Module 3

Summary

This module will provide information on grassroots organizing, resources, and the political process so that participants can use a template to write an individual plan to affect systems change.

Learning Objectives

Key points for this section:

- Demonstrate knowledge of:
  - Grassroots organizing.
  - Coalition building.
  - The political process.

- Development of strategies for an individual action plan.

- Demonstrate the ability to use directories, HHSS resources, and networking to implement action plans.

- Describe ways to utilize the expertise of other advocates.
Learning Outcomes

At the end of this module, participants will be able to:

- Identify some of the waivers in Nebraska and how they differ from traditional Medicaid funding.
- Develop an individual action plan.
- Discuss strategies for networking and developing partnerships.
AGENDA Module 3  
Leadership Training for Individuals with Disabilities and Family Members  
Day 2 continued

This module will build on the earlier sessions and offer tools for advocacy in Nebraska. Topics include how the system works/doesn’t work and resources for impacting that.

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<td><strong>MARK SMITH</strong></td>
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</table>
How To Be An Effective Advocate

Deb Weston, The Arc of Nebraska
Kathy Hoell, Nebraska Statewide Independent Living Council
Brad Mouwans, Nebraska Advocacy Services

Roadmap

• A little bit about us
• Tell us a little about yourself

System Advocacy Activities & Resources

• Education System
  Early Childhood Education
  Regular Education
  Special Education Supports and Services
  State Services (Rehabilitation Act, Section 504)
  Vocational Rehabilitation
• Disability Support Systems
  See Module 2, pp 11, 15, Appendix B and C pp1-3
• Behavioral Health Services
  See handouts in blue folder
• Public Policy & Legislative Advocacy
Grounding

- Need to be grounded
  - "If you don't know what you stand for, you'll fall for anything"
- It's a **PROCESS**

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The Community Imperative:
A Statement Against Institutionalizing
Any Person Because Of A Disability

Center on Human Policy, Syracuse University

*This version of The Community Imperative was developed by and for self-advocates in March 2000.*

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Community Imperative

In Terms of Human Rights:

- All people have basic human and legal rights
- These rights must not be taken away just because a person has a mental or physical disability
- Included in these basic rights is the right to live in the community
Community Imperative

In terms of education and support services:

- All people are valuable
- All people have strength and abilities
- All people have the right to services in their lives that support these strengths and abilities
- These supports are best provided in the community
- So: To meet basic human rights and get the best services, all people, no matter what their abilities, have the right to live in the community.

Systems

- A system is a system is a system, regardless of "context" (e.g., children, developmental disability, behavioral health)
  - Hierarchical
  - Rule-bound
  - Designed to maximize efficiency
  - Although all systems have gaps and are impacted
  - Need to know where entry points are and whom to contact

Systems

- Systems are unlikely to change by themselves, they need some outside stimulus
  - That's where ADVOCACY comes in
- Systems have walls and barriers, but with advocacy, those barriers can be overcome and diverted
Additional Information and Resources

EDUCATION
- The Arc of Nebraska and Local Chapters
- Rule 51, Nebraska Regulations for Special Education Services and Supports
- Rule 55, Nebraska Regulations for SPED Due Process
- Parental Rights
- Nebraska Special Populations Office Staff/Contacts

Additional Information and Resources

DISABILITY SUPPORT SYSTEMS
- Health and Human Services System Contacts
  - Administrative Contacts Sheet
- Nebraska Health and Human Services
  - Map of the 5 Service Areas
- Map of the Developmental Disability Regional Councils of the Nebraska Planning Council on Developmental Disabilities

Additional Information and Resources

- Nebraska Health and Human Services System (HHSS) Waiver Matrix
  - What Is a Waiver?
- NAC 205, (Nebraska Administrative Code) regulations of Nebraska Developmental Disabilities Services within HHSS

4
MONEY FOLLOWS THE PERSON

What is Money Follows the Person?
It is a concept that would allow the Medicaid dollars to follow the person, so that people who are living in nursing homes or other institutions could have the money "follow them" as they move out into the community based services. It is a bill that was initially introduced by Senator Tom Harkin (D-Iowa) but now the Center for Medicaid & Medicare Services (CMS) have initiated it as a grant program for states to "rebalance" their Medicaid budget.

MONEY FOLLOWS THE PERSON

Why do we need it?
A large portion of the money spent in the Medicaid system is for long term care. But, an unequal portion of the funds is for Home & Community Based Services (HCBS). The majority goes for Nursing Homes, ICFMR's, and other institutions. Most people that need long term services and supports would prefer to receive them in home and community settings rather than in institutions.

MONEY FOLLOWS THE PERSON

Why do we need it?
To simplify the system, to have the system lead by the people, not the people lead by the system
VOTING IS POWER!

What is HAVA?
- HAVA is the Help America Vote Act
- Congress' response to 2000 Presidential election
- Provides secret vote for all
- AutoMark voting system in each polling place
- Touch-screen, large buttons, audio, "puff & sip" capabilities

Population Percentages
American Association of Retired Persons (AARP) 14%
Labor Unions 9%
African-Americans 13%
Latino/Hispanic 14%
People with Disabilities 20%
Voting Participation Rates

- American Association of Retired Persons (AARP) 80%
- Labor Unions 85%
- African-Americans 70%
- Latino/Hispanic 70%
- People with Disabilities 35%

There are 256,000 people with disabilities in Nebraska.

25% of the Voting Age Population in Nebraska are people with disabilities.

Approximately 21,230 self-identified people with disabilities ACTUALLY voted in the last general election.

VOTE AS IF YOUR LIFE DEPENDED ON IT... BECAUSE IT DOES.

--JUSTIN DART
Exercise
Read the Lobbyist article
- What are the similarities between these big lobbyists/firms and us?
- What are the differences?
- What can we learn from their example?
- What are our strengths?
- What are our weaknesses?

Strategies for Effective Advocacy

RELATIONSHIP BUILDING
Build a relationship with your senator(s) and other policymakers (for example, Mayor, City Council, other governmental officials)
- "Gross the wheels" of communication (it's a 2-way street)
- Starts to build trust
- Lets them know you exist and you have valuable information
- Enables you and your senator to understand each other's position(s) and viewpoint

Strategies for Effective Advocacy

COMMUNICATION
Effective advocacy also requires communicating with your senator(s) and other policymakers
- Without communication, policymakers won't have complete information and won't know your perspective
- Communication should be on-going—follow up
- Many different methods (for example testifying at a hearing, meetings with senator(s), writing letters/phone calls/legis)
Strategies for Effective Advocacy

ADVANCING YOUR PERSPECTIVE
Advocacy represents the means to add your input into the policymaking process
- Data drives policy, but only gives a certain picture of reality
- Good policy accounts for reality, how policies impact people “on the ground”
- Information and information diversity is essential to creating effective policy

What is Advocacy
- Advocacy is an exercise in relationship building
- Advocacy is all about communication
- Advocacy is providing your perspective or point-of-view to an issue of interest to you in an effort to influence or advance policy outcomes or attitudes

Strategies for Effective Advocacy
Set goals
- What do you want to happen?
- What are the essential things that have to happen—what are the essential components of the new policy that will satisfy you?
- What do you want the policymaker to do?
- Is there something that he/she can do? Who is the appropriate person to address the issue?

“You can't always get what you want, but if you try sometimes, you just might find, you get what you need”
Strategies for Effective Advocacy

Communicate Strategically
- Have a plan of what you want to say to policymaker
  - Tell them what you want them to do and why
  - Make sure your points and solutions make sense, are consistent, and are within his/her authority
  - You only have 15 minutes or so, so try not to go too far off-topic
- Provide good rationale for your demand
  - Make sure you can back up your statements
  - Bring in outside information if you can
  - Be prepared to answer questions or defend your position—think ahead about what opponents might claim

Strategies for Effective Advocacy

Stay informed
- Stay current on the issue(s)
  - Any new information you come across
  - Where the bill is in the legislative process
  - Any amendments? By whom?
- Resources:
  - www.uniconne.com/ne.us
  - www.nebraskaadvocacyervices.org
  - www.nebraskapolicycenter.org

Strategies for Effective Advocacy

Follow up with policymaker
- Keep in contact
  - Let them know you’re watching
  - Hold them accountable
  - Makes you better able to respond to new developments
  - Reinforces that relationship
  - Policymakers see you as a resource
Strategies for Effective Advocacy
Keep in touch with advocacy organizations
- You don’t have to do all the heavy lifting
- Prevents burnout
- Access to information and updates
- Benefits them, too
  - Widens their information and resources base
  - Allows easier coordination to bring strength in numbers to the public dialogue for example a legislative hearing—LB 1046, LB 1063

Strategies for Effective Advocacy
• Strength in numbers
  - Legislative pressure (e.g., votes, calls, letters, testimony) LB 1063
  - Display (e.g., lots of support shown during hearings, rallies, meetings) LB 1248
• Unlikely to get success right out of the chute
  - Process takes time, need to build support—sometimes you have to hit the wall a few times before it comes crashing down

Things to keep in mind regarding Legislative Advocacy
• 1 person can make a difference
  - Lands adoption records bill passes
• 1 letter can make a difference
  - LB 770 foster care children bill passes
  - LB 1063
• 1 coalition can make a difference
  - LB 1248 amendments pass
• 1 senator can make a difference
  - LB 1069
• 200 voices can make a difference
  - LB 1063 & LB 1248 pass
  - LB11900 phone calls
Things to keep in mind regarding Legislative Advocacy

- Develop coping mechanisms
  - Burnout and frustration *BAD*

Tips To Get You Started

- Search for advocacy organizations in your area or statewide
- Get on listservs and internet groups
  - Yahoo/Google/MSN/Blogs
  - Subscribe to the NE Planning Council on DD's "Newslines" mailing list: sharonroberts@ttcsa.ne.gov (or call Sharon at 402 471-2230.)
    - [http://www.centerforpeopleinneed.org/](http://www.centerforpeopleinneed.org/)
- Get familiar with the Unicameral Website
  - [http://www.unicam.state.ne.us/index.htm](http://www.unicam.state.ne.us/index.htm)
- Bill Tracker Service from Unicameral

Tips To Get You Started

- Set up a meeting with your senator
  - Find out who he/she is on the Unicameral website: [http://www.unicam.state.ne.us/senators/index.htm](http://www.unicam.state.ne.us/senators/index.htm)
  - Casual, get-to-know-each-other meeting, coffee or lunch perhaps
- Remember—Senators are people, too!
  - No intimidation factor—you are the experts
    - "Senator" is just a title
    - They don’t know everything, so help them out
    - They are public servants—the public is their boss
    - They don’t grill citizens at hearings, only lobbyists and government department heads
You Don't Need To Be A Weatherman To Know Which Way The Wind Is Blowing

Who's Advocating?

- Nebraska Advocacy Services
  - www.nebraskaadvocacyservices.org
- The Arc of Nebraska
  - www.arc-nebraska.org
- Nebraska Statewide Independent Living Council (NESILC)
  - www.nesilo.org
- The Nebraska Planning Council on Developmental Disabilities
  - www.nhcs.state.ne.us/ddplanning/
- National Alliance for Mental Illness
  - www.nami.org
- Mental Health Association
  - www.mha-ne.org

Who's Advocating?

- Center for People in Need
  - www.centerforpeopleinneed.org
- Munroe-Meyer Institute
  - http://www.unmc.edu/mmi
- The Kim Foundation
  - http://www.thekimfoundation.org/
- Bazelon Center for Mental Health Law
  - www.bazelon.org
- Appleseed Center for Law in the Public Interest
  - www.neappleseed.org
Additional Information and Resources

DISABILITY ADVOCACY

The Arc of Nebraska

The Arc of Nebraska's mission is to ensure that all people with developmental disabilities have the opportunity to achieve their full potential and lead fulfilling lives in inclusive communities.

Contact Us:

The Arc of Nebraska
840 N 16th Street
Lincoln, NE 68508
(402) 475-7400

Local Chapters

The Arc of Nebraska has chapters in:

- Omaha
- Lincoln
- Grand Island
- Council Bluffs
- Norfolk
- Sioux City

To Get Involved:

Visit the Arc of Nebraska's website at www.aurc.org for more information on how you can get involved.
SYSTEMS

You start at the bottom and work your way up – no going backwards!

