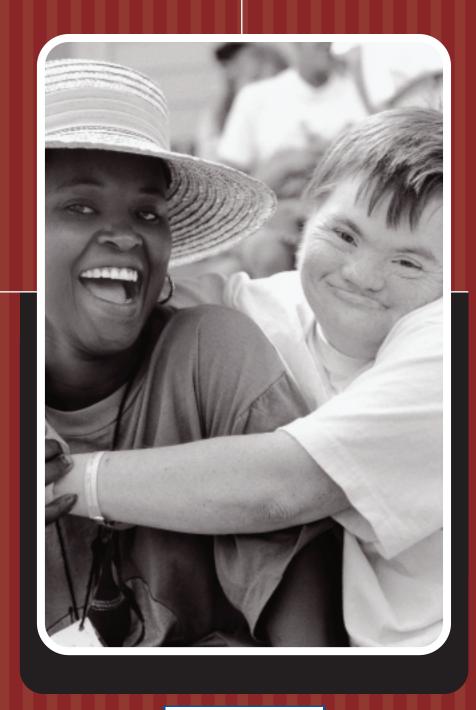
Consumer & Family Guide







MDCH is an Equal Opportunity Employer, Services and Programs Provider.

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United Way Community Services



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INTRODUCTION

If you suspect that you, your child, or another family member has a developmental disability, fear will likely be your first reaction. This is largely because in the past, there was little, if any, help available for people with disabilities and their families. Many people with disabilities were placed in institutions and segregated from their family, friends and community.

Fortunately, times have changed. Systems are now being designed to enable people with disabilities to play an active role in their communities. They are encouraged to seek and direct the kinds of support and services they want to help them live full, rewarding lives.

This manual will acquaint you with service and support systems that improve quality of life for people with developmental disabilities.



WHAT IS A DEVELOPMENTAL DISABILITY?

Each service or support system may have its own definition of what a developmental disability is.

Michigan's Mental Health Code provides a common definition:

Developmental Disability means either of the following:

- 1. If applied to an individual older than five years, a severe, chronic condition that meets all of the following requirements:
- Is attributed to mental or physical impairment or a combination of mental and physical impairments.
- Is manifested before the individual is 22 years old.
- Is likely to continue indefinitely.
- Reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services that are of lifelong or extended duration and are individually planned and coordinated.
- Results in substantial functional limitation in three or more of the following areas of major life activities: Self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, economic self-sufficiency.
- If applied to a minor from birth to age 5, a substantial developmental delay or a specific congenital or acquired condition with a high probability of resulting in developmental disability as defined above.

Common disabilities that may fall under this definition include mental retardation, cerebral palsy, and autism. However, many other disabilities fall under the definition if the above criteria are met.

HOW DO I KNOW IF MY CHILD HAS A DEVELOPMENTAL DISABILITY?

If you suspect that your child has a disability and you have private insurance, you may wish to contact private hospitals, clinics, pediatricians, and other specialty services for an evaluation. School services are discussed further in Schools, p. 9.



WHAT FINANCIAL AND MEDICAL ASSISTANCE IS AVAILABLE FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES?

Social Security Programs, Medicaid and Medicare

SSI

Supplemental Security Income (SSI) is a program of the Social Security Administration (SSA). SSI provides need-based income supplements for elderly, blind, and disabled persons who meet the requirements. Children are eligible for SSI if they have special health care needs as determined by assessment under SSI criteria, if they have a disability under SSA, if they require institutional care but can be cared for at home for less cost, or if they are state wards (i.e. individuals under 18 who are receiving foster care and children for whom there is an adoption assistance agreement). You can apply for SSI at your local Social Security Administration District Office. You may obtain an application form in person, by phone, or by writing. If you are unable to apply, you may have someone else apply on your behalf. It is important that you apply right away because SSI benefits cannot start before the date you file a signed application. The monthly amount received depends on your living situation, such as whether you live on your own, with your family, or with others. If you are over age 18, your parents' income and resources are not considered. If you are found eligible for SSI, you will automatically receive Medicaid. (See Medicaid section, this page)

Any SSI applicant or recipient who is dissatisfied with an action taken on his or her claim or benefit may appeal it. First, you must be provided with written notice of the action from SSA. The notice must be provided prior to a proposed reduction, suspension, denial or termination of SSI benefits. The first step in the appeal process is to have a hearing in front of an administrative law judge. If you are still unhappy, you may file a request for an

Appeals Council Review. After that, you may file a complaint in your local federal district court. You have a right to have an attorney help you at all stages of an appeal. Many advocacy organizations may also be able to help you through this process. (See Advocacy Section, p. 29)

Social Security Retirement, Survivors Health and Disability Insurance

(RSHDI)

This is the program we usually think of as "Social Security". RSHDI protects individuals and families against loss of work-income due to retirement, disability, or death. This is a work-related program; it is not based on financial need. RSHDI benefits are based on a person's prior employment. Cash payments can be made to unmarried children of any age if the child was totally disabled before age 22 and continues to be disabled. Application for benefits should be made at the local Social Security Office. Their number is usually found in the phone book under federal government listings.

