent application: The parent or young adult over 18 will receive an application in the mail if the child is accepted into the program. Completed applications must be sent back to the main CHSCS in Lansing, MI.

CSHCS Family Phone Line: 800-359-3722

https://www.michigan.gov/mdhhs/0,5885,7-339-71547_35698---,00.html

Medicare

Medicare is a federal health insurance program for people 65 or older, people of any age with permanent kidney failure, and certain people with disabilities. An individual is able to receive hospital insurance at age 65 if he/she is given monthly Social Security or has worked long enough to be insured under Social Security.

Medicare provides hospital insurance that covers most hospital services such as nursing services, drugs, lab tests (part A) and medical insurance (part B) that covers medically-necessary services like doctors' services, outpatient care, home health services, and other medical services. In most cases, an insured person's child over age 18 with a disability is eligible for hospital insurance. Anyone eligible for hospital insurance can apply for medical insurance (part B).

Local Social Security offices take applications for Medicare.

800-633-4227

<http://www.medicare.gov/>

TEFRA Medicaid

The Tax Equity and Fiscal Responsibility Act (TEFRA) Medicaid Eligibility Option allows children with disabilities from near-poor and middle-income families to qualify for Medicaid. Through TEFRA, children can receive Medicaid services that address their needs, but still live with their families.

To qualify, your child must:

- Be under 19-years-old
- Meet the SSI definition of “disability”
- Need the level of care provided in a hospital, nursing facility or intermediate care facility for persons with intellectual disabilities (ICF/ID).

The state will only count your child’s income and resources for eligibility. If you think your child might be eligible for TEFRA Medicaid, please contact your local CSHCS office: https://www.michigan.gov/mdhhs/0,5885,7-339-71547_35698---,00.html



Transportation and Lodging

Transportation

There are two types of transportation assistance – mileage reimbursement and medical transportation to and from appointments.

If your child has regular (straight) Medicaid:

If your child has straight Medicaid, and you live in **Wayne, Oakland or Macomb** Counties, you are eligible for mileage reimbursement or medical transportation. To arrange, please contact Logisticare at: 866-569-1908. Logisticare requires a DHHS Form (DHS-5330) to be completed and have on file before you can arrange transportation. Please contact your Michigan Medicine Social Worker to get help with this form.

For all other counties in Michigan, you are eligible for mileage reimbursement. The mileage reimbursement form (MSA-4674) must be brought to the appointment and signed by the doctor or nurse. Please contact your DHHS worker for a medical transportation form or ask for one from your Michigan Medicine Social Worker.

If your child has a Medicaid HMO:

The Medicaid managed care programs provide transportation to and from medical appointments. Some also provide mileage reimbursement. Please contact them directly to find out how to arrange transportation or get reimbursement for gas. The phone number will be on the back of your child's insurance card.

If your child is on Children's Special Health Care Services (CSHCS):

If your child has Medicaid as well as CSHCS, please see previous section regarding reimbursement through Medicaid.

If your child is enrolled in CSHCS (and not Medicaid), there is both a mileage reimbursement and medical transportation benefit. Please contact your local CSHCS office to discuss mileage reimbursement or arranging a ride to an appointment. If you do not have the phone number to your local CHSCS office, please call the Family Help Line at 800-359-3722.

Other options for gas assistance:

- Children who are enrolled in the Infant Support Services Program or WIC may be able to get mileage reimbursement through those programs.
- Contact your local United Way Agency to find out if any agencies in your area provide gas assistance for appointments.
- The Michigan Medicine Department of Social Work has limited assistance for families that meet certain guidelines and do not have mileage reimbursement through any state insurance program.

Lodging and Meals

There are hotels and extended stay facilities (with kitchen facilities) in Ann Arbor that have reduced rates for Michigan Medicine patients and their families. Some hotels in Ann Arbor will bill Medicaid HMO's or CSHCS directly. Please contact the Patient and Visitor Accommodations line to make arrangements at 800-544-8684 or 734-936-0135.

If your child has regular (straight) Medicaid:

If your child has straight Medicaid, and you live more than 50 miles away from Mott, you are eligible for meal assistance only. A DHHS Form (DHS-5330) must be completed and on file before we can assist with arranging meals. Please contact your child's Michigan Medicine Social Worker to get help with this.