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SERVICE NEEDS DETERMINED

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<td>ASSESSMENT</td>
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<td>The Person</td>
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<td>SOCIETY</td>
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The goal should be to go the other direction; starting with the person in society, create individualized plans and build and fund services around each person.
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<tr>
<th>Region</th>
<th>Administrator and Address</th>
<th>Contact Information</th>
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| Region 1 | **Sharyn Wohlers**, Interim Region 1 Regional Administrator 4110 Avenue D Scottsbluff, NE 69361 | Phone: (308) 635-3171  
FAX: (308) 635-7026  
E-mail: swohlers@pmhc.net |
| Region 2 | **Larry Brown, Ed.D.**, Region 2 Regional Administrator 110 North Bailey Street P.O. Box 1208 North Platte, NE 69103 | Phone: (308) 534-0440  
FAX: (308) 534-6961  
E-mail: larry@r2hs.com |
| Region 3 | **Beth Baxter, M.S.**, Region 3 Regional Administrator 4009 6th Avenue, Suite 65 P.O. Box 2555 Kearney, NE 68848 | Phone: (308) 237-5113  
FAX: (308) 236-7669  
E-mail: bbaxter@region3.net  
Website: www.Region3.net |
| Region 4 | **Ingrid Gansebom**  
Region 4 Regional Administrator 206 Monroe Avenue Norfolk, NE 68701 | Phone: (402) 370-3100 ext. 120  
FAX: (402) 370-3125  
E-mail: igansebom@region4bhs.org  
Website: www.region4bhs.org |
| Region 5 | **CJ Johnson**  
Region 5 Regional Administrator 1645 “N” Street, Suite A Lincoln, NE 68508 | Phone: (402) 441-4343  
FAX: (402) 441-4335  
Website: www.region5systems.net |
| Region 6 | **Patty Jurjevich**, Acting Region 6 Regional Administrator 3801 Harney Street Omaha, NE 68131-3811 | Phone: (402) 444-6573  
FAX: (402) 444-7722  
E-mail: pjurjevich@regionsix.com  
Website: www.Regionsix.com |
### Nebraska Medicaid Home And Community-Based Service Waivers

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<th>Katie Beckett Plan Amendment</th>
<th>Traumatic Brain Injury</th>
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<td>Aged adults and adults with disabilities, children with disabilities</td>
<td>Adults with mental retardation or other developmental disabilities</td>
<td>Children with mental retardation or other developmental disabilities</td>
<td>Infants or toddler with disabilities</td>
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<th>Intermediate Care Facility–Mental Retardation (ICF-MR)</th>
<th>Intermediate Care Facility–Mental Retardation (ICF-MR)</th>
<th>Nursing Facility (NF)</th>
<th>Acute (hospital): ventilator-dependent, pulmonary, or other special needs</th>
<th>Nursing Facility Level of Care</th>
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<td>Medicaid (parent’s income not considered)</td>
<td>Medicaid (parent’s income not considered)</td>
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<th>Up to 3510 slots</th>
<th>250 slots</th>
<th>240 slots</th>
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<th>Purchased from services coordination contracting agencies</th>
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<th>Adult Day Health Care, Assisted Living Service, Assistive Technology and Supports, Child Care for Children with Disabilities, Home Care/Chore Services, Home Delivered Meals, Home Modifications, Independence Skills, Management, Nutrition Services, Personal Emergency Response System, Respite Care Transportation, Nursing Home Transition, Habilitation Services, Respite Care Team Behavioral Consultation, Habilitation Services Homemaker Services, Respite Care Environmental Modifications, Habilitative Day Care Team Behavioral Consultation, Respite Care</th>
<th>Medical Services</th>
<th>Specialized Assisted Living</th>
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<th>- Developmental Index - Team Assessments</th>
<th>- Developmental Index - Team Assessments</th>
<th>Available medical and educational information Child and Family</th>
<th>Nursing Assessment Family Needs Assessment</th>
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Aged & Disabled Medicaid

Medicaid is a program financed by the state of Nebraska and the federal government to provide payment for some health care costs for people with limited incomes and resources. Medicaid generally pays the Medicare co-payments and deductible Medicaid.

It also covers the costs of nursing facilities, prescription drugs, inpatient/outpatient hospital services, rural health clinic services, laboratory and X-ray services, and physicians' assistants. Nebraska rules relating to Medicaid eligibility vary depending upon several factors.

Generally, a single person is allowed to retain up to $4,000 in resources and still be eligible for Medicaid. Certain resources are not taken into consideration.

- As long as the person remains in his or her home, the home is exempt. If the single person, however, later moves into a nursing home, he or she would need to sell the home and spend the proceeds on his or her care.
- Up to $1,500 face value in life insurance policies is considered exempt. If the face value of the policies exceed $1,500, the amount for which the policies could be cashed would be considered a resource.
- One car is exempt regardless of its value.
- You're also allowed to have up to $3,000 in an irrevocable burial trust or in an irrevocable burial insurance plan. In addition, you're allowed to purchase a casket, vault, headstone, and burial space and you can prepay for the opening and closing of the grave.

The rules relating to a single person’s income vary depending upon whether the person will be remaining in his or her home or going to a nursing home.

The rules relating to a couple’s resources also vary greatly depending upon their situation. Different rules are in effect depending upon whether one or both members of the couple will remain in their home.

As with a single person, certain resources are never considered in making a Medicaid determination.

- As long as one member of the couple remains in the home, the home is exempt.
- The couple is entitled to keep one car regardless of value.
- Each member of the couple is entitled to have an irrevocable burial trust with a value of up to $3,000. Each can also pre-purchase his or her casket, vault, headstone, and lot and prepay for the opening and closing of his or her grave.
• Finally, each member of the couple can have a $1,500 face value life insurance policy.

• In addition to the exempt resources, the couple can keep $6,000.

If the couple is remaining in their home and their combined monthly income is at the allowable amount, or less, their medical expenses will be paid by Medicaid without having to contribute anything.

If one member of the couple goes into a nursing home, the rules are different. The exempt resources remain the same as those described above.

However, the spouses can divide in half up to $190,200 in resources. The spouse remaining in the home can keep his or her half. The spouse in the nursing home must spend down his or her share of the resources to under $4,000.

Once those resources are spent down, the spouse in the nursing home is eligible for Medicaid. The spouse remaining at home gets to keep all of his or her income.

If his or her income, however, is less than $1,561.25 per month, he or she will get to keep enough from the nursing home spouse’s monthly income to bring him or her up to $1,561.25. All of the nursing home spouse’s remaining income must be spent on his or her care.

These amounts are current for 2005. Most of the income guidelines and some of the resource guidelines for Medicaid are adjusted every year. As a result, you should check with your local Area Agency on Aging or the Health & Human Services System to find out the current income and resource guidelines.

To receive this benefit, you must complete an application and give it to the Nebraska Department of Health & Human Services. For more information, contact your nearest Health and Human Services Office. Or, you may download an application form and mail it to the nearest Health and Human Services Office.

Administered by the Unit on Aging in the Department of Health and Human Services, Services under the Services Director.

For more information, contact:
Department of Health & Human Services
Division of Aging and Disability Services
State Unit on Aging
P.O. Box 95044
Lincoln, NE 68509-5044
Phone: (800) 942-7830
Fax: (402) 471-4623
www.hhs.state.ne.us/ags/admedw.htm
What are Medicaid Waivers?

Medicaid Waivers are state-run programs that use federal and state funds to pay for health care for people with certain health conditions. Without Medicaid Waivers, thousands of children with special health care needs would either go without health care (because of their health condition and/or financial situation), or would be institutionalized in order to qualify for Medicaid. Medicaid Waivers permit states to use flexibility to design publicly financed health care systems outside of certain federal Medicaid statutory and regulatory requirements. Each state has different Waivers with different eligibility requirements or services. Two Medicaid statutes are currently waivered: 1915 and 1115.

Medicaid was designed as an entitlement program for payment of medical services at no cost to those eligible. In recent years, under 1115 waivers some recipients pay a portion of the cost of services. This will be discussed in depth below. The Medicaid program has broad federal requirements that were designed for its original implementation.

Are Waivers All The Same?

All Waivers are not the same, although all are granted under the Health Care Financing Administration (HCFA) within the Department of Health and Human Services (DHHS). The Waiver program began in 1982, when the first Katie Beckett Waivers became part of a state’s Medicaid optional benefits allowed by the Secretary of Health and Human Services.

How Does A State Get A Waiver?

Medicaid Waivers must be filed by the governor, the legislature, or the department in state government with jurisdiction over the Medicaid program. The state Medicaid director is ultimately responsible for developing and implementing the entire Medicaid state plan, which must be filed with HCFA annually. Special rules and additional paperwork are needed should a state choose to ask for and eventually implement a Waiver. A Waiver must be approved before its inclusion in the Medicaid state plan process.

The 1915 Statute Includes Three Types of Medicaid Waivers:

- 1915 (b) allows a state to restrict the providers a Medicaid recipient may use for Medicaid services. There are certain additional restrictions still placed upon this type of Waiver.

- 1915 (c) waives (permits exceptions to) certain federal requirements to provide home and community based services as an alternative to institutionalization. These are often referred to as Katie Beckett Waivers and are limited in scope. These Waivers, for example, permit a family with a child with a special health care need to receive Medicaid in order to have health care services and supports that keep their child at home, rather than in a hospital or institution.

- 1915 (d) allows waivers of certain federal requirements to provide home and community based services to the elderly as an alternative to institutionalization.
What Is An 1115 Waiver?

The 1115 Waivers are often referred to as Medicaid Managed Care Waivers, because managed care is now common in almost all 1115 Waivers. Under the 1115 statute, the Secretary of Health and Human Services can allow states "to experiment, pilot or demonstrate projects which are likely to assist in promoting the objectives of the Medicaid statute." Therefore, these Waivers are research and demonstration Waivers. However, restrictions on the 1115 Waivers are liberal, so states have great leeway in developing Medicaid Plans that suit their state’s health care goals. These Waivers can include the entire Medicaid-eligible population, including AFDC, SSI, and child support enforcement programs. When states accept the 1115 Waivers, there must be an evaluation process to ensure that those whom the original Medicaid law intended to include receive benefits and services. Many states now apply for 1115 Waivers in an attempt to provide health care to more of their poor and near-poor citizens, while also holding down costs through managed care. In some states, children with special health care needs are "carved out," or excluded, from the 1115 Waiver because there is concern that all the health care they need (specialists, therapies, some equipment and products) might not be available within the managed care component of the Waiver. However, eligible children still receive Medicaid and health care through the state's regular Medicaid program.

Can a State Have More Than One Waiver?

States may choose to develop various Waivers to suit the needs of their populations. Some states currently have 1915 (c), 1915(d) and 1115 Waivers. However, these states must follow the guidelines provided by DHHS and HCFA.

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Albuquerque, NM 87106
(505) 872-4774 or (888) 835-5669
Fax: (505) 872-4780
Email: kidshealth@familyvoices.org
http://www.familyvoices.org/hcf/ma-kbw.htm
JB11H
Aged and Disabled Medicaid Waiver

The Aged and Disabled Medicaid Waiver is a service system based upon the belief that people with care needs should have options for receiving services. After thorough needs identification and service planning, eligible persons are offered the choice of receiving home and community-based services or entering a nursing home.

This waiver allows Medicaid money to be used to purchase the following services that are not usually considered "medical":

- Adult Day Health Care**
- Assisted Living
- Chore Services*
- Child Care for Disabled Children
- Home-Delivered Meals
- Independence Skills Management (ISM)***
- Nutrition Services
- Personal Emergency Response System
- Respite Care
- Transportation****

*Includes necessary housekeeping activities, meal preparation, essential shopping errand service, escort service, and supervision. Mileage payments for long-distance medical trips are included.

**A structured program of activities in a supervised setting out of the client’s home which provides for health and social needs.

***Training for adults and children in activities of daily living and to overcome or compensate for the effects of physical disabilities. Training may occur in the client’s home or in a community facility to actively increase the functional or behavioral ability of a person who is aged or experiences a disability to live and function within his/her family or community. This may include training for the caregiver (non-Medicaid provider) or promote independence of the waiver client.

****Provided to community resources identified in the service plan.

The waiver is included in the services available for Medicaid under the Department of Health and Human Services, Finance & Support.
Nothing about Us without Us

What is a SILC? — Statewide Independent Living Councils (SILCs) were established under the Rehabilitation Act of 1973 as amended. Created under Title VII of the Rehabilitation Act SILCs are cross-disability councils comprised of a majority of individuals with disabilities, family members, and advocates. SILCs are mandated to uphold the philosophy of Independent Living.

Independent Living — The philosophy of Independent Living emphasizes the importance of consumer control, peer support, self-help, self determination, equal access, and individual and systems advocacy, in order to maximize the leadership empowerment, independence, and productivity of individuals with disabilities, and the integration and full inclusion of individuals with disabilities into the mainstream of American Society.

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nesilc@alltel.net
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The Center for Disability Rights, Law and Advocacy

INTRODUCTION

Nebraska Advocacy Service, Inc. (NAS), The Center for Disability Rights, Law and Advocacy, operates seven federally funded protection and advocacy (P&A) programs. The P&A system is a nationwide network of Congressionally created, legally based disability rights agencies.

As the protection and advocacy system in Nebraska, NAS has the authority to provide legal representation and other advocacy services to people with disabilities.

NAS investigates incidents of abuse and neglect and may provide legal representation to protect the legal and human rights of people with disabilities. Through a variety of other activities including public education, information and referral, and public policy analysis, Nebraska Advocacy Services, Inc., works to change public attitudes and increase public awareness of the legal and human rights of people with disabilities.