Medicaid

Medicaid is a state and federally funded program administered by the Michigan Department of Community Health (MDCH) to pay medical bills for Michigan residents in need. You may be eligible if you are disabled and have income or assets at or below the Medicaid limits. If you are eligible for SSI, you are automatically eligible for Medicaid. However, the opposite is not always true. Eligibility for Medicaid may NOT mean eligibility for SSI. If you are not receiving SSI, you can apply for Medicaid through your local Family Independence Agency (FIA) office. The FIA has similar income and asset criteria.

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MIChild

MIChild is a program for children under age 19 who live in a family with a low to moderate income, and who currently have no health insurance. A monthly premium payment of \$5 per month per family, regardless of the number of children covered, is required for MIChild participation. There are no co-pays and no deductibles. You may obtain an application from any local human service agency or by calling 1 (888) 988-6300. If you apply for MIChild and your income is below the qualification limits for the MIChild program, you will automatically become eligible for insurance through the Healthy Kids Program (there is no need to re-apply).

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 entitled to hospital insurance at age 65 if he or she is entitled to monthly Social Security or has worked long enough to be insured under Social Security. Medicare provides hospital insurance (part A) and medical insurance (part B). 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). The local Social Security Administration offices take applications for Medicare. For disabled people under age 65, Medicare begins two years after SSD eligibility.

There are other financial benefits from the State of Michigan for which people with disabilities may be eligible. These are discussed in the Family Independence Agency section, p. 18.

What Is Managed Care and What Does It Mean for Me?

Many health care systems across the country are entering what are called "managed care" contracts with health care providers as a new way of providing care to enrolled groups of people. Although most insurance systems have some elements of managed care, we usually think of managed care as a system that replaces the practice of paying health care providers a fee for each service they provide to each patient.

In a managed care system, the health care system pays a set amount for each patient that is enrolled in the health care plan. The health care provider receives this set amount no matter how many services the patient receives during the benefit period (usually one year). Patients generally have lower co-pays and other out-of-pocket expenses in a managed care system. The expectation is that under managed care, there will be less duplication of services and better coordination of all services under a single provider.

In Michigan, if you receive Medicaid you will be enrolled in managed care plan for all your physical health care needs. This means you will be assigned to a particular health care provider depending upon where you live. The provider will have agreements with a number of primary care physicians who will coordinate your physical health care and offer referrals to specialists for medical services. Specialty long-term services for people with developmental disabilities, mental illness, or substance abuse problems have also been established under a separate managed care arrangement with the local Community Mental Health Services Programs. (See section on Community Mental Health Services Programs, p.13)



WHAT FINANCIAL AND MEDICAL ASSISTANCE IS AVAILABLE FOR PEOPLE WITH DEVELOPMENTAL DIS-ABILITIES?

Generally, there are five major public resources available to provide services and support to people with disabilities. These are schools, Community Mental Health Service Programs (CMHSP), the Family Independence Agency (FIA), Michigan Rehabilitation Services (MRS) within the Department of Career Development, and advocacy programs. This section will summarize each public source, the services provided by each, how to access each service, how to appeal decisions made by them, and how each service is paid.

A. SCHOOLS

It is important for you to be familiar with the special education laws that exist, both on the federal and state levels. Since 1973, Michigan has provided special education services for children from birth to age 26. These laws mandate, as part of a "free, appropriate education," that your child's local school system provide assessments to all children with disabilities. In Michigan, you may request an assessment at any time, and your child's unique needs will be evaluated. From these evaluations, an individualized family service plan shall be developed within 30 days.

WHAT SERVICES ARE AVAILABLE?

Infant and Toddler Services

Michigan has always provided infant and toddler service from birth to age two. These services have included at-home assistance and education for parents that focus on infant stimulation and play, physical therapy, and other services that support cognitive, psychosocial, and physical development.

As a result of amendments to federal law, Michigan now has the option of providing early intervention services for infants and toddlers. Early intervention services may be given to those who are experiencing developmental delays or who are at risk of developing such developmental delays, and would benefit from early intervention services. There are five areas included in early intervention services: physical, cognitive, speech and language, psychosocial, and self-help skills.

Federal law requires infant and toddler service to be multidisciplinary and include participation of other agencies, such as public health and mental health. Services must also have a family focus while developing and following an Individualized Family Service Plan (IFSP). An IFSP includes transition plans to preschool programs and identifies a case manager to assist parents in coordinating services.

Preschool Services

Services for preschool children (3-to-5 year-olds) have included private preschool programs and referrals to other programs, including Head Start, school district preschool programs, and Pre-Primary Impaired (PPI) programs.

Special Education Services

In order to be eligible for special education from preschool on, an Individual Education Planning Committee (IEPC) must decide that a student needs a special program, ancillary, or other related service because of a disability. It is important to note that related services is a very broad category and can include any service necessary to allow the student to benefit from special education. Such services can include transportation services, speech therapy, physical therapy, occupational therapy, counseling services, and others.

