METRO - WIDE RESOURCE GUIDE

FOR CHILDREN AND ADULTS WITH DEVELOPMENTAL DISABILITIES AND THEIR FAMILIES

COUNTIES PARTICIPATING

ANOKA
CARVER
DAKOTA
HENNEPIN
RAMSEY
SCOTT
WASHINGTON

April 2000
INTRODUCTION

The purpose of this guide is to provide basic information to individuals with developmental disabilities, their parents, families, guardians, and conservators about the support services that may be available to them. As you read through the guide remember that there is more to know about each service and that there are other support services which are not included in the guide. If you wish to get more information, you should contact your county social worker or social services department.

A definition is provided in the Glossary for terms used in the guide that are followed by a star*. The glossary also includes some common terms which people use when they are providing services for with people with developmental disabilities.

Following the description of services is a guide to providers. Each county social service department has information about the providers in their county. You can contact your county social service department or county social worker to get this information.

• You can find out how many people get services from a certain provider.
• You can find out how many staff people a provider has working for them.
• You can find out about vulnerable adult* reports that have been substantiated (found to be true).
• You can find out if they have had any licensing violations.
Phone numbers for the seven counties in the metro area are listed below.

**Anoka County**  
(612) 422-7054

**Ramsey County**  
Children (651)266-4500  
Adult (651)266-4458

**Carver County**  
(612) 361-1600

**Scott County**  
(612) 445-7751

**Dakota County**  
(612) 891-7400

**Washington County**  
Children (651) 430-6457  
Adult (651)430-6484

**Hennepin County**  
(612) 348-5719

There are organizations that can assist you with finding information regarding services and providers or if you have questions or concerns about the services you are receiving. The following organizations are just a few of the many organizations that offer such services.

**Arc Anoka and Ramsey**  
(651) 783-4958

**Disability Law Center**  
(612) 332-1441

**Arc Hennepin/Carver**  
(612) 920-0855

**PACER**  
(Parent Advocacy Coalition for Educational Rights)  
(612) 827-2966

**Arc Suburban**  
(651) 890-3057

**Twin Cities Autism Society**  
(651) 647-1083

**ACT**  
(Advocating Change Together)  
(651) 641-0297
If you suspect or witness abuse or neglect of a child or vulnerable adult or if you are a child or vulnerable adult experiencing abuse or neglect you should call the number for your county listed below.

**Anoka County**
Child Protection  
(612) 422-7125
Adult Protection  
(612) 422-7070

**Carver County**  
(612) 361-1600

**Dakota County**  
(612) 891-7400

**Hennepin County**
Child Protection  
(612) 348-8526
Adult Protection  
(612) 348-3552

**Scott County**
Child and Adult Protection  
(612) 445-7751

**Ramsey County**
Adult Protection  
(651) 266-4012  
(651) 266-4500

**Washington County**
Adult Protection  
(651) 430-6484  
Child Protection  
(651) 430-6457
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This section provides answers to some basic questions about services.

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SUPPORT SERVICES

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What is Day Habilitation?

Day Habilitation services provide training, assistance, and support to people with developmental disabilities* who are learning about lots of different things like:

- How to get and keep a job
- How to become a volunteer
- How to communicate with others
- How to take care of yourself
- How to get around in the community
- How to get along with other people
Sometimes services such as speech and occupational therapy are available through these programs.

Where would I go for this service?

It may be in a building where lots of other people are going to learn or it may be in a community work place. It depends on what assistance from staff you need and what skills you are learning.

Can I use this service?

To get this service you have to

- Have a Developmental Disabilities county social worker
- Have finished your public school education

When would I go to this?

You would usually go Monday through Friday during the day. You may go full or part-time.

What kind of things would I learn about?

This depends on what you would like to learn about. You, your county social worker, and other people who help you make decisions will make a plan about what kind of things you will learn.
How much help will I get?

It depends on what your needs are. You may have someone with you all the time if you are learning a new skill. You may have someone come only once in a while if you are working at a job that you can do well.
IN-HOME SUPPORTS

What are In-Home Supports?

Staff people come to your home to assist and support you with your daily activities in order to help your family care for you.

What will staff do?

