As part of the Developmental Disabilities Assistance and Bill of Rights Act, and with a strong belief that the American Dream belongs to everyone, three organizations formed a collaborative network to service individuals with developmental disabilities living in North Dakota. The network was named the North Dakota Developmental Disabilities Network (NDDDN), and includes: The North Dakota Protection and Advocacy Project, the North Dakota Center for Persons with Disabilities, and the North Dakota State Council on Developmental Disabilities. The trio strives to assure that individuals with developmental disabilities and their families participate in the design of and have access to culturally competent community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, integration, and inclusion in all facets of community life.

The activities of each entity belonging to NDDDN fall within core emphasis areas established at the federal level. Emphasis areas include:

- quality assurance activities
- education and early intervention activities
- child-care related activities
- health-related activities
- employment-related activities
- housing-related activities
- transportation-related activities
- recreation-related activities
- other services available/offered to individuals in a community, including formal and informal community supports that affect quality of life

To gather current input on these emphasis areas, a series of summit meetings were designed. The summits were structured to encourage discussion and input from participants, and to gather information from professionals working in the emphasis areas. Each summit meeting covered one emphasis area, began with a keynote speaker, involved the audience in small group work, and featured a panel of presenters who discussed their particular experience with some aspect of the emphasis area. During the small group work, participants developed lists of actionable steps that may possibly be used by NDDDN agencies in future strategic goal planning. Results of the summit meetings are published in white papers and disseminated through websites to make information available to a broader range of constituents.

On November 17, 2009, the Days Hotel – Grand Dakota Lodge & Conference Center in Dickinson, ND hosted the Quality Assurance and Disability Summit. The summit opened with an explanation of the
NDDDN and its purpose. Participants of the workshop were introduced, and asked to identify their expectations for the summit. Identified expectations included:

- How we can work as a team and with government
- Transition from H.S. out
- Learn how QA works with services
- Listen/learn
- Learn about QA
- Initiate SA in Dickinson
- Network; hear from others; make a difference
- I.D. needs
- How we can improve
- Learn from each other
- Family perspective at the table
- QA – present & learn
- Consumer perspective
- Learn how SA can help

Issues and challenges surrounding quality assurance and disability included:

- Making sure the product is good
- Consistent; good services
- Quality improvements – fix problems
- Big picture – future
- Efficiency; not duplicating; using all resources
- Monitoring (positives and negatives)
- Analyze trends, data
- QA is ongoing/preventative
- Being open to change
- Checks and balances
- Defining quality – guidelines/standards

Vicci Pederson, Program Administrator for Quality Assurance in the state Developmental Disability Division under the Department of Human Services, was the keynote speaker. Ms. Pederson presented an overview on quality assurance and how it impacts the delivery of services to individuals with developmental disabilities.

Based on the information presented by the keynote speaker, three main topic areas were developed and written on flow charts, which were then placed around the room. Following the keynote presentation, summit participants were directed to pick the topics they were most interested in, and spend fifteen minutes in discussion to identify actionable steps that could address each topic area. This process was completed two additional times, which provided participants the opportunity to discuss all topic areas. Topic areas and actionable steps identified during the small group work included:
Customer Involvement in Quality Assurance:

- Eliminate the “run-a-round” and extra paperwork
- Treated like a person – not a number; fairness
- Time crunches – eliminate bureaucracy (Be quick)
- Schedules need to be more customer flexible
- Flexibility – compassion – protect rights
- Provide user friendly feedback
- Honest on both/all sides
- Work for customer not themselves
- Intimidation or fear of backlash
- Training on both sides
- Assertive (speak up)
- Working together as a full team
- Listening (Active)
- Customer participation on agency boards/committees (safety, sanitation, advisory)
- Focus groups
- Customer satisfaction survey
- Hiring and firing staff
- Involvement with staff evaluations
- Meet and greet (Staff meets customer; who gives input to hire)
- Participate in monitoring team/panel
- DD Advisor Committee
- HR Committees
- Consumer Council
  - residential/day program
  - activities/house rules
  - development of consequences
- Consumer to consumer interviews/focus groups
- Participation with policy development/standards/outcomes
- Statewide self advocacy group to recognize quality
- Ideas from other states – network

Training for Consumers: (ex. conducting own ISP’s)

- Partner with schools for education for parents and child with disability and continue the skills development through transition
- Identify skills needed for conducting ISP (ex. Self-esteem, assertiveness – role play)
- Partner with CIL for training
- Provide options and support – to lead part of the meeting
- Program Coordinator to assist and personalize the agenda
- Accessible meeting place
- Help with scheduling the meeting – who they want
- Decide what they do/do not want to discuss – when to share their information
- Deciding what evaluations or assessments to discuss – getting materials to team before the meeting
- Meeting times altered to accommodate need – Sparc
• Help write the Plan following the meeting/format
• Encourage to try lead the meeting
• Identifying outcomes needed and timelines
• Various print sizes for need
• Communication
• Online training
• Pathfinders (group)
• Not becoming defensive when offered constructive criticism
• Assertiveness training
• Self-determination
• Empathy
• Self Advocacy with medical staff
• Consumer training staff – staff training consumers
• Sensitivity training

