

About Consumer Advisory Committee

What is the Name of Our Consumer Advisory Committee?



We are the North Dakota Center for Persons with Disabilities (NDCPD) Consumer Advisory Council or CAC. This committee helps the Executive Director make and review NDCPD's annual and five-year plans. Fifteen people serve on the committee. Most of the members have disabilities or are family members of people with disabilities.

The CAC meets four times each year. One meeting is held in Minot. This meeting gives the members a chance to see each other face-to-face. The other three meetings are held using video conference technology. Most people go to a video-conference center in or near their home town to participate.

We will tell you more about the CAC later in this manual.

What is the Reason for Having a Consumer Advisory Committee?

We have a Consumer Advisory Committee (CAC) for two reasons:

1. We need ideas from the people we hope will benefit from our teaching, research and services.
2. It's the law. Congress passed a special law called the DD Act. This law requires University Centers to have a CAC.

What is the DD Act?

The DD Act is an important law. It was first passed by Congress in 1970. The DD Act requires your state to provide support to people with disabilities and their families. Without the law, you might not get some important services. The DD Act has been changed several times. Whenever the law is updated that is called a re-authorization.

What does the DD Act mean for me?

Here are some things you should know about the DD Act.

What The DD Act Does	 What Happens in Our State
1. Defines the words "developmental disabilities" or DD.	Our state uses a different definition. This definition is more restrictive.
2. Gives you a place to go with complaints.	The North Dakota Protection and Advocacy Project investigate complaints in ND.
3. Funds new programs to help people	The North Dakota State Council on Developmental Disabilities (NDSCDD) gives out grants every year to help people with disabilities and families.
4. Funds each state's Center of Excellence.	NDCPD is our Center of Excellence.
5. Requires 3 sister agencies to work together.	The sister agencies are NDCPD , the North Dakota Protection & Advocacy Project and the State Council on DD .
6. Requires the Center for Excellence to have a CAC.	The NDCPD has a CAC. You have a chance to serve on the CAC and become a leader in your state.
7. Requires sister agencies to show how well they have done their job. States must: <ul style="list-style-type: none"> • Have a state plan for each agency. • Have goals/objectives that people with disabilities help to make. • Show the progress on goals/objectives. • Ask advisory councils how to improve the plan or how to make progress. 	Each of the sister organizations in ND have a strategic plan with goals and objectives that people with disabilities helped to make. The CAC reviews NDCPD's progress on this plan each year and makes recommendations.
8. Spells out the rights of adults and children with developmental disabilities. Examples of rights: You have a right to be free from abuse or neglect. You have a right to have and keep your own possessions.	The ND Bill of Rights contains many important rights. The Department of Human Services has adopted many of the rights from the DD act.
9. Lists rules for providing services to people with developmental Disabilities.	Examples of service rules: <ul style="list-style-type: none"> • All people with DD who get services must have a written plan for services. The plan must include goals and objectives. • States must offer home and community based services.

How can I learn more about the DD Act?

If you would like to read more about the DD act you can:

Select the link titled History of the DD Act. This link will take you to a simple, easy-to-read history of the act and each amendment.

Go to the website for the Administration on DD at:
<http://www.acf.hhs.gov/programs/add/> and read the entire law.

The DD Act and our CAC.

The DD Act has special rules about CACs. The rules tell:

- Who can serve on a CAC
- What policies every CAC must follow
- Who can lead a CAC
- What tasks CACs must complete

The CAC has by-laws that tell how our committee works. One job we have as members is to make sure our by-laws:

- Follow the rules of the DD act
- Address other issues that Congress left to us to decide

You can read more about the rules that our CAC needs to follow later in this manual.

We hope knowing these rules will help you:

- Feel more confident at meetings
- Be aware of what the DD Act says
- Be an informed member of the CAC

About Our NDCPD

What Can You Tell Me About the History of NDCPD?

About NDCPD:

NDCPD's mission statement is:

“. . . to provide leadership and innovation that advances the state-of-the-art and to empower people with disabilities to challenge expectations, achieve personal goals, and be included in all aspects of community life.”

NDCPD is a University Center for Excellence in Developmental Disabilities Education, Research, and Service. NDCPD is one of 63 similar centers located at universities throughout the United States. There is at least one center in every state.