Staff will help you while you learn new skills. They may talk with you and your family* to help plan what things you should learn and how to help you learn them.

Who can get in-home supports?

To get in-home supports you need to
- Live with your family*
- Have a Developmental Disabilities county social worker

You also need to be on
- Medical Assistance*
- Receiving waivered services*
How much help can I get?

It depends on what skills you are learning and how much assistance and support you need to learn these skills. You, your family*, your county social worker, and your guardian/conservator*, will decide on how often staff need to come.

When will staff come?

It depends on what you, your family*, your county social worker, and your guardian/conservator* decide. A staff person may come every day or just a few times a week.
What is respite?

Respite service can be used when your parent or the family member who care for you takes a break or a vacation and cannot care for you. A respite provider or staff person will be available to give you the assistance and support you may need.

Will I stay in my home?

You may stay in your home or go to someone else's home.
**Will** this be for a long time?

This is usually for a short period of time, a weekend or a few days. It could be for a week or longer.

**How often can I use** respite?

You, your family*, your county social worker, and your guardian/conservator* will decide together on how much respite you can use.

This also depends on how the respite service is being paid for. Your county social worker can tell you more.

**Can I get** respite services?

To get respite services you have to

- Have a Developmental Disabilities county social worker
- Be screened* and eligible* to receive the service

The county sometimes has the money to pay for this service. Sometimes families choose to pay for this service themselves.
What kind of things will staff or the respite provider do?

They will know how to assist and support you with your everyday tasks and activities. They make sure that you stay healthy and safe.

If I go to another home, where will I sleep?

There will be a bed there for you. You may have your own room or you may share a room.

What would I do there?

You will do many of the things that you do with your own family now.

You and your respite provider will talk together about the things that you like to do.

Will they know about my medications?

Yes, they will know all about the medications you take and any other health Issues that you have.
Semi-Independent Living Services (SILS)

What are Semi-Independent Living Services (SILS)?

This service is for people who are learning to live independently in the community. A staff person will come to your home to assist and support you while you learn the skills you need in order to live independently in the community.

What sort of skills will they help me with?

It is staff's job to assist and support you. You, your family, your social worker, and your guardian/conservator* will decide together on how staff will help you. Staff could help you with:

• Budgeting and paying bills
• Cooking

• Shopping

• Running a house or apartment

They can also help you learn about your community.

**How often will staff come?**

It depends on what supports and assistance you need. A staff person may come to your home for a few hours every day or only once a week for a few hours.
How do I get this service?

You have to have a Developmental Disabilities county social worker. The county that you live in will pay for the service if there is money available.

Each county has a limited amount of money and you may have to wait to receive this service even if you are eligible. Some families choose to pay for this service themselves.

Will staff take me out to activities?

Staff may go with you into the community to help you learn new skills. Staff can help you learn how to get to activities on your own. They may help you do things that you cannot do on your own. They are there to support your independence. It is not usually their job to take you to activities or to stay with you if you do not need their assistance.

Will I know the staff person who comes?

You will usually get a chance to meet the staff person before they start working with you. You may have the same staff person come all the time or you may have a few different staff people that come.
What are Supported Living Services (SLS)?

It is a service for people who need staff to help them with their daily activities and tasks.

Where do people live who receive Supported Living Services?

People live in many different places
- In a home with others
- With foster parents*
- With a roommate or friend
- By themselves

How will staff help me?

Staff will help and support you with anything that you need help with or cannot do on your own. Staff can help with
♦ Shopping

♦ Cooking

♦ Managing money

♦ Taking medications

♦ Dressing and other self-care skills

♦ Keeping your home clean
How much help will I get?

It depends on how you need staff to assist you. Staff may stay with you all the time or come only once in a while. Each person is different and the amount of help they need is different. You, your family*, your county social worker, and your guardian/conservator* will decide how much help you need.

What kind of rules will there be?

When people live together they need rules so that everyone is treated fairly. Even if you live alone there will be rules to follow. You have the right to know the rules and to be part of making up the rules.

Will I have to share a room?

It depends on where you decide to live. Some places may have rooms for each person.
In some places, people share rooms.