NOTE: The information on this site is a general summary of the protection and advocacy services offered by Nebraska Advocacy Services, Inc. Please contact us to learn more about how we can help.

The following services are offered through Nebraska Advocacy Services, Inc. (NAS), The Center for Disability Rights, Law, and Advocacy. Additionally, NAS offers a description of facts and eligibility information in the following fact sheets.

- Legal advocacy
- Public policy advocacy
- Consultative Services
- Fact Sheet & Eligibility Guidelines 2006 (English)

Client Eligibility Requirements

Nebraska Advocacy Services, Inc. provides services to persons with disabilities regardless of race, religion, color, sex, disability, national origin, sexual orientation, marital or parental status, age, or ancestry. Each of our funding sources sets basic eligibility requirements for individuals who may be served using their funds:

- **PADD (Protection and Advocacy for Individuals with Developmental Disabilities):** A developmental disability means that an individual must have a severe mental or physical impairment which occurs before the age of 22, is likely to be life-long, results in functional limitations in at least three areas of major life activity (self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living and economic self-sufficiency), and needs an individually tailored plan for care, treatment or other services for an extended period of time.
• **PAIMI (Protection and Advocacy for Individuals with Mental Illness):** Any person with a significant mental illness, as determined by a Licensed Mental Health Professional, who is currently an inpatient or resident of a facility providing care and treatment for mental illness, including persons who have been discharged from a facility within the last 90 days or who present an issue that arose during their stay at a facility or within 90 days after discharge or the person lives in the community. Priority is given to those who present an issue while in a facility. NAS can provide services to people who are confined in a jail for reasons other than serving a criminal sentence.

• **PAIR (Protection and Advocacy for Individual Rights):** Any person with a physical or mental disability that substantially limits one or more major life activities, or with a record of such impairment, or who is regarded by others as having such impairment and who is not eligible for assistance under the CAP (Client Assistance Program), PADD and PAIMI programs. The Client Assistance Program provides assistance to individuals related to vocational rehabilitation services. The CAP office is located in the Nebraska Department of Education, Office of Vocational Rehabilitation (800-742-7594).

• **PAAT (Protection and Advocacy for Assistive Technology):** Any person denied assistive technology devices or services designed to meet the specific needs of an individual with disabilities.

• **PABSS (Protection and Advocacy for Beneficiaries of Social Security):** Any person with a disability receiving Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) and who wants to return to work despite their continuing disabilities.

**PAVA (Protection and Advocacy for Voting Access):** NAS receives federal funding under the Help America Vote Act (HAVA) to ensure the right of individuals with disabilities to participate in the electoral process, including registering to vote, casting a vote and accessing polling places. HAVA funds are not permitted to be used to litigate voter access issues. However, those issues can be addressed through our other protection and advocacy programs.
Advocates for Persons who are Aged and have Disabilities

Protection and Advocacy Agency
Timothy Shaw, CEO
Nebraska Advocacy Services, Inc.
134 South 13th Street, Suite 600
Lincoln, NE 68508
(402) 474-3183
(800) 422-6691 toll free in Nebraska
info@nebraskaadvocacyservices.org
www.nebraskaadvocacyservices.org

League of Human Dignity
Independent Living Center (Satellite of LHD)
400 Elm Street
Norfolk, NE 68701
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TTY: (402) 371-4475
FAX: (402) 371-4625
Ninfo@leagueofhumandignity.com

Center for Independent Living (CIL) of Central Nebraska, Inc.
1804 South Eddy Street
Grand Island, NE 68801
(308) 382-9255
TTY: (308) 382-9255
FAX: (308) 384-9231

CIL of Central Nebraska, Inc (Satellite of LHD)
P.O. Box 1026
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Pamhandle IL Services
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pils@bbc.net
Overview of the Developmental Disabilities System

The Developmental Disabilities System is charged by State Statute with the responsibility for carrying out the Developmental Disabilities Services Act. Responsibilities include certification, technical assistance, regulations and payment for providers of community-based developmental disabilities services, and operation of the Beatrice State Developmental Center (a 24-hour intermediate care facility for persons with developmental disabilities). An integrated system approach for the provision of developmental disabilities services is used by:

- Contracting with and providing general oversite of community-based developmental disabilities service providers to provide specialized services for Nebraskans with developmental disabilities
  - Contracting with 34 public and private providers
  - With 70 certified area programs statewide
  - Additional information on providers statewide can be found in the summary published in the Provider Profile.
- Developing and implementing a comprehensive and integrated statewide plan for services for Nebraskans with developmental disabilities.
  - Currently providing services to about 3,950 individuals
  - Total number of Individuals with services and service coordination about 4,300
- Administering four Home and Community-Based Medicaid Waivers serving 2,925 adults and 250 children
- Having a single point of entry for specialized developmental disabilities services, managed by Service Coordination.
- Operating a statewide registry of persons eligible for specialized developmental disabilities services.
  - Part of the registry includes individuals on what is commonly known as the waiting list.
- Providing training and technical assistance statewide to staff of community-based developmental disabilities service providers and service coordination.
- Providing eligible persons short-term community-based consultation or residential behavioral intervention and training through the Beatrice State Developmental Center’s Outreach and Intensive Treatment Services.
• Collaborating with other state agencies, consumers, families, communities, and specialized developmental disabilities services providers, to ensure the maximum utilization of least restrictive alternatives for persons with developmental disabilities.

• Piloting and implementing the Community Supports Program (CSP), to build upon the individual and family strengths and to strengthen and support informal and formal services already in place. The CSP utilizes a self-directed philosophy, designed to provide choice when determining the services that are needed to maximize the independence of the person with a developmental disability.

• Distributing fiscal resources based on a consistent rationale for reimbursement that is flexible enough to allow funding to follow persons receiving services and to change as service needs change.

• Utilizing outcome-based, consumer-focused managed care to ensure that individuals receive what they need, no more, no less.

• Promoting the development of high quality, cost efficient pilot projects for specialized services.

• Administering all state and federal funds for specialized developmental disabilities programs in the State.

• Administering the Beatrice State Developmental Center (BSDC), which provides 24-hour residential, medical, habilitative, and consultative services for Nebraskans with mental retardation or related conditions.

• Administering the Beatrice State Developmental Center's (BSDC) Bridges Program, which is a 14-bed secure setting designed to provide a structured, therapeutic environment for persons with challenging behaviors that pose a significant risk to members of the community.

• Working with the Advisory Committee on Developmental Disabilities established in compliance with Nebraska Revised Statutes 83-1201. The membership of the committee includes persons with developmental disabilities, elected officials and interested persons from the community. The committee advises the Department on all aspects of the funding and delivery of services to persons with developmental disabilities.

**For more information regarding the Developmental Disabilities System, contact:**
René Ferdinand  
Nebraska Department of Health & Human Services  
P.O. Box 98925  
Lincoln, NE 68509-8925  
Phone: (402) 479-5110  
E-mail: rene.ferdinand@hhss.ne.gov  
Web: www.hhs.state.ne.us/
Nebraska Planning Council on Developmental Disabilities
Department of Health and Human Services
Mary Gordon, Program Administrator
301 Centennial Mall South
P.O. Box 95044
Lincoln, NE 68509-5044
(402) 471-2330; (402) 471-9570 (TTY)
E-mail: mary.gordon@hhss.ne.gov
E-mail: terri.holman@hhss.ne.gov
Web: www.hhs.state.ne.us/ddplanning/

Nebraska Planning Council on Developmental Disabilities

The Nebraska Planning Council on Developmental Disabilities (the State DD Council) undertakes advocacy, capacity building and systemic change activities on behalf of persons with developmental disabilities and their families. These activities contribute to a coordinated consumer and family directed comprehensive system that includes needed community services, individualized supports and other forms of assistance that promote self-determination, independence, productivity and integration and inclusion in all aspects of community life. The Regional Councils are affiliated with the State Council.

The state is divided into six geographical areas called regions, each having a voluntary regional council. Membership on the regional councils is open to any interested person living in the region, including persons with disabilities, family members, service providers and advocates. Operating under regionally approved by-laws, the councils elect officers annually. The majority of the councils meet monthly to handle needed business.

Each Regional Council receives funds from the State Council for use in their areas to support local activities similar to those of the State Council. These include public education/awareness efforts; trainings for individuals, families and service providers; and support to attend relevant conferences or workshops. The regional councils also assist the State Council and its committees in carrying out activities such as grant reviews, hosting public forums and advocacy efforts.

For more information on the Regional Council in your area, locate your county and contact person below.

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Region I Counties: Sioux, Dawes, Sheridan, Box Butte, Scottsbluff, Morrill, Garden, Banner, Kimball, Cheyenne, Deuel.

Contact:
Linda Redfern, Chairperson
2603 Circle Drive, Box 1327
Scottsbluff, NE 69363-1327
Phone: 308-635-3444
lindaohd@charterinternet.com


Contact:
Louise Dannehl, Chairperson
ESU #10
1910 Meridian Avenue
Cozad, NE 68130
Phone: 308-784-4525
ldannehl@esu10.org


Contact:
Rita Skiles, Chairperson
ESU #11
P.O. Box 858
Holdrege, NE 68949
Phone: 308-995-6585
rskiles@esu11.org


Contact:
Cheri Matthews, Chairperson
ESU #1, 211 10th Street
Wakefield, NE 68784-5014
Phone: 402-287-2061
cmatthew@esu1.org
**Region V Counties:** Polk, Butler, Saunders, York, Seward, Lancaster, Fillmore, Saline, Gage, Thayer, Jefferson, Johnson, Otoe, Nemaha, Pawnee, Richardson.

**Contact:**
Karen Jordan-Anderson  
Arc of Lincoln/Lancaster County  
5609 South 49th Street, #1  
Lincoln, NE 68516  
[arcoflincoln@alltell.net](mailto:arcoflincoln@alltell.net)

Mary O’Hare  
1205 South 25th Street  
Lincoln, NE 68502  
[maryohare1@alltell.net](mailto:maryohare1@alltell.net)

**Region VI Counties:** Dodge, Washington, Douglas, Sarpy, Cass.

**Contact:**
Kay Gordon, Chairperson  
13031 Mullen Circle  
Omaha, NE 68144-2548  
Phone: 402-333-7806  
[kbgordon@worldnet.att.net](mailto:kbgordon@worldnet.att.net)

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**The Munroe-Meyer Institute for Genetics and Rehabilitation**

The Munroe-Meyer Institute for Genetics and Rehabilitation (MMI) of the University of Nebraska Medical Center (UNMC), utilizes numerous professionals who specialize in evaluating, treating, and supporting individuals with developmental disabilities and/or genetic disorders. The interdisciplinary team approach used at MMI assures a family-centered, comprehensive, diagnostic, and treatment program that is specific to the client’s needs. Parents, teachers, therapists and community service providers are welcome team members in the provision of all our services. This collaboration with Munroe-Meyer professionals helps to ensure better coordination of services.

As part of UNMC, MMI also provides research, education, and technical assistance to programs across Nebraska. MMI is committed to providing the foundation of knowledge needed by health care professionals who will provide future care to children and adults with special health care needs and their families.
For more information please contact Munroe-Meyer’s Consumer/Family Coordinators:

**Mark A. Smith, M.S.**
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985450 Nebraska Medical Center
Omaha, NE 68198-5450
Phone: (402) 559-5744
Toll Free: (800) 656-3937 ext. 9-5744
Fax: (402) 559-4757
E-mail: msmitha@unmc.edu

**Shirley Dean, B.A.**
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Fax: (402) 559-4757
E-mail: sdean@unmc.edu
The mission of the Nebraska Chapter of the Autism Society of America is to support and advocate for individuals with autism and their families through increasing education and awareness, fundraising, and facilitating community involvement for persons with autism spectrum disorders to achieve their potential by becoming a productive, accepted, and integral part of society.

Contact Us

For further information about the Autism Society please contact us by emailing glenn2@unl.edu or via the information below.

Greta Glenn
1540 Arapahoe
Lincoln, NE 68502
(402) 472-4346
Our Mission

The Arc of Nebraska is committed to helping children and adults with disabilities secure the opportunity to choose and realize their goals of where and how they learn, live, work and play. Disability is a natural part of the human experience and in no way diminishes the right of individuals to live independently, enjoy self-determination, make choices, contribute to society, pursue meaningful careers, enjoy full inclusion and integration in the economic, political, social, cultural, and educational mainstream of American society." Rehabilitation Act 1992. The Arc of Nebraska, Inc. is a nonprofit corporation established in 1954 by parents to improve the quality of life for all people with developmental disabilities and their families.

The Core Values Are:

People First The Arc believes that all people with mental retardation and related developmental disabilities have strengths, abilities and inherent value; are equal before the law; and must be treated with dignity and respect. The Arc represents supports and acts on behalf of individuals and their families regardless of level of disability or membership in The Arc. The Arc believes in self-determination by empowering people with the supports needed to make informed decisions and choices.