If your child has a Medicaid HMO:

The Medicaid HMO's have meal and lodging benefits. Most have specific eligibility requirements. Please call the insurance company directly to find out if you qualify for benefits. Please contact your child's Michigan Medicine Social Worker to get help with this.

If your child is on Children's Special Health Care Services (CSCHS):

If your child has Medicaid as well as CSHCS, please see previous section regarding reimbursement through Medicaid.

If your child is enrolled in CSHCS (and not Medicaid), there is a lodging benefit. There is no meal benefit.

- Please contact the Patient and Visitor Accommodation at 800-544-8684 or 734-936-0135 to make a hotel reservation.
- Then contact your local CSHCS office to obtain a lodging authorization for the hotel stay.

If you do not have the phone number to your County CHSCS office, please call the Family Help Line at 800-359-3722. Please contact your child's Michigan Medicine Social Worker to get help with this.

Other options for lodging assistance:

- Some families have been able to obtain help from churches or agencies in their community to pay for a hotel when their child is in the hospital.
- The Michigan Medicine Department of Social Work has limited assistance for families that meet certain guidelines and do not have lodging and meal benefits through any state insurance program.

If you do not know who your child's Michigan Medicine Social Worker is, call the Guest Assistance Program at 800-888-9825 or 734-764-6893.



Medical Equipment

Many times equipment such as ramps, wheelchair vans, and home remodeling are not covered by insurance. The following resources can be used in order to get help for purchasing medical equipment.

AT Xchange – Assistive Technology

AT Xchange is a Michigan-based Web site where people can buy, sell or give away assistive technology. Do you have a used AT item in storage that could really help someone who has a disability? It could be anything from a wheelchair, stair lift, Braille reader, or reacher! If so, just post a classified ad AT Xchange.org. Include a digital photo. ATXchange is open to vendors who have used equipment for sale also.

<http://www.atxchange.org>

Children with Special Needs Fund (CSN)

The CSN Fund helps children in Michigan with special health care needs when help is not available through any other funding source. Families with a child enrolled, or eligible to enroll, in the CSHCS Program may apply to the CSN Fund. If you are eligible, the CSN Fund may provide a part or full payment for items including but not limited to:

- Wheelchair ramps
- Van lifts and tie downs
- Therapeutic tricycles
- Air conditioners
- Adaptive recreational equipment
- Electrical service upgrades needed by the eligible child's equipment

To apply for assistance from the CNS Fund, contact the CSHCS office at your local health department for an application and assistance with the application process. The application is also available on their website.

(517) 241-7420 or 800-359-3722

www.michigan.gov/csnfund

Lori's Voice

The purpose of Lori's Voice is to provide equipment, educational resources, and medical assistance to children with neuromuscular and other degenerative diseases.

<http://www.lorisvoice.org/>

Michigan Diaper and Incontinence Supplies Program

These supplies are covered if your child is over 3 years old, is on Medicaid, and a doctor has said your child is incontinent. Your doctor will give you a prescription for any of these products you or your child needs:

- All incontinence catheters and accessories
- Irrigation syringes
- Skin barriers
- Under pads
- Incontinence pants
- Incontinence liners
- Pull-on
- Disposable diapers

If your child is on a Medicaid Health Plan, call them directly about this program.

If your child is on Straight Medicaid, call J & B Medical:

800-737-0045; TTY 800-737-0084

http://www.michigan.gov/documents/dipfinal_88492_7.pdf

Michigan Assistive Technology Loan Fund

The Michigan Assistive Technology Loan Fund provides loans to people with disabilities (or their family members) to buy assistive technology devices or services. This included modification of cars/vans and homes. Loans may also cover cost of training to use the equipment, warranties, and service agreements. Assistive technology is defined as any item, piece of equipment, or device that allows a person with a disability to improve their independence and quality of life.

800-828-2714 (MI only) or 517-203-1200

<https://www.ucpmichigan.org/assistivetech>

The Morgan Project

The Morgan Project makes small individual grants to parents/caregivers of special children for travel expenses to attend medical conferences that they would not otherwise be able to afford to attend. They also make small individual grants to parents/caregivers of special-needs children for things like positional seating, adaptive car seats, durable medical equipment not covered by Medicaid or Insurance. This includes non-covered items that would make caring for these children easier on the parent/caregiver and help to improve their quality of life.