There is also a federal law known as Section 504 of the Rehabilitation Act of 1973, which requires schools receiving federal funds to provide services to students with disabilities without discrimination. This is important because the definition of a person with a disability under Section 504 is broader than under state law or the federal Individuals with Disabilities Education Act (IDEA). Some students may be eligible for special education services Under Section 504 even though they are not eligible under the state law and federal IDEA. Some conditions that are protected by Section 504 (and not the others) include ADD/ADHD, AIDS, dyslexia, epilepsy, and mental illness.

Transition Services

At some point, the family and student will want to consider what the student will do once their school program is over. This is done by creating an Individualized Education Program (IEP). Under Michigan's Mental Health Code, the IEP should be initiated as early as age 12, ideally by 14, but no later than 16. Included in the IEP is a statement that indicates the IEPC's consideration of the student's vocational needs.

In the past, there was no preparation or opportunities for work or other life experiences after a special education student graduated or reached age 26. Now, with individualized vocational planning, students have more opportunities. Gone are the days when students were faced only with staying at home, programs offered in local sheltered workshops, or segregated day activity programs or adult activity programs. The development of supported employment offers jobs in integrated settings in which a job coach may be employed to help a worker learn a job or to be sure needed accommodations are provided to attain success in employment. The goal is that the student will become a productive worker in his or her community.

This kind of vocational planning is also known as "transition" planning or services. Transition planning may also include post-secondary education, vocational training, continuing and adult education, adult services, independent living, or community participation. Federal law and the Michigan Mental Health Code require necessary linkages between school services and other community or state agencies that may have a responsibility to provide services for the student.

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How Do I Gain Access to These Services?

As a parent, you may request an evaluation for special education services from your local school district at any time. The evaluation will be used to help determine whether your child is eligible for services. To be eligible for special education, your child must:

- Be between the ages of 0-26
- Have one or more of the disabilities specifically listed in the Michigan Special Education Rules or the federal regulations
- Need special education or ancillary and other related services
- Not have completed a normal course of study and not have graduated

Students who may be eligible for special education are listed in the Michigan Special Education Rules as the following:

- Severely, trainable, or educable mentally impaired
- Emotionally impaired
- Hearing or visually impaired
- Physically and otherwise health impaired
- Speech and language impaired
- Preprimary impaired
- Specific learning disability
- Severely multiply impaired
- Autism
- Traumatic brain injured

Within 30 days, the evaluation by a multidisciplinary team and an individual education plan should be completed. An IEPC meeting should be held, which shall establish the child's eligibility, determine the plan (IEP), and recommend the best placement option for implementing the IEP.



What If a Problem Arises?

Informal meetings and discussions can sometimes resolve issues. If not, a number of due process protections are in place. First, if you disagree with an evaluation, you have a right to request an independent evaluation from someone outside the school system.

If you question whether the present program is appropriate, you can also request a new IEPC to come up with a new plan. As members of the IEPC, parents do not have to sign the IEP if they do not agree with it. If you cannot work out an agreeable plan at the IEPC meeting, you can ask for mediation or an administrative hearing. Such hearings can be very time-consuming and costly, so every effort to resolve differences should be attempted.

If you believe that the school is not doing what is outlined in the IEP, there is a written complaint process that goes first to the Intermediate School District and can then be appealed to the Michigan Department of Education. There are advocacy organizations that can help you resolve differences. These organizations are outlined in the Advocacy Organization section, p. 29. An advocacy organization can make you more familiar with the appeal processes that are outlined in state and federal law.

How Are These Services Paid For?

Just as regular education is provided free to public school students, special education services are provided to students with disabilities. The services are considered part of the "free, appropriate education" that all schools must provide. If your child is a recipient of Medicaid or covered by private insurance, the school district may request payment from the insurer for related services such as speech therapy and counseling. However, you do not have to agree to use your insurance for this purpose, as you may incur financial loss. Financial loss can be in the form of being forced to make co-payments and having cost subtracted from a once-in-a-lifetime benefit, or you may run the risk of the premiums being increased. You do not have to incur any financial loss in order to bill your insurance for the benefit of the school.

B. COMMUNITY MENTAL HEALTH PROGRAMS

There are many services you may need for your disabled child that are not the responsibility of the schools to provide. Learning what other human service systems have to offer in the way of assistance, services, and support can make a tremendous difference both now, and later when your child is no longer in school or living at home.

The state financially supports local Community Mental Health Services Programs (CMHSPs), enabling them to provide a full array of treatment and support services to persons with developmental disabilities. Locally governed CMHSPs are the primary point of entry for all public mental health services in the state. While each community influences the manner in which services are delivered, all must abide by the program standards set by the Michigan Department of Community Health.

Anyone with a developmental disability (as defined by the Mental Health Code) who is eligible for Medicaid is automatically eligible for services from CMHSPs. Whether a person with a developmental disability has private insurance, Medicare, or no insurance, they are still eligible for services. However, the county will prioritize services based upon the severity of the disability and the urgency of the situation. All those in emergency situations (Medicaid eligible or not) will receive immediate crisis stabilization response without having to first proceed through the usual access steps for services.