Democracy A democratic process involving members, through affiliated chapters, is utilized to take positions on important issues, policies and programs.

Visionary Leadership. The Arc leads by promoting the mission, core values and position statements. We lead with integrity, accountability, and by open, honest and timely communication. We work with individuals, organizations and coalitions in a collaborative fashion. There is a valued partnership with volunteer and staff leadership at all levels of the organization that provides mutual support for their respective roles.

Community Participation. The Arc works toward and believes in the community imperative: that all people have the fundamental moral, civil and constitutional rights to live, learn, work, play and worship in safe and healthy communities of their choosing. The Arc has responsibility to ensure the safety and well being of individuals.

Diversity. The Arc values and insists upon diversity in its leadership and membership. The Arc actively pursues and welcomes diverse groups (including but not limited to race, ethnicity, religion, age, geographic location, sexual orientation, gender and level of disability).

Integrity and Excellence. The Arc conducts its business with integrity. The Arc reflects quality and excellence in all its work.

Approved by the Delegate Body, October, 2000.
Adult Behavioral Health Reform

LB 1083, the Nebraska Behavioral Health Services Act, was signed into law by Governor Johanns on April 14, 2004.

Governor Mike Johanns and Senator Jim Jensen worked in partnership on passage of this historic legislation, which will allow persons with mental illness to be served closer to their home communities, support systems, family and friends, while providing safety and protection for the individuals and the community.

The Behavioral Health Reform focus is on people who would have been served at a state-operated Regional Center – persons committed by Mental Health Commitment Boards for involuntary treatment. Approximately 700 individuals are committed to the Hastings and Norfolk Regional Centers each year.

LB 1083 addresses the lack of behavioral health services once individuals no longer need the hospital-based inpatient services provided at Regional Centers or local hospitals. The new community-based system will include many levels of services. Consumers requiring crisis stabilization will access enhanced crisis center services. Community hospitals throughout the state will be able to develop acute psychiatric inpatient and secure residential services with the capacity to have locked units and highly trained staff. Residential rehabilitation services are less restrictive and more appropriate for some persons. Other non-residential community programs can provide services and reduce re-hospitalization. Regional Center beds will stay in place for individuals with high needs, and to provide specific care, such as the sexual offender and forensic programs.

Behavioral health reform creates new, additional funding for community-based mental health services. It also transitions funding currently used for inpatient services at the Hastings and Norfolk Regional Centers to develop similar community services.


LB 1083 creates the Division of Behavioral Health Services within the Department of Health and Human Services (HHS). The new division will ensure that the necessary array of services is available and that placements are appropriate for each behavioral health consumer.
LB 1083 directed the Nebraska Health and Human Services System to prepare and submit a Behavioral Health Implementation Plan to the Governor and the Legislature by July 1, 2004.

The state implementation plan was submitted to the governor on July 1, 2004 and is located on this website at the Implementation Plan page [http://www.hhss.ne.gov/beh/reform/plan.htm].

HHSS developed over 600 deliverables and action steps that are necessary to facilitate the internal changes or processes that need to be in place in order to implement such a plan and support future activities. The following internal HHSS work teams are assisting in the planning: HHSS Organization, Employment, Regional Center Transition, Community Services, Housing, Finance, Human Resources, Strategy, Information/Payment, Communications and Academic Support.

As work activities move beyond internal processes to implementation, HHSS will provide reports to the Oversight Commission as requested. HHSS will also continue to involve a wide variety of stakeholders, including consumers, to get input on what is needed for an appropriate array of services to provide a successful transition from Regional Centers to communities.

http://www.hhss.ne.gov/beh/reform/

**Adult Behavioral Health Reform**

**Consumer Information**

The Office of Consumer Affairs promotes the involvement of consumers at all levels of administrative process and provision of services.

Joel McCleary, Administrator  
Office of Consumer Affairs  
Division of Behavioral Health Services  
Nebraska Health and Human Services  
P.O. Box 98925  
Lincoln, NE 68509-8925  

Office and Voicemail: (402) 471-7853  
Cell: (402) 326-3518  
Fax: (402) 471-7859
This means consumers play a major role in the formulation, development and implementation of initiatives and activities designed to best serve their needs.

The Office of Consumer Affairs serves as the nucleus for a broad range of services and supports for mental health and substance abuse consumer initiatives and activities.

Empowerment is promoted by enabling consumers to take charge of their own recovery through active participation with support systems, advocacy, self-help and educational opportunities. The informed consumer can begin to network with dignity, take action against the challenges and obstacles, and become responsible for their own recovery, which further enhances the quality of life.

The Division of Behavioral Health has consumer advocates on staff. Those experiencing difficulty with Nebraska’s mental health system are encouraged to call them [see below].

**Division of Behavioral Health Services**  
**Central Office**  
**Phone:** (402) 471-7818

| Administrators | Ron Sorensen  
| Administrator,  
| (Ron.Sorensen@hhss.ne.gov)  
| (402) 471-7791 | Barbara Thomas, MSE  
| Assistant Administrator,  
| (Barbara.Thomas@hhss.ne.gov)  
| Certified Paralegal  
| (402) 471-7742 |
| The Office of Consumer Affairs | Joel McCleary, Administrator  
Office of Consumer Affairs  
Division of Behavioral Health Services  
Nebraska Health and Human Services  
P.O. Box 98925  
Lincoln, NE 68509-8925  
joel.mccleary@hhss.ne.gov |
|--------------------------------|----------------------------------|
| Program Managers              | Laurie Sutter, MA  
(Laurie.Sutter@hhss.ne.gov)  
Prevention Program  
(402) 471-7733 |
|                               | Linda Wittmuss, MS, PA  
(Linda.Wittmuss@hhss.ne.gov)  
Managed Care  
(402) 471-7858 |
|                               | Katrina Ondracek, MA  
(katrina.Ondracek@hhss.ne.gov)  
Compulsive Gambling  
(402) 471-7823 |
| Program Coordinators          | Susan Adams, MA  
(Susan.Adams@hhss.ne.gov)  
Children's Behavioral Health Services  
(402) 471-7820 |
|                               | Jim Harvey, LCSW  
(Jim.Harvey@hhss.ne.gov)  
Quality Improvement, Housing, Olmsted  
(402) 471-7824 |
|                               | Mary O'Hare  
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Transition Coordinator  
(402) 471-7793 |
| **MH/SA Regional Program Specialists** | **Lee Tyson**  
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Regional Center Transition  
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|-------------------------------------|-------------------------------------------------|
| **Susan Adams, MA**  
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Regions 1 and 2,  
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| **Kathleen Samuelson, MA**  
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Region 4, Tribal Programs  
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| **Sheri Dawson**  
(Sheri.Dawson@hhss.ne.gov)  
Region 5  
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| **Consumer Liaisons**  
800-836-7660 | **Dan Powers, JD**  
(Dan.Powers@hhss.ne.gov)  
(402) 471-7857 |
| **Phyllis McCaul**  
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| **Compulsive Gambling Program** | **Eric Hunsberger, MS**  
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State Mental Health Representative for Children and Youth
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The administrator for behavioral health is responsible for community-based mental health, substance abuse, compulsive gambling, and the Regional Centers.

Objective of the behavioral health system
To organize and provide for an effective and efficient system of quality behavioral health services for the people of Nebraska.

Intent
Working together in partnership for a unified and comprehensive behavioral health system driven by consumer needs.

Values
- The system is consumer driven
- The system provides for access to needed services
- The system is focused on consumer outcomes
- Strength-based services
- Competent staff
- The system utilizes continuous improvement
Mental Health Association of Nebraska

About Us:

The Mental Health Association of Nebraska (MHA-NE) is a consumer-run, voluntary not-for-profit statewide association with Chapters located in communities throughout Nebraska. MHA-NE brings together service recipients, families, professionals, advocates and concerned citizens to address all aspects of mental health and mental illness.

We are dedicated to ensuring that public mental health policy is just, fair and promotes equality and opportunity.

MHA-NE supports freedom for individuals with mental illness. Freedom to take advantage of any of life’s opportunities. Freedom to decide where one lives, works; and the important thing they will do with their lives, the relationships they establish, how they chose to contribute to their community, and what services they will use. FULL PARTICIPATION NOW.

“...People with mental disorders have a vital role to play in our families, our neighborhoods, our communities, and our country. Their ability to participate fully can no longer be derailed by outdated science, outmoded financing, and unspoken discrimination. They demand better, and they deserve better. Putting children and their parents, adults and older adults with mental disorders at the heart of the health care system must be accomplished now."


Mental Health Association of Nebraska
1645 N Street, Suite A
Lincoln, Nebraska 68508
(402) 441-4371
888-902-2822 (toll free outside of Lincoln)
http://www.mha-ne.org/
NAMI is the National Alliance for the Mentally Ill. NAMI-Nebraska provides statewide support to families and friends of individuals with mental illness. We also educate the public about mental illness using literature, speaking engagements, videos, workshops, conferences and this website. In addition, through ongoing communication with mental health professionals and public officials, we are seeking to improve and expand mental health services. We advocate for statewide mental health reform, equitable medical insurance, affordable housing, employment and civil liberties.

NAMI-Nebraska is a nonprofit, grassroots organization dedicated to education, support and advocacy for anyone whose life has been touched by mental illness. We are funded in part by grants from the Nebraska Department of Health and Human Services and membership dues and donations. Our membership consists of families and friends of individuals with mental illness and concerned mental health professionals. Individuals with mental illness are also active members.

Our toll-free helpline (877) 463-6264 is available for anyone seeking education and understanding about mental illness, a support group, or advocacy resources.

Region 6 Chapter of the Nebraska Federation of Families for Children’s Mental Health
3801 Harney Street 2nd Floor
Omaha, NE 68131
(402) 505-4608; (800) 245-6081
nfsn_advocate@yahoo.com

Advocacy, referral, education, and support for families of children (birth to 21) who have mental, emotional, or behavioral disorders.
Nebraska Federation of Families for Children's Mental Health

Contact Person: Jonah Deppe
Position: Executive Director
Address: 3568 Dodge Street, Suite 2
Omaha, NE 68131
Telephone: (402) 345-0791
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Email: jdeppe@ne-ffcmh.org

Program Description: The Nebraska Federation of Families for Children’s Mental Health (NE-FFCMH) requests assistance to strengthen family support organizations across the state. The project “United Voices for Change” will create a statewide family run organization whose purpose is to ensure choice for all families and children with mental health needs through education, advocacy, outreach, support of families, and the formation of one unified voice to influence policy makers and legislators.

The project builds on the strengths and experience of six established regional affiliates whose membership comprises the NE-FFCMH Board of Directors. Federal funds will support recruitment of an Executive Director, logistical supports, and location in the state capitol. A complementary grant is available from the Nebraska Department of Health and Human Services.

Key activity areas include:

- Statewide collaboration around common issues and concerns affecting families and their organizations in each of the state’s six administrative regions;
- Outreach to families, communities, and other organizations through media presentations, policy briefings, brochures, telephone trees, and a statewide newsletter;
- Provision of educational and training opportunities for families and family serving organizations through a directory of training opportunities, conferences, workshops, forums, educational support groups, and a resource library;
- Advocacy for mental health care reform at local, regional, state, and national levels;
- Support for families through the promotion of support groups, peer matching, information and referral, and individual advocacy;
- Establishment of a 1-800 system and interactive website, linking family organizations and their members to regional, state, and national technical assistance and information;
- Development of strategies for sustainability and growth.
The project is strongly supported by key collaborators at regional and state levels. NE-FFCMH will utilize a diversity of in-state technical assistance, as well as accessing the expertise of other state organizations, national resources, and the Center for Mental Health Services.
This collaborative activity in cooperation with The Partnership IDEAS Network allows you to access the Ask Special Education Web site. The site provides an e-mail forum for discussion with professionals employed within the Nebraska Department of Education (NDE) Special Populations Office.

Ask Special Education provides users with an easy way to e-mail Nebraska Department of Education (NDE) regional special education consultants while providing users with links to information about special education not only within Nebraska but Nationally as well.