<http://www.themorganproject.org/>

United Healthcare Children's Foundation (UHCCF)

The UHCCF is a non-profit charity. UHCCF helps parent's access medical-related services that could greatly improve the health or the quality of life of their child and are not fully covered by the commercial insurance. Support is in the form of a medical grant to be used for medical services not covered or not completely covered by commercial insurance. This assistance is not available to children who are on Medicaid insurance.

855-698-4223

<http://www.uhccf.org/>



In-Home Supports

Many people think that their insurance will cover nursing services to help care for children with disabilities. Nursing services are covered only for disabilities that require skilled nursing care. A skilled nursing service is a service that must be provided by a nurse to be safe and effective. Examples of skilled care needs are ventilator-dependence or intravenous injections. The goals of skilled nursing care are to help improve a health condition or prevent a condition from getting worse.

Most care needed by children with chronic conditions is considered “custodial care,” or care of basic activities of daily living, and is not covered by insurance. This includes things like getting in and out of bed, and providing assistance with feeding, bathing and dressing. The best way to find out if your primary insurance covers in-home care for your child is to call them directly and ask.

We encourage parents that have enough money to hire someone themselves to help with their child’s care. Many parents have hired trained staff from licensed home care agencies to help them with their child. Others have hired someone they know to help care for their child, such as staff from their child’s school.

Government-Sponsored In-Home Support Programs

Adult Home Help Services

Once your child is 18 years old Adult Home Help Services will assist with necessary daily activities that your child cannot perform without help. The goal of this service is to allow young adults to remain in their own homes and to avoid being put in a more restrictive setting (like a nursing home or adult foster care home). This is done by finding a natural support system and strengthening it whenever possible. Services may include personal care (e.g. help with eating, bathing, grooming, dressing, transferring mobility, and incontinence care), household care (cleaning, laundry, making meals, and shopping), or help with giving medications.

For Home Help Services, the application is made through the local county DHS office. Call the office, ask for an Adult Services worker, and tell them you'd like to apply for Home Help Services. A services worker will then make an appointment to come to your home. They will:

- Evaluate your income and resource eligibility
- Do a complete needs-assessment
- Develop a services plan with you
- Help with finding providers
- Approve services (as appropriate) and complete all necessary paperwork except the physician's certification

It is important to remember to get the physician's certification and send it in with the application if you are applying on your own.

Through this program, parents or other family caregivers may be eligible to receive payment for caring for a person with disabilities once they turn 18 years of age.

Community Mental Health Services Program

All of the in-home support programs described below are based upon both income and disability criteria. If eligibility is based upon the child having Developmental Disability, the Michigan Mental Health Code (MCL 330.1100) considers either **physical** or **cognitive** delays in "developmental disability." Please refer to page 4 of this manual for more information.

Respite

Respite is a type of support available to families of children with developmental disabilities (DD) or serious emotional disturbance (SED). The word respite means "break" or "relief." Respite care services are designed to offer families the opportunity for a break from caregiving. Respite gives parents time to do activities that they find relaxing or entertaining while a trained respite provider cares for the child.

A respite break can mean an hour to take a walk while a respite provider cares for your child. It may be a weekend away while your child is cared for outside of your home. It can also mean time to take a nap or chat with a friend while the respite provider takes your child on a community outing.

Your local Community Mental Health Services Program (CMHSP) can determine whether your family is eligible for CMH Services, including respite care services. Eligibility for services is decided based the nature and severity of your child's disability and Medicaid eligibility. Priority is generally given to families with the greatest need for this service. You are not required to receive mental health treatment from the CMHSP in order to receive respite.

https://www.michigan.gov/mdhhs/0,5885,7-339-73971_7117_77104_77105-388308--,00.html

Community Living Supports

Community Living Supports (CLS) are provided through CMHSP. They are used to increase or maintain personal self-sufficiency, facilitating an individual's achievement of his goals of community inclusion and participation, independence or productivity. The supports may be provided in the participant's residence or in community settings (including, but not limited to, libraries, city pools, camps, etc.).