NDCPD was started in 1993. At first we were a satellite of the center in Utah. Then we became a stand-alone center. Today NDCPD employs over 100 staff and students and has many different projects. All of these are funded by grants from the Federal or State government. A list of current projects, a copy of the current five-year work plan and a copy of the annual goals are included in the Appendix.

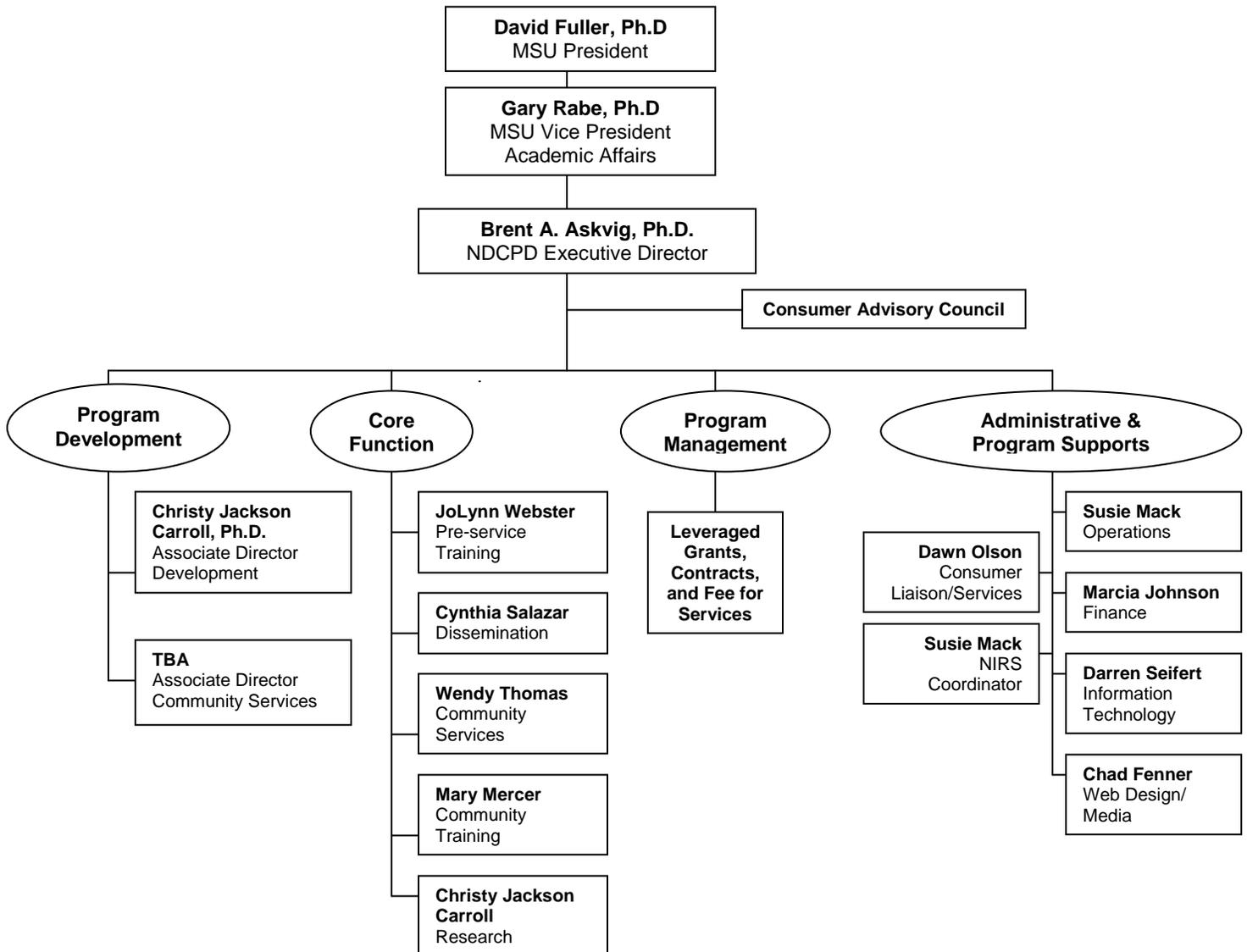
Strengths:

NDCPD has many staff. Some teach university courses. Others work only on grants. The staff members have degrees in special education, psychology, communication, business and information management. This knowledge helps NDCPD:

- Write grants
- Offer services
- Provide training
- Conduct research
- Provide leadership
- Publish information
- Give technical assistance
- Work with ND policymakers
- Find new ways to use technology

Organizational Structure

The chart below shows how NDCPD is organized.