**bo I have to live there if I don't like it?**

Sometimes people have problems with where they live. Often the problems can be solved. If the problems cannot be solved you can always find another place to live. This may take time though. Your county social worker will help you find a place.

**Who will cook and clean?**

You will probably have some responsibilities for helping out and doing chores. After all, it will be your home.

**How do I get Supported Living Services?**

Supported Living Services are paid for through the waiver program. You have to be part of the waiver program to get this service.
**What is the waiver program?**

The waiver program pays for services so that people with developmental disabilities* can live in the community. The program pays for *services based* on your individual needs. The money for the waiver program comes from the federal government and the state government.

**Who can be part of the program?**

People of all ages with developmental disabilities* that are eligible* can be part of the program.

**How can I be part of the "waiver" program?**

You have to have

- a developmental disability or a related condition,
- a Developmental Disability county social worker,
- and be on Medical Assistance*.

Your county social worker will then have a *screening* to determine if you can be part of the "waiver" program.
What is a screening?

A screening is a meeting where your county social worker asks you and your family a set of questions about what your needs are. The answers get written down on a form called a screening document*.

What happens next?

There are many people waiting to be part of the waiver program. There is a limited amount of money to pay for the waiver program. It may take some time before you can be part of the program and get a "waiver." The answers on the screening document help the county determine if you are eligible. The answers also help the county decide when you can be part of the "waiver" program.
The Waiver Program

The Waiver Program's real name is Home and Community-Based Services for Persons with Mental Retardation or Related Conditions (Developmental Disabilities Waiver Program). This program began in 1984. It was created for people who were moving out of large institutions that were closing and to prevent people from having to move into an institution. The program pays for support services so that people can live in the community. The rules for using this money are different from the program that pays for people to live in institutions. The rules are "waived" meaning the rules are less strict. That is why it is called the "waiver program." People who are part of the program have a "waiver."

All people with a developmental disability* who need the same care that people get in an Intermediate Care Facility for People with Mental Retardation (ICF/MR) and are on Medical Assistance may be part of the waiver program.

Some of the money for this program comes from closing large institutions. The money that would have paid for people to live in the institution goes to the waiver program. About half of this money comes from the federal government. The state government pays for the rest of the cost of the program.
To be part of the program you have to go through a screening* process to determine if you are eligible*. Your county social worker conducts the screening with you and your family and your guardian/conservator. The Department of Human Services looks at the screening document and decides if you fit the rules of the "waiver program." If you are eligible your name is then added to the list with the others who are also waiting to get a "waiver."

Because there is a limit on money for the program not everyone can get a waiver right away. The county checks with people regularly to see if they still need or want to get a "waiver."

Each year the state decides how many "waivers" the county gets to give out to people who are waiting. The county looks at many things when they decide who gets a "waiver." Some of the things that they look at are

- What supports and other services you and your family get now
- How much assistance you need
- What kind of help you are asking for
- The cost of what you need
- Your age
The county also looks at how long you have been waiting when they are making their decision.

You may get some services without having a waiver. Your county social worker or your county social service department can tell you about these. Some of these programs are Medical Assistance home care, personal care attendant (PCA), county paid respite, parent case management, Family Support Grant, and vocational services.
This glossary includes definitions for some of the words used in the guide. There are also definitions for some words which people use when they provide services to people with developmental disabilities.

**Adoptive Parent:**
Your adoptive parent is the woman or man who chose to have you as their child. They went to court to legally have the right to be your parent.

**Advocate:**
This is a person who helps you protect your rights.

**Biological Parent:**
A biological parent is someone who you are related to through birth. Your biological mother is the woman who gave birth to you. Your biological father is the man who helped create you in your biological mother’s body.

**Case Management:**
This is what the work that your county social worker does is called.

**Conservator:**
A conservator is a person who has the legal responsibility to make sure that you are protected and safe. They can make some decisions for you but you still have the right to make some of your own decisions. You have the right to vote even when you have a conservator. Often the conservator will be a member of your family like a parent or brother or sister.
County Social Worker:  
You may call them case managers, service coordinators, or social workers. It is their job to help you get the services that fit your needs and wants. They can explain the services, tell you about different providers, and help you fill out applications.