Coverage includes:

- assisting, reminding, observing, guiding and/or training in the following activities:
- meal preparation
- laundry
- routine, seasonal, and heavy household care and maintenance
- activities of daily living (e.g., bathing, eating, dressing, personal hygiene)
- shopping for food and other necessities of daily living

CLS services may not take the place of state plan services, e.g., Personal Care (assistance with Activities of Daily Living in a certified specialized residential setting) and Home Help or Expanded Home Help (assistance in the individual's own, unlicensed home with meal preparation, laundry, routine household care and maintenance, activities of daily living and shopping). If such assistance appears to be needed, the beneficiary must request Home Help and, if necessary, Expanded Home Help from the Department of Human Services (DHS). CLS may be used for those activities while the beneficiary awaits determination by DHS of the amount, scope and duration of Home Help or Expanded Home Help.

If the beneficiary requests it, the PIHP case manager or supports coordinator must assist him/her in requesting Home Help or in filling out and sending a

request for Fair Hearing when the beneficiary believes that the DHS authorization of amount, scope and duration of Home Help does not appear to reflect the beneficiary's needs based on the findings of the DHS assessment.

Staff assistance, support and/or training with activities such as:

- money management
- non-medical care (not requiring nurse or physician intervention)
- socialization and relationship building
- transportation from the beneficiary's residence to community activities, among community activities, and from the community activities back to the beneficiary's residence (transportation to and from medical appointments is excluded)
- participation in regular community activities and recreation opportunities (e.g., attending classes, movies, concerts and events in a park; volunteering; voting)
- attendance at medical appointments
- acquiring or procuring goods, other than those listed under shopping, and non-medical services
- Reminding, observing and/or monitoring of medication administration

Staff assistance with preserving the health and safety of the individual in order that he/she may reside or be supported in the most integrated, independent community setting.

https://www.michigan.gov/mdhhs/0,5885,7-339-73971_7117_77104_77105-388308--,00.html

Children's Waiver Program (CWP)

This program is for children whose families are not on Medicaid. The Children's Waiver Program (CWP) is a federal entitlement program that gives Medicaid funded home and community-based services to children (under age 18) who are eligible for, and at risk of, placement into an Intermediate Care Facility for the Mentally Retarded (ICF/MR).

Children with developmental disabilities who have challenging behaviors and/or complex medical needs are served through this program. The CWP allows children to remain in their parent's home or return to their parent's home from out-of-home placements regardless of their parent's income.

The waiver services include:

- Family training

- Specialty services (e.g. music, recreation, art, and message therapy)
- Community living supports
- Transportation
- Respite care
- Environmental accessibility adaptations
- Specialty medical equipment

The program can serve 464 children statewide. A waiting list is maintained, using a priority rating system to add new children to the program when there are openings. To request more information about this program, contact your local Community Mental Health Services Program.

https://www.michigan.gov/mdhhs/0,5885,7-339-71550_2941_4868_80988-427535--,00.html

Habilitation Supports Waiver (HAB)

This program is for children and adults who are on Medicaid. The HAB waiver is a federal program that gives Medicaid funded home and community-based services to children and adults who are at risk of placement into an Intermediate Care Facility for the Mentally Retarded (ICF/MR).

Eligibility requirements for this waiver:

- Medicaid eligible and enrolled
- Has a serious mental illness or emotional disturbance, substance use disorder, and/or developmental disability (DD)
- No age restrictions
- Would otherwise need the level of services similar to an ICF/MR

Services available:

- Community Living Supports
- Medical Equipment and Supplies
- Pharmacy
- Environmental Modifications
- Family Training
- Goods and Services
- Out-of-home (not job or work) habilitation
- Personal Emergency Response System (PERS)
- Prevocational Services
- Private Duty Nursing
- Respite
- Supports Coordination

- Supported Employment

To request more information about both waiver programs, contact your local Community Mental Health Services Program.

https://www.michigan.gov/mdhhs/0,5885,7-339-71547_2943-334724--,00.html



Special Education

(With special thanks to Debra Chopp, JD, of the Pediatric Advocacy Clinic, for her assistance with this section)

Overview

The Individuals with Disabilities Education Act (IDEA) is a federal law that requires each state to provide special education services and programs to eligible children with disabilities. These programs and services must meet the individual needs of disabled children and prepare them for continued education, employment, and independence. The law guarantees eligible children a “free appropriate public education” (FAPE) in the least restrictive environment.

