

**PRESENTATION TO
LONG-TERM CARE INTERIM COMMITTEE
NORTH DAKOTA LEGISLATIVE ASSEMBLY**

BY

**Eric Monson, CEO
Anne Carlsen Center
Jamestown, North Dakota, 58401**

July 14, 2010

For the record, my name is Eric Monson. I am the CEO of the Anne Carlsen Center in Jamestown, North Dakota. First, I offer our special appreciation to you, Chairman Kreidt, and your Committee, for the invitation to speak to you today. This Legislative Assembly appropriates millions of Medicaid dollars to the Center to carry out the State's legal and moral responsibility to care for our most special, yet the most fragile and challenged of our citizens. We hold a very deep personal and professional pride in being asked by you to carry out that mandate. So, thank you for letting me share some information with you today and tell a few valuable stories about those we serve on your behalf.

A brief background, if I may. The Anne Carlsen Center is one of the State's facilities that serve as an intermediate care facility for the mentally retarded (ICF/MR). The Center was founded in 1941 and proudly bears the name of Dr. Anne Carlsen, perhaps North Dakota's most nationally prominent physically handicapped citizen. As you know, her portrait hangs down the hall in the Rough Rider Hall of Fame.

Dr. Anne's philosophy is still followed today, namely to empower those of our special citizens with developmental disabilities to lead full, meaningful and productive lives to their maximum abilities. In doing so, we try to create the best environment possible to achieve the highest level of independence and productivity that each client can attain – including the most medically fragile and behaviorally challenged that we serve. The nice thing about that is that with greater independence, often comes less cost to the State. The client benefits, along with the taxpayers that help fund their care.

I'd like to share just a small portion of information with you today that might help you know more about what we are doing with the money and the responsibility you give us to carry out your policy.

Among the many services we perform for our State, our principal work centers in 4 main areas. First, we provide institutional care for the State's most medically fragile and behaviorally challenged children, from birth through young adulthood. These kids have complex diagnoses, including Autism Spectrum Disorders, seizure disorders, medically fragile life threatening conditions, cerebral palsy, spina bifida, traumatic brain injuries and the like. In this area of care, we are like a step-down ICU hospital staffed

by specialized pediatricians, masters degree nurses and many other specialized health care professionals.

Second, we provide home and community based services to those that may not need care at our Jamestown Center, but who still need life skills services to help them with their individual needs and plans. We provide client-centered, multi-disciplinary care to children and adults with developmental disabilities to keep them living in their communities. These include in-home supports to children and their families as well as community day supports for adults where we help create a plan for independent living for each client that is unique to them, because they and their disability are unique.

Third, we offer comprehensive, nationally-renowned training and education, including hosting major autism conferences in cities across North Dakota – bringing national experts together with parents and professionals.

Fourth, we are the only such institution in North Dakota that is also certified by the ND Department of Public Instruction as a K-12 school, so that those under our care can achieve the greatest level of public education possible – a belief strongly held by Dr. Anne that continues today.

We provide other services, but these I have mentioned are the ones that take the most time and produce the greatest noticeable results.

So let me focus on some interesting facts and anecdotal stories that might further enhance this picture.

Medically Fragile and Behaviorally Challenged Clients

In February of 2009 the Anne Carlsen Center was alerted to a situation where an 11 month old child was in a Denver rehabilitation hospital with a variety of serious medical issues. Jack was born with poor lung development due to congenital abnormalities requiring CPR shortly after birth. He was airlifted from Dickinson, ND to a Denver facility where he was placed on a heart-lung bypass until certain surgical repairs were accomplished. He was fed via a tube. The State of ND wanted this resident of ND to be returned to the State for further care and rehabilitation. While still expensive, the transfer of the child to the Anne Carlsen Center saved the State of ND \$1,000 per day over the care at the Denver facility. Not only was the care less costly and closer to home for the child, the supportive setting at the Center was more age appropriate and enriching for the child.

In mid-February the infant arrived at the Center flat on his tiny back on a ventilator to help him breathe and on a feeding tube due to his inability to receive food orally.