WHAT IS AVAILABLE?

Emergency Services

All CMHSPs have a crisis stabilization and response service available 24 hours per day, 7 days per week. Crisis stabilization and response should be prepared to respond to individuals experiencing acute emotional, behavioral, or social problems and provide a protective environment for treatment of such problems.

Evaluation Services

All CMHSPs must provide identification, assessment, and diagnosis services to determine the specific needs of the individual and to develop an individual plan of service.

Prevention

Prevention and consultation services serve to inform and educate with the goal of reducing the risk of severe dysfunction.

Person Centered Planning

Once it is determined that a person is eligible for services, the services and support provided by CMHSPs will be determined through a person-centered planning process. This is a highly individualized and person-directed process. It is designed to respond to the expressed needs and desires of the individual and to determine the appropriate services and support. Some services may fall within the responsibility of other systems (i.e. schools, other health plans, other state or county services). In this case, those systems will be identified and referrals will be made to them to assure their provision.

As part of the person-centered process, a person-centered planning meeting will be held to help develop an individual plan. For adults, the individual will decide (as much as possible) when and where the meeting will be held, and who will be involved. The meeting brings together people who care about the person, and are committed to helping the person communicate their vision of a desirable future. The plan could include: where the person wants to live; what kind of employment they may desire; what kinds of friends, relationships and recreational activities they want; how they see themselves as part of their community; and any other experiences they envision for their life.

For children, the Michigan Department of Community Health supports a family approach to service delivery. Thus, the child and family are the focus of service planning and family members play an integral role in the planning process.

Children's Services

If mental health needs have been identified for a child that are not provided by the schools or other service systems, the local CMHSPs may provide it. Examples of services that many CMHSPs provide are respite services in the home or community to give family members much needed breaks, family skill development, in-home support to assist the family in keeping their child at home, support coordination to help find and obtain needed services, Wraparound Services which bring together all service systems needed by a child to provide an integrated delivery approach, and others. In addition, some families who have children with severe disabilities at home are eligible for the Family Support Subsidy Program.

This program provides financial support to families for special expenses incurred while caring for their child. The local CMHSP Board determines eligibility for this program, which is based on disability and income.

Regional Centers

The State of Michigan still provides institutional services at a few locations for people with developmental disabilities who do not have access to services in their community. However, these services are considered a last resort and are generally no longer used. Community alternatives have replaced such services and the numbers of individuals who still reside in regional centers are very small.

Housing

Many CMHSPs provide a variety of housing alternatives. Foster care, group homes, apartment living, and other supported living alternatives now exist. Most service systems are now supporting people in homes of their choice rather than having people move into licensed facilities that are chosen for them. In-home support can be arranged as needed to provide the kind of life experience the person desires. In some cases, the individual is given control over the budget that pays for these services. These arrangements are sometimes self-determination programs. You should check with your local CMHSP to see if such services are available. If not, you should request the ability to live a self-determined life.

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Support and Service Coordination

All CMHSPs provide support coordination, which assists individuals in finding and obtaining needed services including medical, social, vocational, recreational, and community living support. Support coordinators have replaced what used to be called case managers for persons with developmental disabilities.

Assistive Technology

CMHSPs will assist individuals who need adaptive equipment or environmental modifications in order to function to the best of their ability.

Employment and Community Integration

Traditionally, CMHSPs have provided services in local sheltered workshops, adult activity programs or day activity services. Increasingly, more meaningful employment and integrated social opportunities are being provided through supportive employment and community integration programs. In supportive employment, individuals work in their community with the help of a job coach for as long and as much as needed. Other support might include any physical or programmatic accommodations needed in order to make an employment experience successful. In addition, efforts are being made to help individuals become integrated into their communities in other productive ways such as volunteer, recreational, and social activities.

Social and service clubs, churches, and civic activities are some of the ways in which individuals can make a meaningful contribution to their community. Once an individual is no longer eligible for services from their local school system, CMHSPs can assist them in obtaining a valued role in their community.

How Do I Gain Access To These Services?

Every CMHSP works a little differently. It is best to call your county CMHSP program and request services. You will usually find their number listed under county government in the phone book. The intake person will explain the procedures in that county. If you are a Medicaid recipient with a developmental disability, you have a right to services from the CMHSP. If you do not have Medicaid, the CMHSP will provide services based on severity of disability and the urgency of your situation. The CMHSP will determine whether you fall under the definition of having a developmental disability as defined by the Mental Health Code.

If the CMHSP determines that you are not eligible for services because you do not have a developmental disability, they must inform you or whoever applied for services on your behalf that you have a right to a second opinion from the CMHSP Director. If the second opinion also says you aren't eligible, and you are not a Medicaid recipient, there is nothing you can do to appeal the decision. However, if you do receive Medicaid, the CMHSP should provide to you a notice of a right to a Medicaid appeal, and instructions about how to file such an appeal. This is explained in the Medicaid appeal section.

How Are These Services Paid For?