Under Michigan’s Mandatory Special Education Act (MMSEA), Michigan schools must develop educational programs that will maximize the educational potential of students with disabilities.

Is my child eligible for special education services?

To determine whether your child is eligible for special education, the school must evaluate your child in all suspected areas of disability. Parents can request (in writing) a special education evaluation. The school may also identify a child with disabilities on its own and request a parent’s consent to evaluate the child. Under the IDEA the school district has a duty to seek out students with disabilities who may need special education.

There are 13 categories of disability under IDEA. These categories include:

- Cognitive, visual, emotional, hearing, physical, speech and language, and health impairments
- Early childhood development delays
- Specific learning disabilities
- Severe multiple impairments
- Autism spectrum disorders
- Traumatic brain injuries
- Deaf-blindness determinations

In Michigan, once a parent consents to the evaluation, the school has **30 school days** (weekends and holidays do not count) to conduct the evaluation, set up a

meeting to determine eligibility and, if the child is eligible, write an individualized education program for the child.

What is in an Individualized Education Program (IEP)?

An IEP is a formal document created by the child's IEP team that:

- Identifies the child's disability (or disabilities)
- Contains a description about the child's "present levels of academic achievement and functional performance"
- Lists measurable goals and objectives for the child
- Contains the percentage of time the child will be in general and/or special education classes
- Spells out the exact special education services and accommodations that a child will receive from his/her school.

A behavioral plan will be included if it is needed. The IEP is a legally binding document and the school must adhere to the plan. Once an IEP is written, it is revised at least one time each year by the IEP team.

The IEP team includes:

- School district representatives
- Teachers
- Student
- Parents
- Other experts if invited by school or parents

Many kinds of services and accommodations can be included in an IEP. Depending on your child's special education needs, there could be a combination of one-on-one instruction, therapies (e.g. speech, occupational, physical), assistive technology, social work, nursing services, specialized transportation, parent training, and other services. For instance, a hearing impaired child may need a Teacher Consultant, a speech therapist, a hearing device, and a classroom that is fully carpeted. These services and accommodations allow the child with the hearing disability to receive an appropriate education.

Is my child too young for services?

Children in need of special education do not have to wait for the age of five or when they start kindergarten to receive support services or special education. Under the Individualized Family Service Plan (IFSP) children under the age of

three can receive “early intervention” services. Early intervention is the process of providing services, education and support to infants and toddlers aged birth to 3 years with developmental delays or a medical condition likely to lead to a developmental delay. Services are designed to identify and meet a child's needs in five developmental areas, including: physical development, cognitive development, communication, social or emotional development, and adaptive development.

In Michigan, early intervention services are provided by a program called **Early On**. Early On services are provided through your local school district.

Services can include:

- Preschool programs
- Family assistance
- Infant stimulation and play
- Physical therapy
- Speech therapy
- Social work services
- Diagnostic or evaluation medical services
- Other related services to cognitive, social, and physical development

Your doctor can make a referral to Early On, or you can contact them on your own.

<http://www.1800earlyon.org/>
1-800-EarlyOn (1-800-327-5966)

What if my child is in private school?

Children in private schools can receive special education services. The reason for going to the private school will determine what kind of services your child can receive. If you chose to place your disabled child in private school for personal reasons, without regard to the education that can be provided at a public school, your child will receive a “Services Plan,” which is more limited in scope than an IEP. If your child is placed in private school because it is shown that the public school cannot provide a free appropriate public education (FAPE) to him/her or because an IEP team determines that private school is necessary to provide FAPE, your child will still have an IEP.

If Parents Disagree with the School Assessment

There are some options if you disagree with your child’s school about:

- The evaluation performed by your child’s school
- Your child’s IEP is not being implemented
- If you believe your child is not receiving a “free appropriate public education.”

If you disagree with a school’s evaluation, you can request (in writing) an independent educational evaluation at public expense (free to you). The school must either grant the request or go to a hearing to defend its evaluation. If the request is granted, you may choose an evaluator and the evaluation results must be considered at the child’s IEP team meeting.