This past March, slightly more than a year since his admission to the Center, we watched proudly as Jack walked out the front door of our facility and climbed into the back seat of his grandparent's car and was buckled into his child's seat and left for his new home. There is simply no greater reward for us than to see that transition. Needless to say, his family was also delighted.

Jack still requires some in-home day supports and home nursing care, but Jack eats normally and is where he should be and in the least costly setting following rehabilitation – his home.

Community Services

Allow me to share two stories about our community services division – where services are designed for individuals for day and in-home supports closest to their home in a least restrictive setting.

Bobby:

Bobby is an adult male with developmental disabilities who lives in his own apartment. In recent years, Bobby has struggled with extreme anxiety to the point where he would rarely leave his apartment and his parents were extremely concerned about his mental health and well-being. Bobby would cocoon in his bed and stay there all day refusing to even do basic hygiene. Our staff was able to coax him out in baby steps by integrating his strong interests into his daily programming.

Because he loved music and already had a guitar, which he could not play, we suggested and arranged for him to take guitar lessons. The guitar lessons were set up at our office, so he would need to get ready and come out of his apartment, yet be with people he trusted.

Bobby decided a few months back that he would like to host a potluck grill out for the 4th of July holiday. He and his coordinator, Dawn, decided that it would be on the 5th of July since that is a day more people could attend. With support from his staff he made and delivered the invitations, purchased decorations (red, white and blue of course), made a potluck sign up, and invited his friends, family, his DD program manager (who attended), and selected music and game activities. He invited his parents but did not tell them

he was the host. He also made sure all the details were covered by making calls and asking certain people to bring needed items—his coordinator at the Center got a call requesting briquettes and lighter fluid.

He was so excited about the event that he would remind us each time he saw us that it was coming up soon. I would estimate that there were about 25-30 people in attendance at Riverside Park in Grand Forks.

When his parents arrived they saw him at the grill and promptly came over to check out the grilling action. His mom said, I did not know you knew how to grill. As his parents stood by he stated, “yep, I learned everything I know about grilling from my dad.” His parents were very touched. His dad grabbed some extra tongs and helped with the grilling. After a wonderful meal, the activities began. One activity was a dance and Bobby danced with his mother three times. She commented to the Center’s coordinator that she felt like she was at his wedding.

Her statement describes the journey faced by so many parents who raise children with disabilities. Parents seem to silently grieve for all the unrealized hopes and dreams they wish for their children where the focus of planning is often centered on a deficit rather than strengths. Our role, as a provider, is to

discover those interests, strengths and possibilities that support relationships and connectivity to a community.

Bobby is definitely on that journey, he has rough days as we all do, but most of his days he is moving forward, making connections and relationships and growing as an individual. He even surprises and delights those who know him best, his parents.

Grace:

It was an exciting time for a social, outgoing young woman. Grace had just graduated from high school. But anticipation was quickly replaced by frustration. When Grace graduated this past May, she was no longer a child with a disability—she was an adult with a disability. This meant there were limited age-appropriate programs or services available for the 21-year-old in Cooperstown, ND.

The choices presented to her and her family were not that appealing.

Grace could move away from her mom, her dad, a handful of siblings, a grandma, and the only community she had ever known, or she could remain in her hometown and receive no help.

Grace was born with a cognitive disability. Though she possesses wonderful qualities and many abilities that allow her to perform a wide variety of tasks, she does require some assistance. The family did have some help as Grace's grandmother lived next door. This gave Grace a place to stay where there was supervision during the day. But staying with her grandma was not a viable long-term option. Many days were spent in front of the television or computer.

Grace wasn't productive, wasn't spending time with people her own age, and wasn't getting the kind of specific care she required.

ACC staff met with Grace and her family at the end of last summer, crafting schedules that would play to the young adult's strengths and get her involved in her community.