Boards and Committees

What Kind of Committee is the CAC?

Let's think about the different kinds of boards and committees. There are two kinds of committees or boards. One is an advisory board. The other is a governing board.

- Advisory boards give advice
- Governing boards make decisions

On Advisory Boards:

- People with different skills and ideas
- Study important issues
- Review goals and plans
- Collect input from members
- Visit with people in the community
- Make recommendations about issues

On Governing Boards:

- People who know about the agency
- Have roles and responsibilities defined by law
- Make rules and policies about the agency
- Decide how the budget is spent
- Hire and supervise the Executive Director

Which Kind of Board is the CAC?

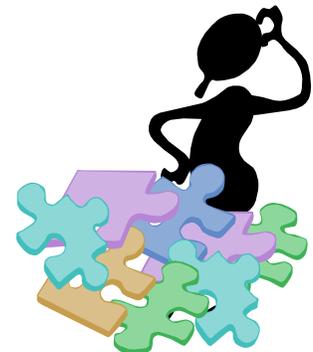
The CAC is an advisory board. The NDCPD's CAC follows by-laws developed by the members. By-laws are written policies or rules. They describe the:

- Purpose
- Mission
- Membership
- Roles
- Terms
- Attendance
- Officers
- Responsibilities

Most committees or boards follow by-laws. You can find our by-laws in this manual and on the NDCPD web page at <http://www.ndcpd.org>.

If you serve on the CAC you may:

- Help yourself and others
- Get information
- Influence others
- Promote change



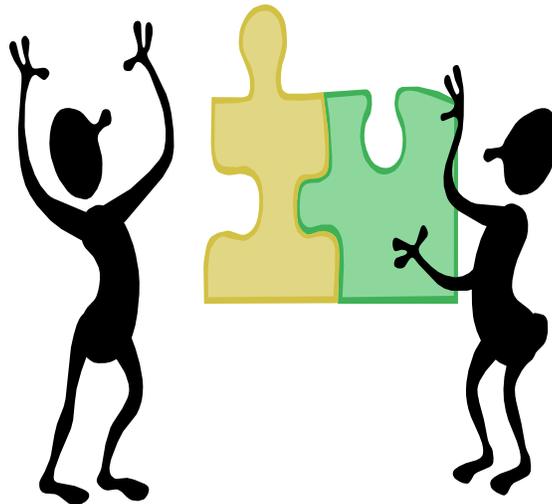
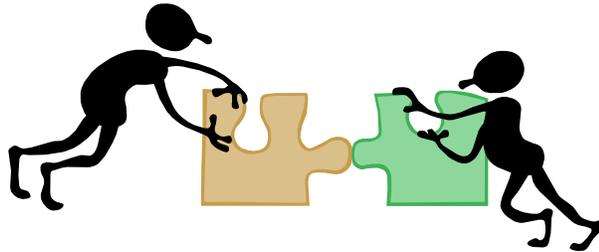
Is the CAC a Good Match for You?

Think about your expectations:

- Will the CAC help you make changes?
- Will the CAC help you learn and grow?

Think about your experience:

- Will your experience give you something to say?
- Can you help or contribute?
- What do you have in common with other members?
- Can you contact and represent others?



Participation

What can I Expect During the Meeting? How do I Participate?

Meetings begin at 9 AM. They are always held on Saturdays. The Chairperson sets the agenda. NDCPD gives her/him a list of topics for the agenda. Members may send topics as well. The Chairperson approves and sets the final agenda and may add topics too. Each member gets a copy. The Chairperson opens the meeting with a gavel.

NDCPD highlights 1-2 projects for the committee at each meeting. NDCPD staff are invited to the meeting and they tell about their project. CAC members ask questions and make recommendations.

Next the CAC reviews the minutes from the previous meeting. Then they take care of any business. The CAC uses a list of important activities to decide what must be done at each meeting.