If a parent disagrees with other aspects of a child’s IEP, he/she can always request another IEP meeting (even it has not been a year since the last IEP meeting) to discuss problems with carrying out the IEP or problems with the content of the IEP. If meeting with the IEP team does not solve the problem, you may request mediation, file a state compliance complaint, or file a due process hearing request. State complaints are generally appropriate when the school is not carrying out a child’s IEP or there has been some other legal violation. The State will investigate and propose resolutions, but there will not be a trial. <http://www.michigan.gov/mde>

Another option is a due process hearing request. This is the way to request a trial before a neutral hearing officer in which you and the school district present evidence on whether a child is receiving a free appropriate public education. Information on due process complaints as well as the IEP process generally can be found at the Michigan Department of Education website.

If you are considering filing for a due process hearing, you should consult with an attorney.

Special Education Advocacy Organizations

Michigan Alliance for Families

Michigan Alliance for Families is a statewide resource to connect families of children with disabilities to resources to help improve their children’s education. We help facilitate parent involvement as a means of improving educational services and outcomes for students with disabilities. Michigan Alliance can assist you in knowing your rights, effectively communicating your child’s needs, and advising how to help them develop and learn
800-552-4821

<http://www.michiganallianceforfamilies.org/>

Michigan Protection and Advocacy Center (MPAS)

MPAS promotes, expands and protects rights of people with disabilities by providing them with information and advocacy. MPAS tries to answer any questions you may have relating to disability. They have experience in the following areas: discrimination in education, employment, housing, and public places; abuse and neglect; Social Security benefits; Medicaid, Medicare and other insurance; housing; Vocational Rehabilitation; HIV/AIDS issues; and many other disability-related topics.

800-288-5923 (in Michigan, voice/TTY) or 517-487-1755 (in Lansing)

<http://www.mpas.org/>

The Student Advocacy Center of Michigan (SAC)

The SAC is the only independent organization in Michigan providing free, non-legal advocacy to students (and their parents) that are eligible for special public education programs. SAC was established in 1975 to focus on the educational experience of students; to identify successful practices and policies as well as the barriers to effective service. SAC provides free individual case advocacy, technical assistance, and training for parents, students, and professionals about children's educational entitlements and due process rights in Michigan.

734-482-0489

<http://www.studentadvocacycenter.org>

Project Find Michigan

Project Find Michigan is a statewide system of service to promote the awareness of special education supports and/or services provided by the public school system. Project Find is devoted to helping individuals, parents, and people who work with families (known as primary referral sources), to connect with the special educational services that may be needed. In Michigan, eligible children, youth, and young adults may receive special educational services from birth through 25 years of age.

800-252-0052

<https://projectfindmichigan.org/index.php>

Washtenaw Association for Community Advocacy (ACA)

Washtenaw ACA Assists ...

- Parents to secure Individualized Education Plans (IEP) with appropriate support for their children

- Youth with disabilities, ages 18-26, to transition from K-12 education and children services to appropriate community based services and supports
- Individuals with disabilities and their families to plan for the future through Person-Centered Planning, estate planning and alternatives to guardianship
- Individuals with disabilities to obtain and maintain benefits, including Social Security Disability, Supplemental Security Income, Medicaid and the Michigan Family Support Subsidy
- Individuals with disabilities to obtain accommodations they may need to navigate the criminal, civil, probate and juvenile court systems

734-662-1256

<http://www.washtenawaca.org/>



Additional Resources

ARC

The mission of The Arc Michigan is to help people with Developmental Disabilities in being valued so that they and their families can participate fully in and contribute to their communities. The Arc Michigan facilitates a statewide network of local chapters assisting persons with developmental disabilities and their families through education, training, technical assistance and advocacy.

800-292-7851

<http://www.arcmi.org/>

Children with Special Needs Fund

The Children with Special Needs Fund provides support for children 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. Your child must be eligible for or enrolled in Children's Special Health Care Services to apply for funding.