ACC Community Program Coordinators visited businesses in Cooperstown and found a variety of employers eager to work with Grace. Grace has several opportunities in her community. For example, at the nursing home, she goes to each room there, knocks on the door, and then goes in and changes out towels and washcloths. She sets up the coffee area at one of the banks in town. She has the ability to do a variety of tasks at the various businesses.

We try to work with a client's strengths and preferences. Grace likes animals, for example, so we put her in contact with a veterinarian office, and she walks dogs there each morning.

Here is the great part! Through the ongoing efforts of Grace, her family, and her day supports that help her keep connected and active in her community, Grace has just purchased her first home, a home of her own in her hometown. She moved in June 1, 2010. She is now a homeowner, just like most of us.

Conclusion

The Anne Carlsen Center is proud to partner with the State in this noble venture. We are pleased that we save State taxpayer's dollars through our specialized pediatric medical care that would otherwise be so much higher in a hospital or out-of-state. We proudly support and respond to the State's mandated legal responsibility to care for our high medically and behaviorally complex citizens. We proudly educate and instructionally enhance their lives. We delight when we can keep folks in their own communities. We serve our clients with extensive therapy, including physical therapy, occupational therapy, speech and language pathology services, sensory integration, aquatic therapy, computer and other specialized adaptive equipment, outpatient

therapy, multi-denominational spiritual nourishment through the Center's chaplaincy program and a host of other services.

We proudly continue the services and philosophy begun by Dr. Anne, who said: "The spirit is a wonderful thing. I know what I can do."

In closing, I leave you with the feelings expressed by the parent of a client at the Center: "Nothing is impossible when you are working with someone who believes in you, someone who is advocating for you. Because of the Anne Carlsen Center, my son's days have been filled with meaningful activities. He's had a chance to build his own life."

With my gratitude, on behalf of the Center and those we serve, I thank you, Mr. Chairman and Committee members. Please allow me to respond to any questions.

Eric Monson, CEO, Anne Carlsen Center

Anne Carlsen Center

Programs and Services

July 1, 2010

**Medical-Behavioral
Education
Community Services
Outreach Services
Conferences-Workshops
Recreational-Social Life**

Medical-Behavioral

**Programs
Licensure
Accreditation
Recipients
Services**

Medical-Behavioral

Program Description:

- Residential – 5 home areas (3 cottages and 2 homes within the Center)

Licensure/Accreditation:

- Department of Health Title XIX – ICR/MR Provider

Recipient:

- Children and young adults, birth – 21 years of age with intellectual and developmental disabilities including those with medical fragility and behavioral challenges or children at risk for developmental delays.

Program/Service Components:

- ADLs
- Restorative Therapy
- Nursing Care including Rehabilitation Nursing
- Physician Care
- Speciality Care – Physiatry, Psychiatry
- Behavioral – Psy
- Program Coordination
- School Nursing Care
- Adaptive Equipment Support
- Assistive Technology

Medical-Behavioral Data 2009-10

Oregon Scores – Medical

Total Score	1,062.5
Highest Score	84
Lowest Score	16
Clients High Range (61-100)	8
Clients Mid Range (31-60)	6
Clients Low Range (13-30)	11

Oregon Scores – Behavioral

Total Score	5,461
Highest Score	261
Lowest Score	13
Clients Range 0-50	1
Clients Range 51-100	7
Clients Range 101-150	6
Clients Range 151-200	10
Clients Range 201-250	10
Clients Range 251+	1



Anne Carlsen
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Nurturing abilities. Changing lives.

Education

Programs
Licensure
Accreditation
Recipients
Services

Education

Program Description:

- School Program consists of regular 9 month
- School year and Extended School Year (ESY)

Licensure/Accreditation:

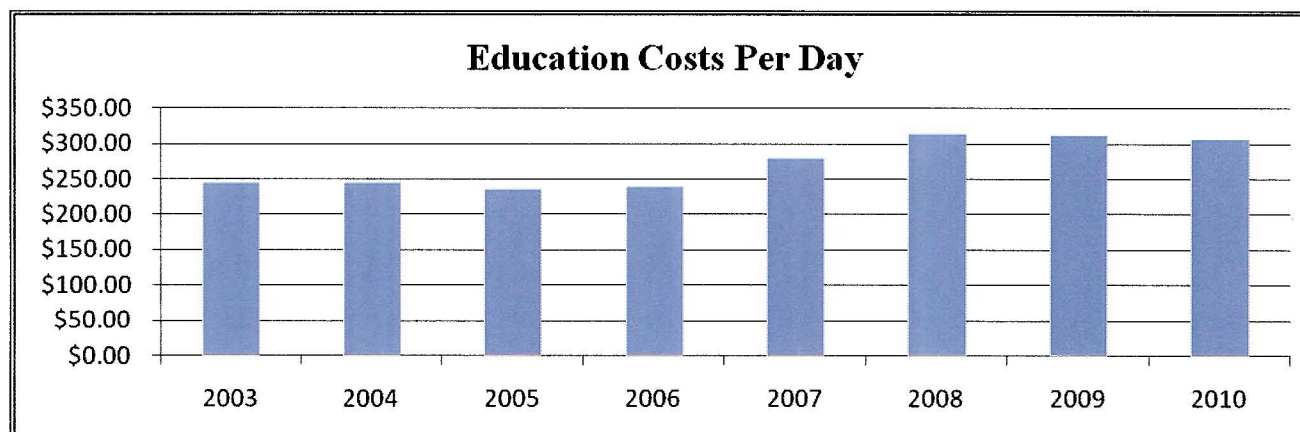
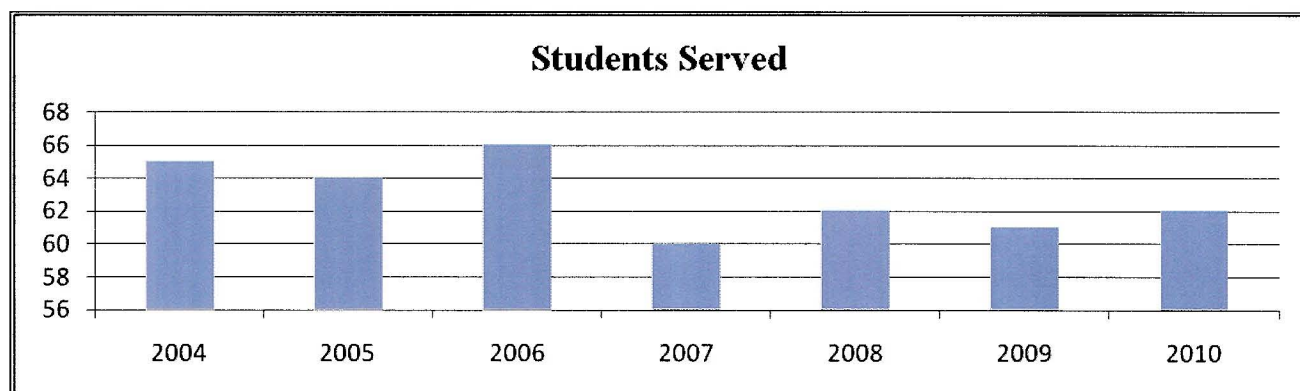
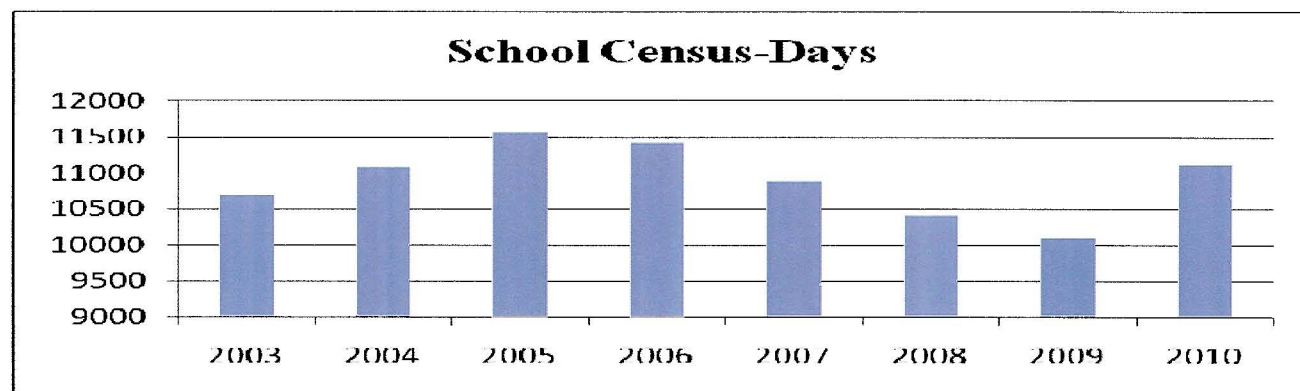
- ND Department of Public Instruction (ND DPI)
- North Central Association/Council on Accreditation and School Improvement (NCA/CASI)