Developmental Disability: 
A developmental disability is a disability like mental retardation, which may affect how well you are able to do some tasks or activities. Disabilities like autism and cerebral palsy are also called developmental disabilities.

Eligible: 
To be eligible means that you meet the rules of the program

Family: 
People have all sorts of different kinds of families. You may have people related to you like your biological parents, brothers, sisters or uncles in your family. Some people have adoptive parents or foster parents and foster brothers and sisters as their family. Some people have stepparents and step-brothers and sisters in their family.

Federal Government: 
This is the government of the United States, which is in Washington, D.C. This government makes the laws for all people living in the United States. The president is the elected leader of this government.

Foster Parent: 
Your foster parent is the man or woman who is taking care of you because they choose to care for you. They have permission from the county to provide this care. Some people live with foster
parents for many years. Some people live with foster parents for just a short time, like a few months.

Guardian:
A guardian is the person who has the legal responsibility to make sure that you are protected and safe. Often this person will be a family member such as a parent or brother or sister. Sometimes your county social worker or other professional may act as your guardian. You may also be your own guardian.

ICF/MR:
The letters mean Intermediate Care Facility for people with mental retardation. An ICF/MR could be a very large building with a hundred people living there or it could be a small building with only a few people living there.

Interdisciplinary Team:
Some people just say team. You, your family, your guardian/conservator, your county case manager, staff, and other people who care for you are part of the team.

Medical Assistance:
Medical Assistance is a program that provides health care to people who do not have the money to pay for it themselves. You may have to pay for part of the cost yourself depending on how much money you make.

[For individuals less than 18 year of age eligibility for Medical Assistance is determined by parental income. Parents may be required to pay a fee in order to be eligible for services. Families have the option of purchasing services on a private fee basis if they chose.]
**Mental Retardation:**
A score of 70 or below on an IQ test that measures how you think and what you know.

**Ombudsman:**
It is the ombudsman's job to make sure that provider and their staff are providing the highest quality of care to their clients.

**Provider:**
This is the person or agency that provides the service. They are responsible for hiring and training staff.

**Screening:**
This is when your county social worker asks you questions about your needs and abilities. They will ask about what services you currently are using and what services you would like to get. You and your family, or guardian/conservator will be there to help answer the questions.

**Screening Document:**
This is the form with all the questions that the county social worker asks when they are doing a screening.

**Services:**
The different programs of assistance and support you can get are called services. Some of the different services you can get are:

- Day Habilitation
- Supported Living Services
- In-Home Supports
- Respite Care
- Semi-Independent Living Services

You can ask your county social worker about the other services.
Staff:
These are the people that work directly with you. Sometimes they are called direct service workers or direct service professionals, or they can be personal care attendants (PCA).

State Government:
This is the government that makes the laws for hMnnesota. The governor is the elected leader of this government.

TEFRA:
Authority to consider Medical Assistance eligibility for children under 18 years of age based on the child's income.

Vulnerable Adult:
A vulnerable adult is a person that is not able to protect himself or herself from being harmed or taken advantage of.

Waivered Services:
Services that are paid for by the waiver program that help people with developmental disabilities to live in the community.
COMMON ACRONYMS