<https://www.michigan.gov/csnfund>

Emily Ann Griffin Foundation

The Emily Ann Griffin Foundation was established in the spring of 2002 in the memory of our daughter - a delightful, spirited, red-haired little girl who despite her special needs radiated love through her precious smile. Through the foundation, we have been able to touch the lives of other families who are not able to afford the costly medical equipment often prescribed to support and enhance their child's life. We can think of no greater way to honor our daughter's life than through service to others in her name. We thank YOU for making it possible. - Matt and Inger Griffin

(734) 542-0469

<http://eagf.org/>

Lekotek

Lekotek makes the world of play accessible to children with all types of disabilities through special play and learning centers where they can have fun with traditional toys, adapted toys, books and computers. While they are playing, Lekotek kids are learning new skills that build the base for literacy, mathematical reasoning and computer use. At Lekotek, families learn fun, creative and healthy ways to play together and to include their children into family and community activities. Children borrow adapted and traditional toys, books and software from Lekotek toy lending libraries for use at home.

773-528-5766

<http://www.lekotek.org/>

Lori's Voice

The purpose of Lori's voice is to provide equipment, educational resources and medical assistance to children with neuromuscular, degenerative diseases and mobility issues.

PO Box 66, Coopersville, Michigan 49404

<http://www.lorisvoice.org/>

Michigan Assistive Technology Loan Fund

The Michigan Assistive Technology Loan Fund allows people with disabilities and seniors (or their family members) to buy assistive technology devices or services, including modification of vehicles and homes.

800-828-2714 (MI only) or 517-203-1200

<http://ucpmichigan.org/at/loan-funds/>

Patches of Light

Patches of Light assists the families of critically ill children with transportation, utilities, rent payments, etc. The limit of assistance is \$350 per family. Patches of Light only accepts requests from social workers, family financial advocates and other hospital officials. If you or a family member needs assistance from our organization, please contact your hospital social worker.

614-946-7544

<http://www.patchesoflight.org/>

Share A Smile

Share A Smile is a Michigan-based charitable organization founded in 1999 to meet the unmet needs of ordinary citizens struggling with financial crisis, due to unemployment, health crisis or natural disaster. One of the groups they focus on helping is special needs children. Share a Smile is organized to serve people in need in two ways:

1. Providing direct assistance through bill payment to individuals and families struggling to obtain the basic needs of life
2. Creating and funding programs targeted at serving specific needs in the communities they serve

248-601-5055

<http://www.shareasmile.org/>

United Cerebral Palsy Association

United Cerebral Palsy of Michigan (UCP Michigan) is a non-profit advocacy organization that works for life without limits for people with cerebral palsy and other disabilities. All people with and without disabilities have a right to be part of their communities and to choose how they want to live their lives.

800-828-2714 (MI only) or 517-203-1200

<http://www.ucpmichigan.org/>

United Healthcare Children's Foundation (UHCCF)

The UHCCF is a non-profit charity. UHCCF helps parent's access medical-related services that could greatly improve the health or the quality of life of their child and are not fully covered by the commercial insurance. Support is in the form of a medical grant to be used for medical services not covered or not completely covered by commercial insurance. This assistance is not available to children who are on Medicaid insurance.

855-698-4223

<http://www.uhccf.org/>

Variety Detroit

Since 1932, Variety - the Children's Charity Detroit has been simply helping kids - no matter the need - by providing vital support and essential services to children with special needs in our community. Through core programs which provide assistance to underserved children with cognitive and/or physical

challenges or who are victims of disadvantage, poverty, or natural disaster, Variety - the Children's Charity Detroit is changing the lives of children in Southeastern Michigan each day. Unlike most charitable organizations that address a singular cause or effort, Variety Detroit focuses on multiple unmet needs of children who are disadvantaged or live with disabilities and other special needs. Our aim is to maximize real, long-term positive social impact for all children.

(248) 258-5511

<http://variety-detroit.com/>



Conclusion

Many resources are available to help families of disabled children. We hope that this manual helped you understand these services and supports. All children are different, as are all families. There is no cookie cutter way to plan what services to get for your child. With this manual we hope that you will consider contributions from your family, the school, representatives from service agencies, and other involved community members to help improve your child's life.

This booklet is only a brief introduction to the issues that will impact you and your child. If you are just beginning your journey as a new parent of a child with special needs, we encourage you to connect with other parents. The following organizations offer a way to connect with other parents of children with special needs.

<https://www.bridges4kids.org/>

<http://www.michiganallianceforfamilies.org/>

<http://www.pacer.org/>

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