Each county will assess your ability to pay based on income and family size. Fees are assessed on a sliding scale established by the Michigan Department of Community Health. If you have Medicaid, your ability to pay is zero. If you have Medicare or private health insurance, those insurances will be billed for services. If you have to pay deductibles or co-pays, those amounts

cannot exceed the ability to pay amount.

If you wish to contest the ability to pay determination, you can ask for a re-determination in writing to the CMHSP and a re-determination meeting with the CMHSP will be held. If you are not satisfied with the outcome of the re-determination meeting, you can appeal to the Probate Court in the county where you reside.

What if a Problem Arises?

Since all services and support flow from the personcentered plan, the first step to take if a problem arises is to ask for a person-centered planning meeting. You should be aware that if the CMHSP wants to suspend, reduce, or terminate your services, it must give you a written warning. This is called Notice. You must receive it at least 10 days before the date of the change. If you are unable to resolve the problems at the personcentered planning meeting, you have three options. You may 1) file a rights complaint with the Office of Recipient Rights, 2) file a grievance with the CMHSP, or 3) file a Medicaid appeal (if you are a Medicaid recipient). You can use one or all of them, as appropriate. An explanation for each follows.

Recipient Rights Complaint

Anyone who receives services from a CMHSP program has certain rights. Those rights are protected by the Michigan Mental Code and other civil rights laws. Upon receiving services, you should be given a booklet outlining your rights and telling you how to file a complaint. If you think any of your rights have been violated, including the right to appropriate treatment, you should contact the Rights Advisor for that CMHSP program and obtain a complaint form to file with the Office of Recipient Rights. Within five days of filing the complaint, you should receive a letter from the Rights

Office telling you whether they will investigate your complaint. They must finish their investigation within 90 days, giving you reports every 30 days. When they finish it, it is submitted to the CMHSP Executive Director who will give you a report within 10 days telling you whether your complaint is

10 days telling you whether your complaint is substantiated or not and what action will be taken to resolve the complaint, if any.

If you are not satisfied with the report or the timeliness of the investigation, you have 45 days to appeal the decision to the local appeals committee. They must review the appeal and make a decision within 30 days. If you still believe the findings are not consistent with the facts or relevant laws, rules, policies, or guidelines, you have 45 days to appeal to the Michigan Department of Community Health.

If you are not satisfied with the Michigan Department of Community Health's (MDCH) response, you have 21 days to file an appeal in the Circuit Court in the county where you reside. You also have the right to request mediation of your dispute after the Office of Recipient Rights has finished their investigation. If you choose mediation, time frames for responses and appeals stop. If mediation is

not successful, you then have the right to continue with the rights complaint process and pursue your appeal.

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Grievance Process

Anyone who has a complaint about his or her services from CMHSP has a right to file a grievance. This is a CMHSP internal grievance procedure and the CMHSP should give you information about how to file it. You will receive, in writing, the decision of the CMHSP. If you are not satisfied and are a Medicaid recipient, you may request a Medicaid appeal. If you are not a Medicaid recipient, you may appeal to the MDCH Alternative Dispute Resolution process. The MDCH must try to resolve the problem within 15 business days. However, if MDCH decides your situation is an emergency (i.e. services in question will have an immediate and adverse impact upon your health and safety), they must refer your case within one business day for action.

Medicaid Appeals

In order to start a Medicaid appeal, ask for a Request for Hearing form from the CMHSP, complete it, and give it back to them for processing. You will be given notice of a hearing at which you can present evidence to an administrative law judge. You may bring a lawyer with you, but you don't have to have one. If you are not satisfied with the judge's decision, you can appeal it to a circuit court. Since these hearings are more complicated, you may want to ask Michigan Protection and Advocacy Service, a local Legal Aid program, or other advocacy groups for help in this process.



C. FAMILY INDEPENDENCE AGENCY

The Family Independence Agency (FIA) is a state agency that provides assistance to people in need based on income and assets. Some of their programs can benefit people with disabilities, especially those not eligible for CMHSPs or other services.

WHAT IS AVAILABLE?

Family Independence Program (FIP)

The Family Independence Program (FIP) is an income assistance program that provides monetary payments and employment-related services to families with children. Families must meet asset and income standards as well as other criteria in order to receive these payments. Recipients of this payment must also participate in a work program.

State Disability Assistance (SDA)

SDA is a program that offers monetary payments to meet the basic personal and shelter needs of people with disabilities who are not eligible for FIP. These payments are based on income and disability.

Adult Home Help Services

Adult Home Help Services will assist you with necessary daily activities that you cannot perform without assistance. The goal of this service is to allow you to remain in your own home and to avoid placement in a more restrictive setting (e.g. nursing home or adult foster care home). This is accomplished by identifying your natural support system and strengthening it whenever possible. Services may include personal care (e.g. assistance with eating, bathing, grooming, dressing, transferring mobility, and incentingness gare), household care (cleaning)

and incontinence care), household care (cleaning, laundry, meal preparation, and shopping), or assistance with self-administering medications. Recipients of Supplemental Security Income (SSI) or Medicaid are eligible. Others may also be eligible. You choose your providers and FIA covers the cost of the provider jointly.