A sample of activities for each meeting includes:

1. Leadership

- Highlight two NDCPD projects
- Report on member activities

2. Old business

- Review previous minutes
- Review membership
- Review committee reports
- Review recruitment
- Review NDCPD staff changes

3. New business

- Review changes in DD Act
- Review annual goals
- Review progress on annual goals
- Review annual reports
- Review five year reports
- Other special tasks as needed

4. Participatory action research

5. Other topics & close

You can contribute during each meeting in many ways:

- Listen and observe what others do
- Be prepared; Study information before the meeting
- Be supportive and say positive things about others
- Be brief; Save long stories for later
- Use critical thinking; Share good ideas
- Make or second a motion: "I move that we . . ."
- Offer to help with fundraising
- Become informed. Share what you know.

You can also contribute after each meeting:

- Read the minutes
- Get and read a copy of the Collaborator (NDCPD newsletter)
- Be active in your community to benefit people with disabilities or families



Advocacy

Can NDCPD help me Advocate for What I/My child needs?

NDCPD is a University Center. We advocate for people with disabilities in special ways. We:
Conduct research

- Help agencies build capacity
- Teach
- Test and design new services
- Build technology
- Work with policymakers
- Find new funds
- Work with advocate groups

NDCPD does not advocate for individuals. We refer people to other appropriate supports for individual advocacy.

CAC members often tell their story during meetings. They talk about issues that are important to them. We encourage members to do this. They know that it does not mean that NDCPD will take on that issue. We will consider all input in setting goals and in looking at new projects.

You have many different roles as an advocate for yourself or your child. NDCPD has different roles too. Serving on an advisory committee for a University Center is one role you have. Look at the chart on the next page.

The Advocacy Continuum

The many roles of a disability advocate

Typical CAC activities are shaded

CAC Advisory Capacity



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(Chart created by Laura Walker- AUCD Policy Fellow – 2006)

This chart shows different ways of advocating. Some you do as an individual. You may write letters, chain yourself to a tree, picket the courthouse or meet with your child's teacher. As a member of the CAC you may take on other roles. These include helping with a conference, attending a meeting, reviewing information or telling about your experiences as a person with a disability.

Sometimes we *educate* and sometimes we *advocate*. CAC members advise the University Center for Excellence in Developmental Disabilities (UCEDD) and educate people in the community about the work of the UCEDD. When you advocate for yourselves, for family members or other people, you represent yourself or others, not NDCPD.

You represent NDCPD in the community as an *educator*, not an *advocate*. Examples:

- Volunteer to sit at a display booth at a conference
- Educate policymakers about the resources the UCEDD provides to people with disabilities in your state
- Tell your friends, community members, and other organizations you support about the resources of NDCPD

When you attend a CAC meeting, your experience is important to NDCPD.

Membership

Who serves on the NDCPD CAC?

Membership:

The NDCPD Consumer Advisory Committee (CAC) has 15 members. Members serve for one 3-year term. They can be invited to serve for an additional 3 years. This limits membership and allows new leaders to have an opportunity to participate.

- A majority of the members must be people with disabilities or family members
- At least half the members must represent people with disabilities or family members
- One person must represent a self-advocate group
- One person must represent the ND State DD Council
- One person must represent the ND Protection & Advocacy Project
- These three people cannot be counted as representing people with disabilities or family members because they are representing an agency or group
- The members must represent the ethnic & geographic diversity of the state.
 - One member who is Native American
 - One member who is Hispanic
 - Members from all parts of the state

A brief biography about the CAC members is located in the Appendix of the manual.

Officers:

The CAC has a Chairperson and a Vice-Chairperson. The Chairperson sets the agenda, forms committees, holds meetings, helps with recruitment and guides the meeting. The Chairperson also sends correspondence to the Executive Director as needed. The Vice-Chairperson assists the Chairperson as requested and fills in if the Chairperson cannot attend a meeting.

Committees:

The CAC can have several committees. Currently we have two:

Scholarship Committee:

The purpose of this committee is to review applications for an annual NDCPD scholarship. They set the criterion for how the dollars will be awarded. They also decide how the applications will be judged. The judging process usually takes place by conference call and happens in the spring of the year.

Recruitment Committee:

This committee reviews applications of people who want to serve on the CAC. They make a formal recommendation to the Executive Director for the person they prefer.

Responsibilities

What Are the Responsibilities of the CAC?

The CAC has several important responsibilities. *All* members are expected to help with the work of the committee by attending meetings, serving on committees, reviewing information and making recommendations. The members must:

- Hold at least two meetings per year
- Recruit enough members for a quorum
- Periodically review the mission statement
- Become familiar with the DD Act
- Review annual priorities
- Help to establish & review NDCPD's 5 year plan
- Help to establish & review NDCPD's annual plan
- Review progress toward both plans
- Make recommendations to the Executive Director

NDCPD has developed an annual or quarterly schedule to guide the CAC in completing important tasks. The Chairperson can follow this schedule in setting the agenda.