"Ask Special Education?"
http://www.nde.state.ne.us/sped/ideas/askndesped.html

State Department of Education: Special Education
Gary M. Sherman, Administrator
Special Populations Office
Nebraska Department of Education
301 Centennial Mall South
P.O. Box 94987
Lincoln, NE 68509-4987
(402) 471-2471 (V/TTY)
gary.sherman@nde.ne.gov
www.nde.state.ne.us/SPED/sped.html

State Coordinator for NCLB (No Child Left Behind)
Special Populations Office
Nebraska Department of Education
301 Centennial Mall South
P.O. Box 94987
Lincoln, NE 68509-4987
(402) 471-2471 (V/TTY)
www.nde.state.ne.us
Programs for Children with Disabilities: Ages 3 through 5
Jan Thelen, Coordinator
Special Populations Office
Nebraska Department of Education
301 Centennial Mall South
P.O. Box 94987
Lincoln, NE 68509-4987
(402) 471-4319
jan.thelen@nde.ne.gov
www.nde.state.ne.us

Nebraska ChildFind, Rights, Resources, & Referrals for Children with Disabilities: Birth through 21
Steve Miller, Statewide Coordinator
Nebraska ChildFind
5143 S. 48th Street, Suite C
Lincoln, NE 68516-2204
(402) 471-0734; (888) 806-6287 (in NE)
smiller@atp.state.ne.us
www.nde.state.ne.us/ATP/childfind.asp

State Vocational Rehabilitation Agency
Frank Lloyd, Director
Vocational Rehabilitation
Nebraska Department of Education
301 Centennial Mall South, 6th Floor
P. O. Box 94987
Lincoln, NE 68509-4987
(402) 471-3649
frank.lloyd@vr.ne.gov
www.vocrehab.state.ne.us

Office of State Coordinator of Vocational Education for Students with Disabilities
Donna Vrbka, Director
School Counseling
Nebraska Department of Education
301 Centennial Mall South
P.O. Box 94987
Lincoln, NE 68509-4987
(402) 471-4811
donna.vrbka@nde.ne.gov
www.nde.state.ne.us/CARED/
Coordinator for Transition Services
Jack Shepard, State Transition Coordinator
Special Populations Office
Nebraska Department of Education
6949 S. 110th Street
Omaha, NE 68128
(402) 595-2171
jack.shepard@nde.ne.gov
www.nde.state.ne.us/SPED/sped.html

Programs for Children and Youth who are Blind or Visually Impaired
Dr. Pearl Van Zandt, Executive Director
Nebraska Commission for the Blind and Visually Impaired
4600 Valley Road, Suite 100
Lincoln, NE 68510
(402) 471-2891
pearl_vanzandt@ne.gov
www.ncbvi.ne.gov

Programs for Children and Youth who are Deaf or Hard of Hearing
Rhonda Fleischer, Interim Director
Programs for Sensory Impairments
Special Populations Office
Nebraska Department of Education
301 Centennial Mall South
P.O. Box 94987
Lincoln, NE 68509-4987
(402) 471-2471;
(800) 311-2065 (Parent Number)
rflieisch@esu9.org

Nebraska Commission for the Deaf and Hard of Hearing
Tanya Wendel, Executive Director
4600 Valley Road, Suite 420
Lincoln, NE 68510-4844
(402) 471-3593 (V/TTY);
(800) 545-6244 (in NE)
tanya.wendel@ncdhh.ne.gov
www.ncdhh.ne.gov
PARENT RIGHTS
IN SPECIAL EDUCATION

As a parent of a child with a disability, you have certain rights which are guaranteed by state (92 NAC 51) and federal (Individuals with Disabilities Education Act (IDEA)) laws. Those procedural safeguards are contained in this document.

If you would like further information or have any questions regarding your rights, you may wish to contact your school district's school superintendent or special education director.

Nebraska Department of Education
Special Populations Office
301 Centennial Mall South
P.O. Box 94987
Lincoln, NE 68509
402.471.2471

A copy of the Procedural Safeguards Notice must be provided to parents one (1) time a year.

A copy must also be provided:
   a. Upon request by the parent;
   b. Upon initial referral or parental request for evaluation; and
   c. Upon the first occurrence of the filing of a due process complaint.

A parent may choose to receive notices via e-mail if the school district makes that option available.

A school district may place a copy of the procedural safeguards notice on a website.

Prior Written Notice

Parents have the right to receive a written notice within a reasonable amount of time before the school district proposes or refuses to initiate or change the identification, evaluation, or educational placement of a child or the provision of a free appropriate public education (FAPE).

This notice must include:
   a. a description of the action proposed or refused by the school district;
   b. an explanation of why the school district proposes or refuses to take the action;
   c. a description of each evaluation procedure, assessment, record or report the school district used as a basis for the proposed or refused action;
   d. a description of other options considered by the IEP team and the reasons why those options were rejected;
   e. a description of the factors that are relevant to the school district's proposal or refusal;
   f. a statement that the parents of a child with a disability have protection under the procedural safeguards set forth in federal law, and if the notice is not an initial referral for an evaluation, the way in which a copy of a description of the procedural safeguards can be obtained; and
   g. sources for parents to contact to receive assistance in understanding their rights as parents of a child with a disability.

The prior written notice must be written in an easily understandable manner, and provided in the parent's native language unless it is clearly not possible to do so. If the parents' method of communication is not a written language, they have the right to be notified by other appropriate means.

A parent may choose to receive prior written notices via e-mail if the school district makes that option available.
Parental Consent

Consent means that:

a. the parent has been fully informed of all information relevant to the activity for which consent is being asked, in his or her native language, or other mode of communication.
b. the parent understands and agrees in writing to the proposed activity;
c. the consent describes the proposed activity and lists the record (if any) that will be released and to whom; and
d. the consent is voluntary and may be revoked at any time.

If a parent revokes, or takes back, their consent, that revocation is not retroactive which means it does not stop an action that has occurred after consent was given and before the consent was revoked.

Parental consent must be given before a school district:

a. conducts an initial multidisciplinary evaluation;
b. conducts a reevaluation; and
c. places a child with disabilities for the first time in a program providing special education and related services or early intervention services to infant and toddlers.

Informed parental consent is not required before a school district conducts a reevaluation if the district can demonstrate that it has taken reasonable steps to obtain that consent, and the parent has failed to respond.

Informed parental consent is not required before reviewing existing data as part of an evaluation or reevaluation or administering a test or other evaluations that are given to all children unless consent is required of parents of all children.

A school district will not be required to obtain informed consent from the parent of a child for an initial evaluation to determine whether the child is a child with a disability if:

a. despite reasonable efforts to do so, the school district cannot discover the whereabouts of the parent of the child;
b. the rights of the parent of the child have been terminated in accordance with State law; or
c. the rights of the parent to make educational decisions have been taken away in accordance with State law, and consent for an initial evaluation has been given by an individual appointed by the judge to represent the child.

If a parent refuses to provide consent, the school district has the option of initiating a due process complaint hearing to determine if a child can be evaluated or reevaluated without parental consent. A due process hearing officer may order that an initial evaluation or reevaluation be conducted, and a parent may appeal the hearing officer's decision through the court system.

A school district may not initiate a due process complaint hearing if a parent refuses to provide consent for initial placement into special education and related services.

If a parent refuses to consent to the provision of special education and related services, or if the parent fails to respond to a request to provide consent:

a. the school district will not be considered to be in violation of the requirement to make available a free appropriate public education (FAPE) to the child; and
b. the school district will not be required to develop an individualized education plan (IEP), or convene an IEP meeting.

A parent’s consent for an evaluation does not mean that their can child can be evaluated and placed in a special education program. If a parent provides consent to conduct an evaluation, they must also provide written consent if the school district wishes to place their child in a special education program.
A school district may not use a parent's refusal to consent to one service or activity to deny the parent or child any other service, benefit, or activity, for which the parent has provided their consent.

**Access to Educational Records**

Parents have the right to inspect and review any educational records which are collected, maintained or used by the school district with respect to the identification, evaluation and educational placement of their children and the provision of a free appropriate public education (FAPE).

The school district shall comply with the request without unnecessary delay and before any meeting regarding an individualized education program (IEP) or hearing relating to the identification, evaluation, or placement of the child, and *in no case, more than forty-five (45) days after the request has been made.*

The right to inspect and review educational records includes:

a. the right to a response from the school district regarding reasonable requests for explanations and interpretations of the records;

b. the right to request that the school district provide copies of the records if not providing those copies would prevent the parent from inspecting or reviewing them;

c. the right to provide or withhold consent to disclose the records;

d. the right to review records unless the school district has other information that denies the parent authority under state law (guardianship, divorce, etc.)

e. the right to inspect only the information relating to their child if the record contains information about more than one child;

f. the right to have a representative of the parent inspect and review the records;

g. the requirement of the school district to keep a record of persons obtaining access the child's education records (except access by the parent and authorized employees of the school district), which includes the name of the party, the date access was given, and the purpose for which the party is authorized to use the records;

h. the requirement of the school district to assume that the parent has the authority to review records relating to their child unless the school district has other information that denies the parent authority under state law (guardianship, divorce, etc.);

i. the right to request a list of the types and locations of education records collected, maintained, or used by the school district; and

j. the right to request that the school district amend the information in the record if the parent believes the information is inaccurate or misleading or violates the privacy or other rights of the child.

A parent has the right to request a hearing if the school district refuses, upon request by the parent, to amend the record. If a hearing is requested by the parent to challenge the contents of the record, the school district must conduct the hearing.

The school district must decide whether to amend the information at the request of the parent within a reasonable period of time upon receipt of the request.

If, as a result of the hearing, the school district decides that the information contained in the record is inaccurate, misleading, or a violation of the child's privacy, the district must amend the record and inform the parent in writing of the amendment.

If, as a result of the hearing, the school district decides that the information contained in the record is accurate, not misleading, and does not violate the privacy of the child, they must inform the parent of their right to place in the record maintained on the child a statement regarding the reasons the parent disagrees with the school district's decision.

**Parental consent must be obtained** before personally identifiable information is disclosed to anyone other than officials of the school district collecting or using the information unless specifically not required in the Family Education Rights and Privacy Act (FERPA).

A school district may charge a fee for copies of records which are made for parents if the fee does not prevent the parents from exercising their right to inspect and review those records.
A school district **may not charge a fee to search for or retrieve** information.

The school district must **retain special education records for five (5) years** after the completion of the activities for which special education funds were used.

The school district must inform parents when personally identifiable information collected, maintained, or used by the district is no longer needed to provide educational services to the child. The information must be destroyed at the request of the parents. However, a permanent record including the child's name, address and phone number, grades, attendance record, classes attended, and grade level and year completed may be kept by the school district without time limitations.

**Evaluations**

Evaluations means procedures used to assist in the determination of whether a child has a disability and the nature and extent of the special education and related services that the child needs.

**Independent Educational Evaluations**

An independent educational evaluation (IEE) is an evaluation conducted by a qualified examiner who is **not employed by the public school that is responsible for the child's education**. Parents have the right to request an IEE at public expense if they disagree with the results of the evaluation conducted by the school district. Public expense means that the school district either: (a) pays for the full cost of the evaluation; or, (b) insures that the evaluation is otherwise provided at no cost to the parent.

When a parent requests an IEE, the school district **must**:

- a. insure that an IEE is provided at public expense; or
- b. initiate a due process hearing to show that its evaluation is appropriate.

A school district **must** provide parents with information on how and where to obtain an IEE. If a parent requests an IEE, the school district may ask the reason why the parents object to the district's evaluation. However, a parent does not have to give a reason, and the district cannot unreasonably delay either providing the IEE or initiating a due process to show that their evaluation is appropriate.

If an IEE is at public expense, the criteria under which the evaluation is obtained, including the location of the evaluation and the qualifications of the examiner must be the same as the criteria that the school district uses when it conducts an evaluation to the extent that those criteria are consistent with the parent's right to an IEE.

If a school district initiates a due process hearing and the hearing officer requests an IEE as part of the hearing, the cost of the evaluation is **at public expense**. If the final decision in the hearing is that the school district's evaluation is appropriate, parents still have the right to an IEE, **but not at public expense**.

If an IEE is obtained at the expense of the parent, the school district **must consider the results** of the IEE in any decision it makes about the child's educational program.

Parents may also share the results of an IEE at a due process hearing.

**Mediation**

Mediation is a process in which a qualified, impartial mediator who is trained in effective mediation techniques and is knowledgeable about laws relating to special education and related services meets with the parents, school district personnel, and others involved in a disagreement about any part of the special education process. Each session in the mediation process must be scheduled in a timely manner.
and must be held in a location that is convenient to the parties involved in the dispute.

There is no charge to school districts or parents for using the mediation option. Mediation is voluntary for all parties. It may not be used to deny or delay a parent's rights to a due process hearing.

Discussions which occur during the mediation process must remain confidential, and parents may be required to sign a confidentiality pledge.

Discussions conducted during mediation may not be used as evidence in any due process hearings or civil proceedings.

In the case that a resolution is reached to resolve the complaint through the mediation process, the parties shall execute a legally binding agreement that sets forth the resolution and that:
   a. states that all discussion that occurred during the mediation process shall be confidential and may not be used as evidence in any subsequent due process hearing or civil proceeding;
   b. is signed by both the parent and a representative of the school district who has the authority to bind such agency; and
   c. is enforceable in any State court of competent jurisdiction or in a district court of the United States.

Further information regarding the mediation process may be obtained by contacting the local school district's superintendent or special education director or by contacting the Nebraska Department of Education.