For Home Help Services, application is made through the local (county) FIA office. Their number is usually found in the phone book under state government offices. 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, conduct a thorough needs assessment, jointly develop a services plan with you, assist with locating providers, authorize services (as appropriate) and complete all necessary paperwork except the physician's certification. A medical certification by a physician or a physician's statement of your need for services is required before authorization can be made for any personal care services. Additionally, all services plans are reviewed and approved by a registered nurse, through FIA.

Before applying for Home Help Services it is suggested that you or your family keep a diary of services provided on a day-to-day basis, and make a list of services provided on an irregular basis (such as haircuts and nail trimming). This can prove very useful when the FIA services worker visits your home to do the needs assessment.

Other Programs

A variety of other programs may also be useful to low-income individuals with disabilities. The State Emergency Relief Program (SER) provides financial assistance to meet emergency needs for food, clothing, housing, utilities, and other essential services. FIA administers the Food Stamp program, which provides coupons that can be used like money to buy food at most grocery stores. Housing-related services include assistance with relocation, ownership, home repair, and legal protection for renters.

How Do I Access These Services?

Any individual, regardless of age, may apply for FIA program benefits. Either you or someone authorized to act on your behalf may apply. An application can be obtained from any local county FIA office in person, by telephone, or by mail. Local offices are usually found in the phone book under state government. After the application is filed, the FIA notifies you of any missing information that is needed to complete the application and, if it is required, the need to schedule an interview. FIA must decide whether or not you are eligible and notify you in writing within a certain amount of time, depending on the program for which you apply.

How Are Services Paid For?

Medicaid pays for services if you are a Medicaid recipient. If you are not eligible for SSI or Medicaid as a result of your income, you may be found eligible for services if you are disabled and meet all other SSI requirements. In those cases, FIA determines the appropriate client fee for services according to income.

What if a Problem Arises?

As with other services provided by Medicaid, the FIA must provide you a notice with appeal rights whenever a service is refused, suspended, reduced, or terminated. You will have a right to a hearing in front of an administrative law judge. You can submit evidence and ask questions about why the services were refused, suspended or reduced. You have a right to bring an attorney to help you. If you are not happy with the judge's decision, you can appeal to the circuit court in the county where you live.

D. MICHIGAN REHABILITATION SERVICES

Michigan Rehabilitation Services (MRS) is a division of the Michigan Department of Career Development. MRS provides career services to people with a wide range of disabilities, including developmental disabilities. MRS works independently or with school programs and CMHSPs to help round out the services and support a disabled person's needs and desires in his or her life. This usually includes employment planning. You may be eligible for MRS services if your disability causes problems in preparing for, finding, or keeping a job. You must also require MRS services in order to work.

WHAT IS AVAILABLE?

At MRS, your can choose to work with a rehabilitation counselor. Together, you and the counselor decide on an employment goal. Assessments may be needed to determine this, such as medical exams, vocational testing, work evaluations, and job try-outs. A plan will be developed that will identify the services that will be needed, who will identify them, and how to determine if they are beneficial. Some services will be provided directly by the counselor or other MRS staff. Other services may be purchased or provided by other agencies. Services provided by the plan may include job-seeking skills training, job placement assistance, accommodations and assistive technology, job coaches, tools, equipment, licenses, job training, prostheses and other medical services, support services such as interpreters, readers, and transportation.

The ultimate goal, of course, is to find the right job. Once that happens, the counselor follows up for at least 90 days to make sure both the employer and you, the new employee, are satisfied. Additional services are sometimes needed. In that case, MRS can begin working with you again to make sure you are able to stay on the job.

How Do I Gain Access to These Services?

Any person with a disability who is interested in receiving job rehabilitation services may call the nearest MRS office. Family members, hospitals, school counselors, mental health professionals, social workers, churches, and other community agencies also may make referrals. For a listing of the MRS office locations across the state, call toll-free (800) 605-6722 (voice) or (888) 605-6722 (TTY). What If a Problem Arises?

If you are not satisfied with a decision made by your counselor about your MRS program, you can appeal the decision. You can try to resolve it informally with your assigned counselor. You can also ask for help from the district manager to resolve the situation. At any time, however, you may ask for a formal hearing from the MRS agency director. You must ask for this within 30 days of the decision that you do not agree with (an impartial hearing officer will send you a copy of his or her decision within 30 days of the date of the hearing). That decision will take effect within 20 days unless the agency director decides to review it. You will be informed if this review is going to take place. If there is a review by the director, you will be informed of the director's decision within 30 days of the review. If you do not agree with the decision, you can file a case in the circuit court in the county where you live. At any time in this process, a recipient of MRS services may call the Client Assistance Program (CAP) for help in resolving problems.

The CAP provides information and advocacy, without charge, to people with disabilities who are receiving or want to receive services under the Rehabilitation Act. The CAP will assign staff to help the individual resolve the problem, and may provide assistance in appealing decisions at the administrative hearing or circuit court level. The toll-free number for the CAP program is (800) 292-5896.