Annual/Quarterly Schedule:

January – Video-conference meeting

- Review progress on the five year plan to date
- Review recruitment strategies/initiative for coming year
- Outline priorities for the coming year

April - Video-conference meeting

- Review responsibilities under the DD Act
- Review mission statement
- Review by-laws

July - Video-conference meeting

- Plan CAC initiatives for the coming year
- Meet and exchange information with NDCPD staff
- Update the biography for existing members
- Review officer roles and hold elections as needed

October – Face-to-face meeting

- Share annual NDCPD and ADD reports
- Discuss progress made toward annual goals
- Set dates for the coming year

Five-Year Plan and Annual Plan Review:

Every five years NDCPD must re-apply for core funds from the Administration on Developmental Disabilities. These funds are then used to find or get other grants that NDCPD uses to carry out its mission.

The five-year plan is a set of goals for each year (annual) that show how the core funds will be used. The core funds are usually not enough to achieve the plan. NDCPD uses those funds to find other grants and find partners to help carry out the goals. NDCPD usually works closely with its sister agencies in carrying out the plans.

A copy of the most recent five-year and annual plans are included at the end of this manual.

CAC members will be asked at times to review both the five-year and the annual plans. This review involves:

What We Do	How We Accomplish That Task
Set Priorities	<ul style="list-style-type: none"> • NDCPD prepares a list of key issues or topics • CAC reviews the list and may add to them • Each CAC member considers them from their point of view • CAC members rank or rate them in order of importance
Establish the Five-Year Plan	<ul style="list-style-type: none"> • NDCPD uses the CAC priorities to draft goals and objectives • CAC members review the draft goals and objectives • CAC members consider if the goals match our mission • CAC members consider if the goals reflect the priorities • CAC members make sure no priority was left out of the plan • NDCPD finalizes the goals and objectives
Establish the Annual or Yearly Plan	<ul style="list-style-type: none"> • NDCPD shares a list of the goals/objectives for the year • CAC members review the goals and objectives • CAC members offer input based on ongoing changes in the state
Review progress toward the Five-Year Plan	<ul style="list-style-type: none"> • NDCPD provides a brief report of progress on goals to the CAC • NDCPD shares charts & graphs to clarify information • CAC members review progress and offer recommendations

The results of these activities are documented in the CAC meeting minutes.

Other Important Responsibilities:

The CAC has traditionally been involved in:

- Reviewing the mission statement at least once every five years
- Reviewing the by-laws at least once every five years
- Offering feedback or input on important projects at every meeting
- Participating on committees as requested
- Participating in research activities, attending workshops or conferences or participating in the grant development process

NDCPD provides special training and support when CAC members show interest in any of these activities.



Recruitment

How Do We Find People To Serve on the CAC?

Membership:

There are several rules in the DD Act about CAC membership.

1. CAC members must match the racial and ethnic diversity of our state.

NDCPD uses numbers from the 2000 Census to make decisions about the racial diversity in ND. This means that while most members may be Caucasian, at least one must be Hispanic or Latino and one must be Native American.

2. We try to recruit members from throughout ND, not just from Minot.

It has been more difficult to recruit members from the western side of the state outside of Minot.

3. We also try to find people with different kinds of disabilities to serve.

Membership on the CAC is often the first leadership experience for many people. A chart in the Appendix shows the membership for our CAC and the racial and ethnic diversity.

Service:

People decide to serve on the CAC for many different reasons. Understanding why people serve can help you participate in recruitment activities as a member of the CAC. NDCPD has spoken with current and past members as well as CAC members from other communities and states. This is what they said:

Top reasons for agreeing to join and staying:

- Having fun together
- Free meal
- Reviewing the 5 year plan in advance
- Knowing in advance what NDCPD expects
- Having a place to go to express opinions and be taken seriously
- Representing a constituent group
- Learn about resources and duplication
- Getting to know people and forming relationships
- Learning all about the different projects
- Being asked to give some input in the process

CAC members like to know what to expect at the meeting and how to participate. When planning the agenda, the Chairperson should let members know if they need to:

- Take part in a discussion
- Come to a conclusion
- Make a motion
- Make recommendations
- Arrive at a consensus
- Do participatory action research or PAR

Recruitment:

Finding new members is the responsibility of everyone. The most common way to find new CAC members has been through word of mouth. If each CAC member asks at least one person they know to serve on the committee every year it can really help with recruitment. Other strategies that the CAC can use include:

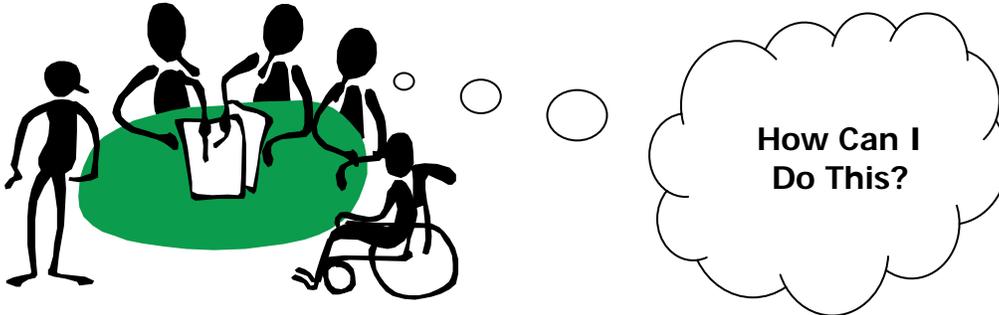
- Get recommendations from the NDCPD staff
- Bring posters and handouts about CAC to conferences
- Use radio and TV PSAs to find new members
- Hold community recruitment meetings with meals and a speaker
- Display posters in human service centers and colleges
- Send out letters, brochures and applications

Recruitment materials:

NDCPD has developed several different recruitment brochures and posters. Copies may be found in the appendix.

Support

What Support Can I Get to Serve on the CAC?



People with disabilities often have physical, sensory or learning challenges. This can make it difficult to get information or travel to meetings. NDCPD offers support. We value your ideas and life experience. We want *all* of the members to be equal players on the committee.

Talking about support is everyone's job. Don't wait for someone else to bring it up. When you agree to be on the committee, please feel free to tell us about your needs. Why not start with a simple question: *Tell me what support you offer members with disabilities or their families!*

Both NDCPD and you have an important job when it comes to planning support.

Your Job	NDCPD'S Job
<ul style="list-style-type: none"> • Think about your needs • Ask about support • Talk about details • Ask for what you need • Be flexible • Make wise decisions 	<ul style="list-style-type: none"> • Listen to people's needs • Be flexible • Think outside the box • Look for resources • Live within a budget • Meet ADA rules

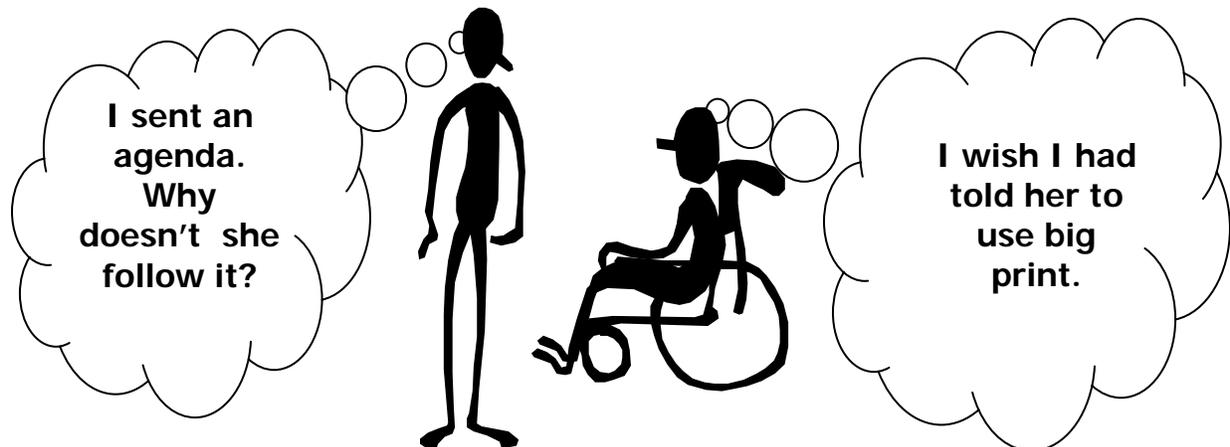
You might wonder what to say about your situation:

- Do I tell people about my disability?
- How much information should I give?
- How exactly do I ask for help?
- How do I want people to see me?
- How do I get what I really need?
- Where do I start?