Due Process Hearings

The parents of a child with a disability have the right to file a due process if they do not agree with school district's identification, evaluation, or proposed placement of their child.

In order to request a due process hearing, the parent must file a petition with the Nebraska Department of Education (NDE). A sample petition is contained in 92 NAC 55, and a copy of that information may be obtained by contacting the Department.

The petition must contain the following information:
   a. the name and address of the petitioner and must be signed by the party filing the petition (or, when represented by an attorney, the signature of the attorney);
   b. the name and address of the school district or educational agency against whom the complaint is made;
   c. the name of the child whose special education is the subject of the petition, the address of the residence of the child, and the name of the school the child is attending;
   d. a description of the nature of the problem of the child relating to the proposed or refused initiation of, or change in, the identification, evaluation or educational placement of the child, or the provision of a free appropriate public education to the child including facts relating to the problem; and
   e. a proposed resolution of the problem to the extent known and available to the party at the time.

A parent must request a due process hearing within 2 years of the date they knew or should have known about the issues in the due process petition. This timeline will not apply to a parent if they were prevented from requesting a hearing due to:
   a. specific misinformation by the school district that it had resolved the issues contained in the due process petition; or
   b. the school district withheld information from the parent that was required to be provided to the parent.
The due process hearing will be conducted by a hearing officer appointed by the Nebraska Department of Education (NDE), and a list, including qualifications, of persons who serve Nebraska as hearing officers is maintained.

A hearing officer:
   a. must not be an employee of the Department of Education or the school district involved in the education of the child;
   b. must not have a personal or professional interest that conflict with their objectivity in the hearing process;
   c. must possess knowledge of the special education process and laws;
   d. must possess the knowledge and ability to conduct hearings in accordance with appropriate, standard legal practice; and
   e. must possess the knowledge and ability to render and write decisions in accordance with appropriate, standard legal practice.

Regarding the due process hearing, parents have the right to:
   a. be informed of any free, low-cost legal or their relevant services if requested or if the school district initiates the due process;
   b. prohibit the introduction of any evidence at the hearing that has not been shared at least five business days before the hearing is conducted;
   c. be accompanied and advised by legal counsel and other individuals with special knowledge or training with respect to children with disabilities;
   d. present evidence and question witnesses;
   e. receive a written or electronic record of the hearing;
   f. open the hearing to the public, if desired;
   g. have the child present during the hearing; and
   h. receive written or electronic findings of fact and a decision no later then 45 days after the request of the hearing unless a waiver of timelines is granted by the hearing officer at the request of the parent or school district.

Resolution Session

After a due process is filed and before a due process hearing is conducted the school district has the opportunity to convene a meeting with the parents and other relevant members of the IEP team who have specific knowledge of the facts identified in the due process petition.

The resolution session:
   a. must be convened within 15 days of receiving notice of the parent's due process filing;
   b. must include a representative of the school district;
   c. may not include the school district's attorney unless the parent is accompanied by an attorney;
   d. offers an opportunity for the parents to discuss the issues in the due process; and
   e. offers the school district the opportunity to resolve the due process issues, unless the parents and the school district agree in writing to waive the session, or agree to use the mediation process.

If the school district has not resolved the due process issues to the satisfaction of the parent within 30 days of the receipt of the due process, the due process hearing will proceed.

The timeline for issuing a final decision begins at the end of this 30-day period.

The failure of a parent filing a due process complaint to participate in the resolution meeting will delay the timelines for the resolution process and due process hearing until the resolution meeting is held.
If the issues in the due process are resolved during the resolution session, the school district and parents must execute a legally binding agreement that is:
   a. signed by both the parent and the school district; and
   b. enforceable in any State or District court.

If the school district and parents execute such an agreement, either party may void the agreement within 3 business days of the agreement's execution.

Maintenance of Current Educational Placement

With the exception of disciplinary issues, during the pendency of any due process proceedings, the child will remain in their current educational placement, unless the State, school district, and parent agree otherwise. If the child is applying for admission into a school district, with the consent of the parent, the child be placed in the school district program until all due process proceedings have been completed.

Civil Action

If either the school district or the parent does not agree with the findings and decisions made by the hearing officer, they have the right to file a court action. The action may be brought in state court or in federal district court. The party bringing the court action will have 90 days from the date of the decision of the hearing officer to bring such an action.

In any civil action, the court:
   a. will receive the records of the administrative proceedings;
   b. will hear additional evidence at the request of either party; and
   c. grant relief as the court determines is appropriate, based on the evidence.

Attorney Fees

School districts can recover attorney fees from the parent's attorney who files a due process that is frivolous, unreasonable, or without foundation, or against the attorney of the parent who continues to litigate after the litigation clearly became frivolous unreasonable, or without foundation.

School districts can recover attorney fees from the parent's attorney or parent if the parent's due process was presented for any improper purpose, such as to harass to cause unnecessary delay, or to needlessly increase the cost of the litigation.

The court, in its discretion, may award reasonable attorneys' fees as part of the costs to a prevailing party.

Fees awarded will be based on rates prevailing in the community in which the hearing arose for the kind and quality of services furnished.

No bonus or multiplier may be used in calculating the fees awarded.

Attorneys' fees may not be awarded and related costs may be not be reimbursed in any action or proceeding for services performed subsequent to the time of a written offer of settlement to parent if:
   a) the offer is made within the time prescribed by Rule 68 of the Federal Rules of Civil Procedure or, in the case of an administrative proceeding, at any more than 10 days before the proceeding begins;
   b) the offer is not accepted within 10 days; and
   c) the court or administrative hearing officer finds that the relief finally obtained by the parents is not more favorable to the parents than the offer of settlement.

Attorneys' fees may not be awarded relating to any meeting of the IEP team unless such meeting is convened as a result of an administrative proceeding or judicial action or at the discretion of the State, for
mediation that is conducted prior to the filing of a request for a due process hearing. A resolution session will not be considered a meeting convened as a result of an administrative hearing or judicial action.

An award of attorneys' fees may be made to a parent who is the prevailing party and who was substantially justified in rejecting the settlement offer.

The court will reduce, accordingly, the amount of attorneys' fees awarded whenever the court finds:
   a. the parent, or the parent's attorney, during the course of the action or proceeding, unreasonably delayed the final resolution of the controversy;
   b. the amount of the attorneys' fees otherwise authorized to be awarded unreasonably exceeds the hourly rate prevailing in the community for similar services by attorneys of reasonably comparable skill, reputation, and experience;
   c. the time spent and legal services furnished were excessive considering the nature of the case; or
   d. the attorney representing the parent did not provide to the school district the appropriate information regarding the prior notice requirement informing the school district of the intent of the parent to file a due process petition.

A reduction in attorneys' fees shall not apply in any action or proceeding if the court finds that the State or school district unreasonably delayed the final resolution of the action or proceeding or if there was a violation of Section 615 (Procedural Safeguards) of IDEA.

State Complaint Procedures

A parent has the right to file a complaint with the Nebraska Department of Education (NDE) regarding the special education and related services of their child if they believe the school district is not complying with state or federal regulations.

The complaint must:
   a) include a statement that the school district has violated a requirement of 92 NAC 51 (Rule 51);
   b) include the facts on which the statement is based;
   c) contain the signature and contact information of the individual filing the complaint;
   d) include the name, address, and school of the child;
   e) include a description of the nature of the problem of the child; and
   f) a proposed resolution of the problem to the extent known and available to the party at the time the compliant was filed.

The complaint must allege a violation that occurred not more than one year prior to the date that the complaint is received.

The party filing the complaint must forward a copy of the complaint to the school district serving the child at the same time the party files the complaint with the Department. This is to ensure that the school district has knowledge of the complaint issues raised and; therefore, an opportunity to resolve them directly with the parent.

Disciplinary Removal of Students with Disabilities

Authority of School Personnel

1. School personnel may consider any unique circumstances on a case-by-case basis when determining whether to order a change of placement for a child with a disability who violates a code of student conduct.
2. School personnel may remove a child with disability who violates a code of student conduct from their current placement to an appropriate interim alternative educational setting (IAES), another setting, or suspension for not more than 10 school days (to the extent such alternatives are applied to children without disabilities).

3. If school personnel seek to order a change of placement that would exceed 10 school days and the behavior is determined not to be a manifestation of child's disability, the relevant disciplinary procedures which apply to children without disabilities may be applied to child in the same manner and for the same duration in which the procedures would be applied to children without disabilities, except services would have to provided, although they may be provided in an IAES.

4. School personnel may remove a student to an IAES for not more than 45 school days whether or not the behavior is determined to be a manifestation of the child's disability if the child:
   a. Carries or possesses a weapon to or at school on school premises or at a school function under the jurisdiction of a State or local educational agency;
   b. Knowingly possesses or uses illegal drugs, or sells or solicits the sale of a controlled substance, while at school, on school premises, or at a school function under the jurisdiction of a State or locale educational agency; or
   c. Has inflicted serious bodily injury upon another person while at school, on school premises, or at a school function under the jurisdiction of a State or local educational agency.

5. The interim alternative educational setting (IAES) will be determined by the IEP team.

Not later than the date on which the decision to take disciplinary action is made, the local educational agency must notify the parents of the decision and of all procedural safeguards.

When a due process regarding placement or the manifest determination has been requested by the parent or school district, the child will remain in the interim alternative educational setting (IAES) pending the decision of the hearing officer or until the expiration of time period of the IAES, whichever occurs first, unless the school district and parent agree otherwise.

Unilateral Placement by Parents of Children into Non-Public Schools

A school district is not required to pay for the cost of education, including special education and related services, for a child with a disability at a nonpublic school if the school district has made a free appropriate public education available to the child, and the parent chooses to place the child in a nonpublic school or facility as a means of obtaining special education and related services.

If the parent of a child with a disability, who previously received special education and related services from a school district, enroll the child in a nonpublic preschool, elementary, or secondary school without the permission of, or a referral by, the school district, a court or hearing officer may require the school district to reimburse the parent for the cost of that enrollment, if the court or hearing officer finds that the school district had not made a free appropriate public education (FAPE) available to the child in a timely manner prior to the enrollment and that the nonpublic placement is appropriate.

Reimbursement to parents may be reduced or denied if:
   a) at the most recent IEP meeting that the parents attended before removing the child from the public school, the parents did not inform the IEP team that they were refusing the placement proposed by the school district to provide a free appropriate public education to the child, including stating their concerns and their intent to enroll the child in a nonpublic school at public expense; or
b) at least ten (10) business days (including any holidays that occur on a business day before removing their child from the public school, the parents did not give written notice to the school district of their concerns and their intent to enroll the child in a nonpublic school at public expense; or

c) before the parents removed the child from the public school, the school district informed the parents, by written notice, of its intent to evaluate the child, but the parents did not make the child available for the evaluation; or
d) a court finds that the actions taken by the parents were unreasonable.

However, **reimbursement to parents may not be reduced or denied** for failure to provide notice to the school if:

a) the parent is illiterate and cannot write in English;
b) continued placement in public school would likely result in physical or serious emotional harm to the child;
c) the school prevented the parent from providing notice; or
d) the parent had not received written notice of their responsibility to provide notice to the school district.
Parent Training and Information Nebraska

Our Mission:
The mission of PTI Nebraska is to provide training, information and support to parents in Nebraska who have a child birth through twenty six with special needs. Resources are provided for parents, other family members, school personnel and interested others.

PTI Nebraska is a statewide resource for families of children with disabilities and special health care needs.

- PTI Nebraska's staff are parent/professionals who are available to talk to parents and professionals about special education, other services and disability specific information.
- PTI Nebraska conducts relevant workshops across the state. Parents, professionals and others are encouraged to attend at no cost. Requests for specific workshops are welcome.
- PTI Nebraska has printed and electronic resources available at no cost.
- PTI Nebraska encourages and supports parents in leadership roles locally and statewide.

You are encouraged to contact us or visit the office, if:

- You would like information about your child's disability
- You have a question about your child's special education program
- You would like to schedule a workshop in your community
- You would like to talk to another parent

Contact Information:
PTI Nebraska - 3135 North 93rd Street - Omaha, Nebraska 68134
(402) 346-0525 - (800) 284-8520 - info@pti-nebraska.org
www.pti-nebraska.org

The Arc of Nebraska also provides information and advocacy on Special Education.
Highlighted Practices:
Some Ways to Get There
Grassroots Organizing

The term “grassroots” refers to organizing at the local level. People who may have no other involvement in policy-making can get together to make changes that are important to them. There is power in numbers. It’s harder for policy makers and politicians to ignore a group of people with the same message than to ignore one person. It starts with one…the power of one…and grows as we network and organize. Members each bring a unique talent to the assembly. The work can be spread out among them. It is even more effective when members write letters, email, and call government officials and those in charge and give the same message. We want action!