MRS provides disability assessments, vocational evaluations, counseling, job placement services, and job follow-up services free of charge. Other services are purchased from public and private agencies in the community. You are asked to help pay for these services if you are financially able to do so.

There are numerous organizations whose purpose is to help you access the various human service systems. They can be helpful in providing information and steering individuals in the right direction. They can be helpful if there is a problem obtaining needed services and appealing decisions of human service agencies. Many advocacy organizations also provide information and education programs related to disability issues. Some are very proactive in making improvements in the service systems through legislative and other organizational lobbying. A list of some of the advocacy organizations is included in Appendix A.



How Are These Services Paid For?

E. ADVOCACY ORGANIZATIONS

WILL I NEED TO BECOME MY CHILD'S GUARDIAN?

Families are naturally concerned about what will happen when their child turns 18, or when the parent is no longer around or able to advocate and monitor the care of their child. It is important to keep in mind that guardianship is a legal process, in which a public declaration of the individual's incompetence is made. When this is done the individual's rights to make decisions in all or selected areas are stripped away, and the opportunities for growth and true self-determination are severely limited. There are many alternatives to this extreme legal measure that can address whatever limitations an individual with disabilities may have.

WHAT ARE THE ALTERNATIVES TO GUARDIANSHIP?

Representative Payee

If you are a recipient of governmental benefits, (SSI, SSB, Veteran's Benefits, etc.) and are unable or unwilling to handle the funds for whatever reason, a "representative payee" is appointed to manage the money for you. The payee must, by statute, account to the administering federal agency for how the funds are spent, just as a guardian would account to the court for funds of the individual. Thus, there is no need for a guardian to be appointed if the only income is governmental benefits.

Power of Attorney

Generally, a power of attorney is a document in which a person gives legal authority to act on his or her behalf to another person. A DURABLE power of attorney gives the other person power to act even if the individual becomes incapacitated. Many people with developmental disabilities are not incapacitated and are legally able to execute durable powers of attorney.

In 1990, the Michigan Legislature authorized a durable power of attorney for health care. The statute allows any person 18 years of age who is of sound mind to designate someone else to make decisions for them concerning care, custody, and medical treatment decisions. It is important to note that in order to designate a person to make medical decisions through a power of attorney, the individual does NOT need to understand all the medical ramifications of their treatment. They need only understand that they are designating someone else to make medical decisions for them. Many people with developmental disabilities are able to understand this and can avoid the legal process of a guardian appointment by simply making this

Amenities Trusts

Amenities trusts can bring peace of mind to parents and enhance the lives of disabled individuals. Parents who leave money in their will to a trust for their disabled child usually set up these trusts.

For children who depend on governmental benefits and the public mental health system for support to live in the community, amenities trusts can supplement the bare necessity existence that government benefits require. Funds from such trusts can buy medical and dental treatment beyond what Medicaid will pay for, educational or vocational programs not paid for by public systems, recreation expenses or outings that would be impossible on the personal funds allowed by Medicaid, travel to visit siblings, books, phone calls and other non-SSI and Medicaid funded items. Under certain conditions, trust funds can even buy a home and rent it to the individual who is the beneficiary.

One of the important advantages is that trust funds can be used to pay an advocate or other person to regularly monitor the individual for the purpose of ensuring that their quality of care, environment, and support are appropriate for their needs and desires. This is something a guardianship cannot do. There is no requirement that a guardian ever visit their ward. A trust can specify not only that there be monitoring visits, but also what the monitor will address, with a report to go to the trustee of the funds to direct the trustee about the needs of the individual.

Most parents find this to be a far superior method of ensuring their child's care than establishing a guardianship that goes into force after they are gone. Under federal law, these kinds of trusts can also be created for people with disabilities who receive unexpected funds, for example, from a lottery or personal injury lawsuit. In order to make sure that these amenities trusts are valid and not open to question by funding sources, there are legal requirements that must be met. For instance, it must specify that the trust is to be used for amenities only, not for the basic support of the individual that government benefits are paying for. Also, the trustee must have sole discretion over how the funds are to be spent. The trust must be drafted by an attorney who is familiar with these trusts and the laws that regulate them. A parent who is interested in creating an amenities trust for their child with a disability should contact their local Arc for a referral to an appropriate attorney (see Resource Appendix).

23 designation.

Protective Orders

A protective order is an alternative to guardianship that works particularly well when court authorization is needed for an isolated transaction. A protective order may be made if the court determines that the person is unable to manage his or her property and affairs effectively. Any interested party may file it. Further, the law states that a protective order does not affect the capacity of the protected person.

Voidable Contracts

A very real concern for many people with a disabled family member is their vulnerability, which may allow others to take advantage of them. For instance, what if a used car salesman convinces an individual on SSI, with no driver's license, to sign a contract to buy a car? Do you need to be a guardian to get the individual out of the contract? It is true that if a person has a guardian with power over contractual obligations, the contract would be automatically void. However, without a guardian, the contract is still voidable if the individual did not understand what they signed. Furthermore, creditors cannot attach SSI benefits, so the salesman would not be able to collect on it. A phone call to the business explaining these simple facts usually is enough to remedy these situations.