You do not need to share too many details about your disabilities. We do not need to know your life history. Focus instead on what would be helpful for you. Please think about your situation. Make a list of what would help you:

- Get to the meeting
- Get information and understand
- Be an equal player

Then talk to NDCPD's Chairperson (contact information is in the back of the manual) or Consumer Affairs Coordinator. Remember: Even when another person can see that you have a physical or sensory challenge, they may not realize what you need.



Feel free to share your needs with confidence. You may have had difficult experiences in the past. We hope that won't be the case with us. If problems do happen, just let us know and we will do our best to solve them together.

Past members of the CAC have suggested strategies that work well in helping people gain confidence and overcome past experiences as a victim.

What Works Well	Self-Defeating Strategies
<ul style="list-style-type: none"> • Get to the point • Ask for what you need • Let your light shine • Look for ways to help • Focus on what works • Look for solutions 	<ul style="list-style-type: none"> • Demand attention • Give too many details • Complain • Criticize others • Hold back in fear • Wait to be rescued

Plan Your Support Needs:

Location: The annual fall meeting is held:

- In Minot
- On the MSU campus
- In Memorial Hall
- This building is accessible
- A map will be provided
- This is our chance to meet face-to-face

Video-conference meetings:

We will contact you to learn where you live. Then we will locate a video conference center near your home that is open on Saturday. We will call you with the address and arrange for the building and room to be open.

Transportation:

It is your responsibility to get to and from the meeting. These are options we are aware of and you may know of more:

- Drive your own car
- Ride with another CAC member
- Take a cab
- Ride a bus or dial a ride vehicle
- Get a ride from a support agency
- Ride a train

Participation Costs:

You will be asked to sign a form at the meeting to request reimbursement of your meeting participation cost.

- NDCPD pays a \$100 stipend to each member for their meeting participation
- We provide a \$50 stipend for a personal attendant or child care as needed (may require a paid receipt)
- We will reimburse members for mileage at \$0.40 per mile if you live outside of Minot
- You will be reimbursed for meal cost (per State rates and policies) if you travel to Minot for a meeting
- We will reimburse members for lodging (per State rates and policies) if you live more than two hours away from Minot.
- Special supports such as interpreters or providing materials in Braille are arranged on an individual basis.

Pre-Expense Cost Support:

We know that some CAC members may need up-front support for the costs associated with attending a meeting. It is appropriate to ask for payment for any participation costs not already listed above that are related to your disability or a minor child. Please visit with the Chairperson at least two weeks in advance if you need support to attend.

Pre-expense cost support may include:

- Purchase of a bus or train ticket
- Partial cost of transportation sent to you in advance
- Lodging expense arranged by and paid by NDCPD if you live more than two hours away from Minot

What Information will be Shared at the Meeting?

NDCPD will send you an agenda for the meeting a few days in advance. Copies of the handouts are often provided at the same time. Materials can be sent in alternate formats. It is common for members to ask that materials be sent electronically. Call two weeks before a meeting to let us know about needs or changes.

Let NDCPD staff know if you need additional supports to participate. Do you need to?

- Sit near speakers
- Use an FM system
- Use an interpreter
- View materials in advance
- Use captioning

Be sure to think about what else would help you participate. What would help? These are some items that members have asked for over the last several years:

- Pictures & key words
- Summarizing what was said
- Extra time to take it all in
- Special lighting
- Frequent breaks
- Activities to help me focus
- A sighted guide
- Space or water for a service animal
- Information on area child care providers
- A lower or higher table during meetings
- Name tags to help remember names
- Information about Robert's Rules of Order (Special rules that people follow in formal meetings)

Be sure to let us know what language you use for communication.

- English?
- Spanish or Latino?

- Other _____
- Sign language?

Appendix

- Appendix 1. Alphabet Soup
- Appendix 2. Application Form
- Appendix 3. Recruitment brochure
- Appendix 4. Recruitment poster
- Appendix 5. Reimbursement Form
- Appendix 6. Membership List
- Appendix 7. Photo release form
- Appendix 8. By-Laws