Seek out other advocates. You may find them anywhere. Get together wherever you’re comfortable. At first, you may meet at a café or coffee house. Later, you may find you need more room. There are often places that you can go for little or no money. Some churches, especially if one of you belongs, will let you use their meeting rooms. Libraries may have separate areas where groups can gather. You have a better chance for success if you have a plan for putting it together. You can do this from the very beginning if you consciously set out to start one. More likely you’ll find several others to help you. Let’s look at some of the things that will make a difference.

A Successful Group Has the Following:

- **Qualified members:** What qualifies people to become part of the group depends on your goal or mission. Decide who would be a good addition. Then, think about others who might not come to mind so easily. See if another group is already working on the same or a similar issue. Ask colleagues and friends if they are interested. How about the PTA President, the members of a local support group, social service organizations, etc?

- **Commitment to the group:** People who are committed to the “cause” are more likely to take action. Make sure everyone has a chance to participate in group process, goal setting, planning, etc. That doesn’t mean you force everybody to talk…it means make sure they have a chance.

- **Good communication:** Without good communication, the group will quickly fall apart. Figure out what might work for you. Frequent meetings might be great when a lot is going on, but maybe phone calls or emails would work well. Flyers are also helpful in keeping the community informed.

- **Organization:** Some groups die out because of chaos, boredom, or disinterest. Organization can help avoid that. The group should decide on how much structure (rules,) etc. Just be aware that if things start become increasingly disorganized or you find your numbers dwindling, you may need to change things around. Use the group’s wisdom to help work this out – it becomes part of your ongoing work plan.
- **Good Leadership:** Leadership, or the lack of leadership, can make or break a group. But that doesn't mean that your leader tells everybody else what to do. Good leaders guide the group as it develops and members test out their skills.

- **Members who expect the best:** Sure, there will be a time for compromise, but successful groups don't settle for second best unless it's a step towards their goals.

- **Members who recognize and praise each other:** Recognition of the talents of group members helps to keep the group from becoming discouraged. When we are noticed and valued, we are less likely to get burned out. It keeps the energy flowing. Remember our overall philosophy about Social Role Valorization: People have value just as they are. Make sure we let each other hear that loud and clear.
Coalitions are organizations of organizations. They are formed because of some common issue, something they all want to work toward. They may have nothing else in common. Coalitions may be limited to a single issue or have a broader purpose on which the members agree. One example in Nebraska was during the Unicameral session when Medicaid Reform was being designed. Social service organizations, legal advocates, providers of Medicaid services, and grassroots advocates joined together to make sure the resulting legislation was as good as it could be. That was their purpose. The intent was that the group would work on the reform and then they would probably disband. Other coalitions, like the Nebraska Coalition for Citizens with Disabilities, have long-term goals they share. Advocacy for people with disabilities, civil rights, policies that show we value all people, are examples of ongoing coalitions.

In joining a coalition, or in starting one for that matter, ask yourself what issue you share that you can unite and advocate. Decide if there are resources you could share, like expertise on different perspectives on the same topic.

Ground rules may seem obvious, but make them explicit.

- First, potential members want to know what is expected of them. What commitments are they expected to make in terms of time, resources, and money. A sample “job description” is included with these in the following.
- Recognize that members may have somewhat different interests. Expect there to be disagreements, because there will. Be. Disagreements do not signal the end of the group but are part of the process.
- Respect each other and the structure of each other’s agencies/organizations. You can’t always expect every member to be able to agree to sign onto a statements, petitions, or letters immediately. Some representatives will have that ability. Others may have to take it to their organization for approval.
- Having gotten this far, you’ll need to be clear on what you are all about. Put together a mission statement that describes the values of the group. Designing it can be a difficult chore, but there are ways to make it easier. (There are tips included in the Support Materials.)
- Define the process of decision making. This isn’t going to happen overnight. Commit your energy to sticking with it as the process evolves.

As with any group activity, whether a grassroots organization, or a coalition, you need a way to communicate with each other. How will you let everybody know if a meeting place is changed or if some urgent business comes up?

And never be afraid to ask yourselves if you need to gather more information. Use the resources of the group but remember to look for outside materials to help make decisions, design and implement plans, or provide expertise.

You can expect obstacles to come up. We are all too familiar with barriers. In fact, we usually are working to break down those barriers. Keep your eyes on the
prize and recognize each victory no matter how small and you’ll be well on your way to success.

What’s a Mission Statement?

- An organization’s mission is an expression of the values you want to see implemented in your community.
- A mission statement is a stable foundation on which to base planning—both for the long- and short-term.
- Mission statements serve as a good measure of the integrity of a team—there must be consistency among and between the values, vision, goals and objectives, and strategies.
- The heart of a vision of mission is not the actual words, but the process and act of creating it, and then making a commitment to carry it out.

Example of a Coalition Member Job Description

Members of the Coalition will develop and implement plans to accomplish the mission of xxxxx. This team will identify, promote, and coordinate projects that encourage people with disabilities to xxxxx.

Specific Responsibilities:

- Attend Coalition meetings
- Serve as a member of a standing committee, ad hoc committee, task force and/or action team, as needed
- Help assess community needs and identify existing resources
- Develop action plan(s) to carry out the Coalition’s mission
- Develop a mechanism for evaluating and monitoring the strategies

Time Commitment:

- XXX year position
- Xxxxx coalition meetings per year (approximately x hours per meeting)
- Committee/task force/action meetings as needed

Personal Qualities:

- Commitment to xxxxx in the disability community of Nebraska
- Cross disability focus
- Enthusiasm
- Resourcefulness

Serving will provide members with opportunities to:

- Broaden their knowledge
- Gain new experiences and skills
- Increase communication skills
- Work with other community advocates
Nebraska Consortium of Citizens with Disabilities Statement

In recent years, Nebraskan’s with disabilities have faced serious challenges in the areas of disability rights, access to quality health care, mental health care, access to home and community based services, and supports necessary to be productive, independent, and full participating members of our communities. Systemic barriers to access are as wide ranging as disability itself, and can include lack of awareness, failure to commit adequate resources to create responsive service-delivery systems, physical barriers, and, for people with sensory impairments the lack of effective communication.

Independent, productive, healthy people with disabilities are a vast untapped resource, and short-sighted cuts in our investment in this resource will, without question, create even more expensive problems in the future.

The member organizations are committed to policies that support access, choice and control by people with disabilities about where they live, where they get their services, and who provides their services. We are also committed to the principle that people with disabilities must be directly involved in the development of policies that affect their lives, if those policies are to be successful.

Resource issues pose formidable challenges to health care. It is our position that all responses to those challenges must be values-based and must be based on the premise that it is possible to significantly improve services to people with disabilities without inflating the Medicaid budget. We must look to a redistribution of health care resources away from unnecessary use of expensive nursing homes toward community-based services that permit seniors and people with disabilities to remain at home. We must also be prepared for the possibility that if we do not redistribute health care resources, we may need to seek additional funding.

Any community's hope is in its young people. We have a legal and moral obligation to provide an inclusive quality education to children with disabilities. Michigan should also invest in its future. by assuring that all children receive adequate health and mental health care.
Purpose Statement

The purpose of the Nebraska Consortium for Citizens with Disabilities is to provide a forum for groups to identify, discuss, and work toward common legislative goals and the empowerment of people with disabilities.

Through legislative and systems change, cooperative endeavor, and using the talent and expertise of its members, the Nebraska Consortium seeks to improve the quality of life for persons with disabilities by promoting and supporting legislation and regulations that foster:

- independence and human dignity
- a presence and participation in community life
- a status as valued community members
- a potential for growth and development
- an adequate level of high quality services to meet the needs of children and adults with disabilities and their families

(Approved June 15, 1990)
(Reaffirmed July 18, 1994)
**What is Independent Living - A Personal Definition**

Independent Living is a philosophy and a movement of people with disabilities who work for self-determination, equal opportunities and self-respect.

Independent Living does not mean that we want to do everything by ourselves and do not need anybody or that we want to live in isolation.

Independent Living means that we demand the same choices and control in our every-day lives that our non-disabled brothers and sisters, neighbors and friends take for granted. We want to grow up in our families, go to the neighborhood school, use the same bus as our neighbors, work in jobs that are in line with our education and interests, and start families of our own.

Since we are the best experts on our needs, we need to show the solutions we want, need to be in charge of our lives, think and speak for ourselves - just as everybody else.

To this end we must support and learn from each other, organize ourselves and work for political changes that lead to the legal protection of our human and civil rights.

As long as we regard our disabilities as tragedies, we will be pitied. As long as we feel ashamed of who we are, our lives will be regarded as useless. As long as we remain silent, we will be told by others what to do.

Independent Living Philosophy

The philosophy of independent living is the belief that each person with a disability is unique and has the same civil rights as people who do not have a disability. IL advocates place emphasis on:

- People with disabilities should be able to live, work, shop and play where they choose within the community.
- In order for people with disabilities to live in the community, instead of a hospital environment, the community has a responsibility to be accessible.
- Expecting equal access to social, economic and political opportunities for people with disabilities can be compared to expecting equal access for ethnic minorities.
- People with disabilities are not sick. A person with a disability may become ill, but disability is not always an illness.
- People with disabilities should not be in a hospital environment, unless they are sick and in need of acute medical care.
- People with disabilities have the same aspirations as people who do not have disabilities.
- People with disabilities do not wish to be described as "very brave" when they are successful, nor do they seek pity in the manner of the "poster child" image.
- People with disabilities know best what their barriers to independence are and what they need in order to live independently and should have a say in what happens in their community that affects them.

Therefore, people with disabilities are in the best position to guide, direct, and control programs for people with disabilities.

http://www.rehab.cahwnet.gov/ils/ilphil.htm
Sample letter to a Senator
Asking the Senator to cosponsor a bill already introduced

Don’t forget to date the letter.

Tell the senator what you want done.

Include the benefits of doing what I want.

Put in only the contact information you are comfortable with giving out.

Today’s date

Dear Senator XXX:

I am contacting you about Legislative Bill XXX. I would like you to become a cosponsor of the bill because it would make services for people with disabilities easier to obtain.

I am a person with a disability who hopes to continue living in my community, where I can go to movies, to the park, or to stores. I want to have a life just like anybody else would.

The way services are provided today in Nebraska leaves people without the services which would allow them to live independently in the community. We are frustrated. We are afraid we’ll be institutionalized. We want to live at home, not in a nursing home or a state hospital.

LB XXX would reduce the barriers to community based services faced by Nebraskans with disabilities. I urge you to support this bill, in particular by cosponsoring it. Please help it get to a vote on the floor and to pass into law in this session.

Respectfully,

Your name
Your address
Your phone number
Your email address (if you have one)
Main Points of HAVA


The law encourages states to replace punch card and lever voting machines and requires:

- voters to show ID before voting.
- states to provide provisional ballots for voters whose registration status in unclear when they arrive to vote.
- states to provide a way for those with impaired vision or hearing to cast a secret ballot.
- states to make polling locations and voting machines accessible to voters with physical disabilities.
- voting machines to allow voters to verify ballots before they are cast.
- that voters be able to correct a mistake or leave a blank, i.e., not cast a vote in a particular contest.
- that voters be notified if they "misvote," i.e., cast votes for two different candidates running for the same office. Voters must also be told if a misvote will void their ballot.
- voting systems to leave a record that can be audited.
- voting systems to leave a permanent paper record that can be used as an official record should a recount become necessary.
- that states, in some cases, provide ballots for voters who don't speak English.
- states to create and maintain electronic voter registration databases and improve efforts to remove ineligible voters from the registration rolls.
- states to offer sample ballots for voters to review before the date of the election.
- absentee voters to provide copies of IDs or an ID number for voter verification, but states must maintain the secrecy of the vote.
Olmstead for ‘Newbies’

The Olmstead Decision—Background and What It Says and Means

Introduction

This is a lesson about the decision made in the U.S. Supreme Court in June of 1999. It is called Olmstead vs. L.C. The Olmstead decision can help people with disabilities to live in the community and make choices for their own lives...

Lois and Elaine (The Background)...

Lois Curtis and Elaine Wilson had disabilities and lived in a Georgia state hospital. They asked the state if they could live in their own homes. The state said “no.” Susan Jamieson, a Legal Aid attorney, filed a lawsuit for Lois and Elaine to help them live in the community. This lawsuit went to the U.S. Supreme Court.

Lois and Elaine said that they weren’t getting their rights that they deserved in the Americans with Disabilities Act (ADA), under Title II. They should be able to live in the community....

The state said that Lois and Elaine were in institutions to get help. Doctors said that they could get the same help living in the community.

In June 1999, the Supreme Court made the Olmstead vs. L.C. decision. The Court said that Lois and Elaine were right. They could live in the community. The Court said that the state of Georgia was discriminating, or leaving them out, by not letting them live in the community.

What the Decision Says:

Victory

On June 22, 1999, the United States Supreme Court said in Olmstead vs. L.C. that the Americans with Disabilities Act may make states help people with disabilities get services in the community instead of in an institution.