Risk Assessments:

• Not having accessible transportation
• Not having wheelchair lifts
• Businesses or building are not accessible
• Exploitation – money
• Training on how to deal with solicitation
• Telemarketers (Do not call #)
• Dealing with neighbors and landlords
• Access to police – direct lines
• Assertiveness training
• Training with money issues – who to contact
• Family support/advocates
• Cost/benefit analysis
• Lack of communication
• Lack of trust
• Lack of accessibility
• Risk of privacy – accommodations
• Financial interests
• Burn bridges/cold shoulder
• Shortage of staff @ agencies (QSP’s) – common ground
• Holding grudges
• Exploitation
• Use or misuse of system (both ways) customer or provider
• Integrating with non-governmental groups ex. Native American Reservations
• Train significant others to support customers (ex. Risky behavior – drinking, sex)
• Emergency preparedness (tornados, flooding, blizzards, pandemic disasters)
• Survival kits
• Emergency backup plan (develop social capital – supporting networks)
• Priority list for emergency (ex. Oxygen)
• Use of therapy – for serious events
• Training for CPR/First Aid (Nutrition)

After completion of the small group work, a panel presentation took place. Panelists shared their perspectives and experiences, identifying challenges they face, unmet needs they have identified, and potential solutions for those needs. The panel, composed of a combination of professionals and consumers, included:

Beth Johnson – Director of Quality Assurance for Community Options, Inc. Prior to this position Ms. Johnson was Program Administrator also for Community Options, Inc.

Linda Madsen – Dissemination Coordinator and a Project Director at the North Dakota Center for Persons with Disabilities at Minot State University. Ms. Madsen has over 20 years experience working with people with disabilities.

Diane Glovatsky – Staff Development Specialist of Able, Inc., Dickinson ND.

Outcomes/Lessons Learned:

Upon completion of the panel discussion, participants of the workshop were asked to vote on what they felt were the highest priority steps that had been identified during the earlier small group work. Each participant was instructed to cast three votes, and had the options of voting for three separate issues, or casting all three votes for one issue that they felt the strongest about. Actionable steps identified as highest priorities as well as the number of votes cast for each are as follows:

<table>
<thead>
<tr>
<th>Number of votes</th>
<th>Issue</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td>Working together as a full team</td>
</tr>
<tr>
<td>4</td>
<td>Partner with schools for education for parents and child with disability and continue the skills development through transition</td>
</tr>
<tr>
<td>3</td>
<td>Identify skills needed for conducting ISP (ex. Self-esteem, assertiveness – role play)</td>
</tr>
<tr>
<td>3</td>
<td>Lack of Accessibility</td>
</tr>
<tr>
<td>3</td>
<td>Emergency back up plan (develop social capital – supporting networks)</td>
</tr>
<tr>
<td>2</td>
<td>Not having accessible transportation</td>
</tr>
<tr>
<td>1</td>
<td>Honest on both/all sides</td>
</tr>
<tr>
<td>1</td>
<td>Intimidation or fear of backlash</td>
</tr>
<tr>
<td>1</td>
<td>Customer participation on agency boards/committees (Safety, sanitation and advisory)</td>
</tr>
<tr>
<td>1</td>
<td>Customer satisfaction survey</td>
</tr>
<tr>
<td>1</td>
<td>Involvement with staff evaluations</td>
</tr>
<tr>
<td>1</td>
<td>Participate in monitoring team/panel</td>
</tr>
<tr>
<td>1</td>
<td>HR Committees</td>
</tr>
<tr>
<td>1</td>
<td>Participation with policy development/standards/outcomes</td>
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<tr>
<td>1</td>
<td>Statewide self advocacy group to recognize quality</td>
</tr>
</tbody>
</table>
The identified issues and proposed actionable steps can now be used to guide future strategic planning for the three partners of the NDDDN, providing the agencies with a road map of needs and priorities to reference when designing programs and work plans for the future. Although the summits were originally designed to elicit feedback from constituents on priority issues and actionable steps, indirect outcomes also resulted from the interactive group work, including:

- Networking among professionals from various agencies
- Education regarding services offered by agencies and programs
- Identification of new/increased priority areas for agencies
- Identification of possible funding sources for additional training
- Discussion of how agency personnel can collaborate on various issues

Although the summits were originally designed to elicit feedback from constituents on priority issues and actionable steps, indirect outcomes also resulted from the interactive group work, including:

The primary objective to gather current information on issues and identify actionable steps during the Quality Assurance and Disabilities Summit was successfully met. As a result of the excellent interactive group work and lively discussion among attendees, participants unexpectedly identified individual action steps for themselves and their agencies.

NDDDN agencies now have current information to carry forward into planning processes. Using the information gleaned from the summit meeting, NDDDN members can structure work plans and design programs that are relevant to the needs of consumers and that ensure individuals with developmental disabilities have access to high quality programs and services that will promote self-determination, independence, productivity, integration and inclusion in all facets of community life.

Sponsored by the

North Dakota Developmental Disabilities Network (NDDDN)