AAMR: American Association on Mental Retardation
ADA: Americans with Disabilities Act
ARC: Association for Retarded Citizens
CP: Cerebral Palsy
DD: Developmental Disability
DHS: Minnesota Department of Human Services
DTAH: Day Training and Habilitation
E/BD: Emotional/Behavior Problems
ECFE: Early Childhood Family Education
ED: Emotionally Disturbed
ELP: Essential Lifestyle Plan
EMH/R: Educable Mentally Handicapped/Retarded
EPS: Early and Periodic Screening
FAE: Fetal Alcohol Effect
FAPE: Free Appropriate Public Education
FAS: Fetal Alcohol Syndrome
FERPA: Family Education Rights and Privacy Act
GRH: Group Residential Housing
HCBS: Home and Community Based Services
ICF/MR: Intermediate Care Facility/Mental Retardation
IDEA: Individuals with Disabilities Education Act
IDT: Interdisciplinary Team
IEP: Individual Educational Plan
IFSP: Individual Family Service Plan
IHP: Individual Habilitation Plan
IJP: Individual Justice Plan
IPP: Individual Program Plan
IQ: Intelligence Quotient
ISP: Individual Service Plan
ITP: Individual Transition Plan
LRE: Least Restrictive Environment
MA: Medical Assistance
MH: Mental Health of Mentally Handicapped
MI: Mental Illness
MR/RC: Mental Retardation and Related Conditions
MR: Mental Retardation
MSA: Minnesota Supplemental Assistance
OASDI: Old-Age, Survivors and Disability Insurance (also RSDI)
OT: Occupational Therapy
PCA: Personal Care Attendant
PCM: Parent Case Management
PCMR: President's Committee on Mental Retardation
PCP: Person-Centered Planning
PFP: Personal Futures Planning
PKU: Phenylketonuria
PL: Public Law
**PSG:** Parent Support Grant
PT: Physical Therapy
QA: Quality Assurance
QMRP: Qualified Mental Retardation Professional
    Retarded
RSDI: Resident Survivors Disability Income
RTC: Regional Treatment Center
SILS: Semi-Independent Living Services
SLS: Supported Living Services
SSA: Social Security Administration
SSDI: Social Security Disability Insurance
SSI: Supplemental Security Income
SW: Social Worker
TBI: Traumatic Brain Injury
TEFRA: Tax Equity and Fiscal Responsibility Act
TDD: Telecommunications Devices for the Deaf
VA: Vulnerable Adult or Vulnerable Adult Report
CONSUMER RIGHTS

Support Services to individuals with developmental disabilities and their families are described in Minnesota State Statue. The following is the consumer rights section from statue 245b which governs many of the support services listed in the guide.

CONSUMER RIGHTS
(Minnesota Statute 245b.04 Subdivision 1)
License holder's responsibility for consumer's rights. The license holder must:

1) provide the consumer or the consumer's legal representative a copy of the consumer's rights on the day that services are initiated and an explanation of the rights in subdivision 2 and 3 within five working days of service initiation. Reasonable accommodations shall be made by the license holder to provide this information in other formats as needed to facilitate understanding of the rights by the consumer and the consumer's legal representative, if any;

2) document the consumer's or the consumer's legal representative's receipt of a copy of the rights and an explanation of the rights; and

3) ensure the exercise and protection of the consumer's rights in the service provided by the license holder and authorized in the individual service plan.
SERVICE-RELATED RIGHTS
(Minnesota Statute 2456.04 Subdivision 2)
A consumer's service-related rights include the right to:

1) refuse or terminate services and be informed of the consequences of refusing or terminating services;

2) know, in advance, limits to the services available from the license holder;

3) know conditions and terms governing the provision of services, including those related to initiation and termination;

4) know what the charges are for services, regardless of who will be paying for the services, and be notified of changes in those charges;

5) know, in advance, whether services are covered by insurance, government funding, or other sources, and be told of any charges the consumer or other private party may have to pay; and

6) receive licensed services from individuals who are competent and trained, who have professional certification or licensure, as required, and who meet additional qualifications identified in the individual service plan.
PROTECTION-RELATED RIGHTS.
(Minnesota Statute 245b.04 Subdivision 3)

The consumer's protection-related rights include the right to:

1) have personal, financial, services, and medical information kept private, and be advised of the license holder's policies and procedures regarding disclosure of such information;

2) access records and recorded information;

3) be free from maltreatment;

4) be treated with courtesy and respect for the consumer's individuality, mode of communication, and culture, and receive respectful treatment of the consumer's property;

5) voice grievance, know the contact persons responsible for addressing problems and how to contact those persons;

6) any procedure for grievance or complaint resolution and the right to appeal under section 256.045;

7) know the name and address of the state, county, or advocacy agency to contact for additional information or assistance;

8) assert these rights personally, or have then asserted by the consumer's family or legal representative, without retaliation;

9) give or withhold written informed consent to participate in any research or experimental treatment;

10) have daily, private access to and use of a non-coin-operated telephone for local calls and long-distance calls made or paid for by the resident;
11) receive and send uncensored, unopened mail;

12) marital privacy for visits with the consumer's spouse and, if both are residents of the site, the right to share a bedroom and bed;

13) associate with other persons of the consumer's choice;

14) personal privacy; and

15) engage in chosen activities.
QUESTIONS FOR PROVIDERS

These are some questions that you may wish to ask the provider directly when you are making a *decision* about services.