The decision is a victory because it supports these points:

- **Most integrated or included setting**: The U.S. Department of Justice’s laws say that a state must give services to people with disabilities in the most integrated settings, or places included with everyone else.

- **Unjustified isolation**: The ADA says that unjustified isolation, or making a person with disabilities stay somewhere alone, a way from everyone else, is considered wrong.

- **Secure community living opportunities**: It shows that Congress is making sure that it will follow the Developmental Disabilities Act and Rehabilitation Act to get people with disabilities a chance to live in the community.
Requirements

The Supreme Court also told the states that they:

- **Must provide services in a fair and equal manner:** A state must see what services it has provided one person with disabilities and do the same for other people with disabilities.

- **May rely on assessments of its own professionals:** A state can believe what their own doctors say if a person with disabilities qualifies for programs (see *For More Information* at the end of this module).

- **Is protected by law if meets requirements:** If a state has a good working plan to include people with disabilities with everyone else, and has a waiting list that moves quickly, it will be protected in a lawsuit.

What the Decision Means

This means that states must show that they have working plans to place people with disabilities who qualify in the most included places to receive their services. They also must show that their waiting lists are not slow.

New Freedom Initiative

On February 1, 2001, President George W. Bush announced the New Freedom Initiative. The goals of this plan focus on giving people with disabilities more chances to get education, jobs, housing, transportation and equipment to assist people in daily life.

In June 2001, President George W. Bush signed the Olmstead Executive Order. This says that states are supposed to let people with mental disabilities live in the community and not make them live in an institution when:

- the doctors say its right.
- the person with disabilities says it is okay.
- the state can make the placement without problems.

The Olmstead decision applies to people with all types of disability -- not only to people with mental disabilities like Lois and Elaine.
“At Risk” Issue

Some states say that the Olmstead decision covers those “at risk” of institutionalization. For example, if someone with a disability needs more services than they can get in the community, then the person is “at risk” of needing more care than the institution can give. Some states don’t agree and they are going to court over the issue.

But the Olmstead decision agrees with the ADA. The Court said “yes” to the right of individuals with disabilities to get public benefits and services along with everyone else, as long as it fit the person’s needs.

Tommy Olmstead

Tommy Olmstead was the Commissioner of the Georgia Department of Human Services. In that position, he represented the State of Georgia in Lois and Elaine’s lawsuit against the State.

Fact Sheet: 
Person-Centered Planning

Q. What is Person-Centered Planning?
This phrase refers to an entire family of approaches to organizing and guiding individual and community change in collaboration with individuals with disabilities, their families, and their friends. PCP requires important investments in order to build both personal and community support.

Q. What Are Some of the Approaches That Use Person-Centered Planning?
- Whole Life Planning;
- Personal Futures Planning;
- Making Action Plans (MAPS);
- Planning Alternative Tomorrows with Hope (PATH); and
- Essential Lifestyles Planning.

Q. What is Family-Centered Planning (FCP)?
This phrase refers to principles which if followed lead to partnership and collaboration between parents and professionals to ensure the best possible supports and services for a child with a disability and for the child's entire family.

Q. What Are The Key Characteristics of Person-Centered Planning?
1. The person who is at the focus of the planning, and those who love the person, are the primary authorities on the person's life direction.
2. The primary purpose of PCP is to learn through shared action (i.e., the process is more than producing paperwork, it is about taking action to reach goals) and reflection/evaluation of that action.
3. PCP aims to change common patterns of community life (e.g., segregation and congregation of people with disabilities, devaluing stereotypes, inappropriately low expectations, denial of opportunity).
4. PCP requires collaborative action and fundamentally challenges practices that separate people and perpetuate controlling relationships.
5. Respect for the dignity and completeness of the focus person.
6. PCP calls for sustained search for the effective ways to deal with difficult barriers and conflicting demands.
7. Promotes and values accurate individual services and supports, and clarifies individual interests and needs.

8. Shaping services to support a person’s vision of a valued lifestyle.

9. Facilitates change in services to be more responsive to, the interests of people.

10. Search for capacities.

11. Organize efforts in the community to include person, family, and direct support professionals.

12. Focus on quality of life and emphasize dreams, desired outcomes, and meaningful experiences.

Q. What Are The Key Characteristics of Family-Centered Planning?

- Incorporate into policy and practice the recognition that the family is the constant in a child’s life, while the service system and support persons fluctuate.

- Strive for family and professional collaboration in all settings (home, community, hospital, school), especially in the areas of care giving, program development, program implementation, program evaluation, program evolution, and policy formulation.

- Exchange complete and unbiased information between families and professionals in supportive manner at all times.

- Incorporate into policy and practice the recognition and honoring of cultural diversity, strengths, and individuality within and across all families: including, ethnic, racial, spiritual, social, economic, educational, and geographic diversity.

- Recognize and respect different methods of coping.

- Implement comprehensive policies and programs that provide developmental, educational, emotional, environmental, and financial supports which meet the diverse needs of families.

- Encourage family-to-family support and networking.

- Ensure that all service and support systems for children with disabilities and their families are flexible, accessible, and comprehensive in responding to diverse family identified needs.

- Appreciate families as families and children as children, recognizing that they possess a wide range of strengths, concerns, emotions, and aspirations beyond their need for specialized services and supports.
Q. What Are the Limitations of Person & Family-Centered Planning?

- Belief that only certain families or individuals can use or will benefit from PCP/FCP,
- Lack of training in understanding and honoring cultural diversity,
- Tendency for professionals to be seen in the role of expert,
- Lack of open and effective communication,
- Traditional model of service delivery is entrenched,
- Moves slowly if the focus person's vision is not clear,
- Requires a lot of learning to develop the supports and create the opportunities the person needs,
- Family members and professionals can define people in clinical terms,
- Often done in isolation from other complementary systems change efforts.
- Requires a large expenditure of time and,
- Not a quick fix or a cure all for people's difficulties.

AAMR's Policy

The AAMR has no official position on person or family centered planning.

References

Resources

1. Virginia Institute for Developmental Disabilities, Virginia Commonwealth University, 301 West Franklin Street, #1514, P.O. Box 843020, Richmond, VA, 23284-3020. Point of contact: Anne Malatchi, (804) 828-8593, (804) 828-0042.


4. Rehabilitation Research and Training Center on Supported Employment, Virginia Commonwealth University, 1314 West Main Street, Richmond, VA, 23220. (804) 828-1851. Fax: (804) 828-2193.

5. Communitas, Inc., P.O. Box 374, Manchester, CT, 06040. (202) 645-6976.

Last Updated: March 23, 2005 1:46 PM
Planning Process

Gather Information

Describe Desired Outcomes

Propose Alternatives

Analyze Alternatives

Select the Best Alternatives

Plan Action Steps

Take Action

Evaluate

Notes:
“More on Waivers”

HCBS Waivers Section 1915 (c)

States may offer a variety of services to consumers under an HCBS waiver program and the number of services that can be provided is not limited. These programs may provide a combination of both traditional medical services (i.e. dental services, skilled nursing services) as well as non-medical services (i.e. respite, case management, environmental modifications). Family members and friends may be providers of waiver services if they meet the specified provider qualifications. However, in general spouses and parents of minor children cannot be paid providers of waiver services.

States have the discretion to choose the number of consumers to serve in a HCBS waiver program. Once approved by CMS, a state is held to the number of persons estimated in its application but has the flexibility to serve greater or fewer numbers of consumers by submitting an amendment to CMS for approval.

APPLICATION & APPROVAL PROCESS

The State Medicaid agency must submit to CMS for review and approval an application for an HCBS waiver, and the State Medicaid Agency has the ultimate responsibility for an HCBS waiver program, although it may delegate the day-to-day operation of the program to another entity. Initial HCBS waivers are approved for a three-year period, and waivers are renewed for five-year intervals.

PROVISIONS WAIVED

Section 1902(a)(1), regarding statewideness. This allows states to target waivers to particular areas of the state where the need is greatest, or perhaps where certain types of providers are available.

Section 1902(a)(10)(B), regarding comparability of services. This allows states to make waiver services available to people at risk of institutionalization, without being required to make waiver services available to the Medicaid population at large. States use this authority to target services to particular groups, such as elderly individuals, technology-dependent children, or persons with mental retardation or developmental disabilities. States may also target services on the basis of disease or condition, such as Acquired Immune Deficiency Syndrome.

Section 1902(a)(10)(C)(i)(III), regarding income and resource rules applicable in the community. This allows states to provide Medicaid to persons who would otherwise be eligible only in an institutional setting, often due to the income and resources of a spouse or parent. States may also use spousal impoverishment rules to determine financial eligibility for waiver services.

PROGRAM REQUIREMENTS

Within the parameters of broad Federal guidelines, States have the flexibility to develop HCBS waiver programs designed to meet the specific needs of targeted populations. Federal requirements for states choosing to implement an HCBS waiver program include:
• Demonstrating that providing waiver services to a target population is no more costly than the cost of services these individuals would receive in an institution.
• Ensuring that measures will be taken to protect the health and welfare of consumers.
• Providing adequate and reasonable provider standards to meet the needs of the target population.
• Ensuring that services are provided in accordance with a plan of care.

**OLMSTEAD & HCBS WAIVERS**

In the 1999 Olmstead v. L.C. decision, the Supreme Court affirmed the right of individuals with disabilities to receive public benefits and services in the most integrated setting appropriate to their needs. The Olmstead v. L.C. decision interpreted Title II of the American with Disabilities Act (ADA) and its implementing regulations. Medicaid can be an important resource to assist states in fulfilling their obligations under ADA. The HCBS waiver program in particular is a viable option for states to use to provide integrated community-based long-term care services and supports to qualified Medicaid eligible recipients.

**CURRENT STATUS**

Forty-eight States and the District of Columbia offer services through HCBS waivers, and Arizona operates a similar program under section 1115 research and demonstration authority. There is no federal requirement limiting the number of HCBS waiver programs a state may operate at any given time, and currently there are approximately 287 active HCBS waiver programs in operation throughout the country.

Page Last Modified: 1/4/06 9:19 AM
Nebraska Early Childhood Interagency Coordinating Council

CONTACTS

Note: For information about ECICC or ECICC membership, please contact Susan Dahm, Secretary

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Principles of Family Involvement

Developed by the Federal Interagency Coordinating Council

Demonstrate family independence and contribution.

- Develop a plan for identifying a diverse, representative group of families to participate.
- During and after meetings, specifically recognize the value of the family's participation.
- Recognize individual family strengths while respecting the different methods of coping and adjustment.¹
- Demonstrate how Federal programs support families to attend national conferences.

Provide family identified supports to assist the family's participation.

- Provide convenient meeting times and locations for family members.
- Compensate families for their time, expertise, and expenses.
- Clearly identify a staff person to be the primary contact person for reimbursement and other issues. Be sure she/he understands that timely reimbursement and contacts are essential.
- Develop provisions that ensure that parents are present to participate in policy related activities including direct staff support, stipends, travel expenses, and childcare.
- Identify these supports in RFP's, grants, and policy.
- Provide complete, appropriate information prior to meetings in a timely manner.
- Match veteran parents with inexperienced family members to ensure that new members feel supported in their roles as advisors and have the opportunity to share their ideas.
- Consider incorporating a "family leave" policy so family members can choose an inactive role but maintain their membership should family circumstances require some time off.
  - Recognize that some family members may require more and different kinds of support than others to participate in a meaningful way.
  - Encourage and facilitate family-to-family support and networking.²

Provide formal orientation for families and provide information for involving them.

¹ Source: Caring for Our Children: National Resource Center for HTML
² Source: Caring for Our Children: National Resource Center for HTML
- Provide orientation to both family members and staff about the issues, participants, and process.
- Provide informational support for parents to be prepared to participate as equal partners on a "level playing field" with their professional counterparts.
- Provide technical assistance, leadership mentoring, training, and other parent leadership teaming.

**Ensure diversity among family members:**
- Honor the racial, ethnic, cultural, and socioeconomic diversity of families.\(^3\)
  - Provide all materials in the families' preferred language.
- Recruit broadly from the community and the population the program serves.
- Bring in new families.
- Adapt collaborative models to diverse cultures.
- Manage changing distribution of power and responsibility. Incorporate principles of collaboration into professional education.\(^4\)
- Insure broad representation among parent groups based upon the community(s) in question.
- Be particularly careful to include members of traditionally underserved groups.
- Avoid any appearance of tokenism.

**Be ready to hear what families say:**
- Encourage and support family members to find their voice.
- Ensure that parent perspectives are not considered a separate component of the policymaking process, but instead are infused throughout.
- Always consider an individual parent’s story as being valid.

**Respect the passion families have for change.**

**Celebrate the partnerships of working together for change.**
- Support staff in developing an understanding of the value of family participation.
- Provide clear information about the goals of the board, task force, or committee and the role of individual members and the roles of family members.
- Balance membership on committees between families and professionals.
- Consider shared leadership - parent and professional co-chairs or teaming.

2 ibid.

3 ibid.