WHAT CAN I DO TO IMPROVE EXISTING SERVICES FOR PEOPLE WITH DISABILITIES?

Individual Advocacy

The best way to assure that you are able to live the kind of life you want and need is to take part in the planning process of the system from which you are receiving services. All systems have an initial planning meeting and it is right at the beginning that effective advocacy can begin. Know your rights in each system and make sure your needs are met. It is specifically stated in the CMHSP contracts with the state that the delivery of support and services will support consumer self-determination and independence. In that system, the person-centered planning process is key. It is important to participate and exercise the right to choose a life you wish. Similar language can probably be found in the other service delivery systems. Schools have IEPC's, MRS has planning meetings, and FIA has initial determination for service meetings. Attend these meetings and advocate for your wishes. You can invite your family, friends, and others important to you to participate in this process.

There are numerous ways in which people with disabilities and their families can advocate for systemic changes and better services. Most organizations now have requirements for consumer and family involvement in the design and delivery of their services. For community mental health services, there are now such written requirements in the law and in the contracts that the Michigan Department of Community Health has with the county CMHSPs that provide services. It is specified that community mental health boards must have consumers and their families represented as members of their boards. Each board must have a method for involving consumers as participants in the planning, performance and management process of the mental health program.

This can be done through advisory boards, by employing people with disabilities, by having a "consumer navigator" to help other consumers through the system, or through other methods. However it is done, it must be identifiable.

You can ask your local mental health board how this requirement is fulfilled in your area. There should be consumer and family involvement in the planning of services, in the development of requests for services, and on evaluation teams that decide what kind of services will be provided and who will provide them. Consumers receiving services should be involved in the evaluation of the services provided by the boards. You can ask your local mental health board how this requirement is fulfilled in your area. Find out how you can be involved in assuring consumer involvement in these and other areas.

Legislative and Administrative Processes

Legislation is frequently introduced that affects people with disabilities. Advocacy organizations keep track of such legislation on behalf of people with disabilities. They often need people to write letters or give testimony on behalf of issues that affect people with disabilities and their families. Stay in touch with your state and local advocacy organizations to get involved in this process (See Advocacy Section, p. 28). You can also initiate a relationship with your local legislators and senators to let them know what you think is needed for people with disabilities to become more independent and integrated into your community. State government officials also have an interest in what service and support is available to consumers and how it is provided. Letters to key officials and attendance at public hearings are effective means of advocacy.



ADVOCATE RESOURCES

The Arc Michigan **1325 Washington Ave. Lansing, MI 48910** (800) 292-7851 (517) 487-5426 www.arcmi.org

This organization provides advocacy, education, and referrals for people with developmental disabilities. There are also local chapters of The Arc Michigan.

Autism Society of Michigan 6035 Executive Dr., Ste. 109 Lansing, MI 48911 (517) 882-2800 (800) 223-6722

The Autism Society provides advocacy, education, training, and referrals to people with autism in Michigan.

Developmental Disabilities Institute (DDI)

Wayne State University
4809 Woodward Ave., Ste. 268
326 Justice
Detroit, MI 48202
(313) 577-2654

DDI provides evaluations, research, training, education programs, and consultation regarding people with developmental disabilities in Michigan.

Disability Network 877 East Fifth Ave. Flint, MI 48503 (810) 742-1800

The Disability Network advocates and provides services to help people live independently in their communities.



Epilepsy Center of Michigan **26211 Central Park Blvd., Ste. 100 Southfield, MI 48076-4154** (248) 351-7979 (800) 377-6226

The Epilepsy Center provides information and referrals, workshops, training, and advocacy services for people with epilepsy and other disabilities.

The following is a list of service and advocacy organizations for people with disabilities that may be helpful.

Michigan Association of Centers for Independent Living (MA CIL)

780 West Lake Lansing Rd., Ste. 400 East Lansing, MI 48823(517) 333-4253

MACIL promotes system change through a common set of independent living values. It supports a network of CIL's throughout the state, provides professional training and support to its members, and advocates for the rights of people with disabilities.

Michigan Disability Rights Coalition

740 W. Lake Lansing Rd., Ste. **400** East Lansing, MI **48823-2753** (517) 333-2477

MDRC is a statewide network of individuals and organizations that advances the issues of Michigan's disability community through grass-roots activity, public education, and advocacy.

Michigan Protection and Advocacy Service, Inc. **4095 Legacy Parkway, Suite 500 Lansing, MI 48911-4263** (517) 487-1755 (800) 288-5923

MPAS provides legal and other advocacy services, information and referral, education and training, and publications for people with disabilities.

UCP Michigan

3401 E. Saginaw, Suite 216 Lansing, MI 48912(517) 203-1200
(800) 828-2714

UCP Michigan provides legislative advocacy, information and referral, training. It also offers workshops on cerebral palsy and self-advocacy.