- How experienced are your staff people? or How long have staff been employed here on average?
- How can I be involved in making *decisions* that affect me?
- How are staff people taught to promote self-determination?
- How are staff people taught to listen to me?
- What should I do if I have a concern?
- How many different staff would work with me?
- What is the staff ratio?
- What sort of training do new staff members receive before they can start working?
- What kinds of activities are people involved in?
- What do you charge for your services?
- How do I get to be involved in making decisions about the support *services* I need? How do you involve family in making decisions about supports?
- How often do staff people receive training once they are employed by your agency?
• How does your agency ensure that staff people actually use what they have been taught in training?

• In what ways and in what roles are families currently involved with your agency?

• How often do staff people communicate with family members to let them know that things are going well? Are there routine updates?

• What type of emergency medical training do staff receive? Does everyone employed by your agency get this training as well as regular updates?

• Describe how staff support individuals/families in making informed choices and decisions?

• How do you ensure the health and safety of those you serve? How do you determine the vulnerabilities of the people you serve and how to protect them?

• What training do staff receive to ensure that at all times they respect and support the rights of consumers?

• How do I contact staff after work hours? Is there an emergency number?

Every provider is required to conduct satisfaction surveys of the people they serve. You can contact a provider and ask them to send you a copy of the results of their most recent survey.
IF YOU ARE CONSIDERING:

Day Habilitation Services:

• Please describe your program to me.
• How many people have jobs in the community?
• Who decides where I will be working?
• Where do other people work?
• What sort of activities or work is there for people who do not work in the community?
• What hours during the day are people in your program?
• How do people get to work?
• What health and safety precautions are followed?
• What is your procedure for emergencies? How would you notify parents and family?
• How do I get paid? How much is the pay? Does the employer or the day program pay me?
• Do people work together in groups or by themselves?
• Can I work in the evenings?
• Do you have physical therapy (PT), occupational therapy (OT), or speech therapy?
In-Home Supports:

- Please describe your program to me.
- Who will train staff?
- What if staff do not come when they are scheduled?
- How flexible are you regarding schedules?
- How do you screen your employees?
- Can I meet the people before you hire them?
- If staff cannot come who will be responsible for covering hours? Would you expect family to cover hours?

Respite:

- Please describe your program to me.
- Who will provide transportation?
- How often can you provide services to me?
- What activities will staff do with me?

Semi Independent Living Services:

- Please describe your program to me.
- How many hours a week do you provide services?
- What will you teach me?
• How do you decide what skills I should learn?
• How do you decide on activities to go to?
• How happens if I need short term more intensive support?
• Are you available during emergencies by pager?
• Can you take me out into the community to activities?

**Supported Living Services:**

• Please describe your program to me.
• What do people do in their free time?
• Can I spend some time here and get to know people before I decide to move here?
• What furniture do you provide? What services do you provide?
• Will you help manage finances?
There are other resources available which have additional information about support services, how to select providers, how to access services. Below is a list of some of these resources and where to get copies of them.

**Through Asking The Right Questions ...You Can Reach Your Destination**

- **Institute on Community Integration, University of Minnesota and Developmental Disabilities Division**
  - Available from Hennepin County Developmental Disabilities Division

- **Residential Services - A Guide to Getting What You Want**
  - Available from Arc Hennepin County

- **Residential Assessment**
  - Available from Arc Hennepin County

- **Evaluating Provider Agencies - A Sample Checklist**
  - Available from Arc Hennepin County

**Finding the Support You Need**

- **Department of Human Services, Blue Earth County, Dakota County, Olmstead County**
  - Available from Dakota County Social Services

**Waivered Services Program for Persons with Mental Retardation and Related Conditions**

- **Minnesota Department of Human Services and Arc Minnesota**
  - Available from Minnesota Department of Human Services