Recipient:

- Children and young adults = 3-21 years of age

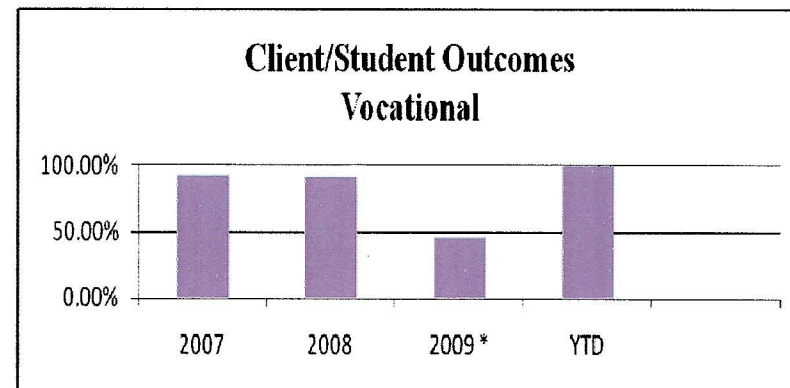
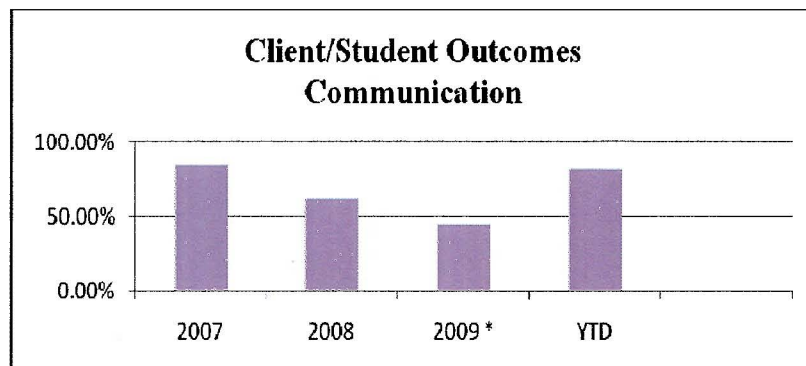
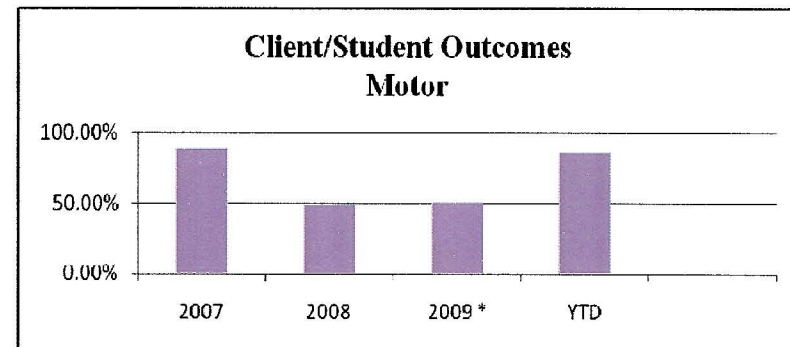
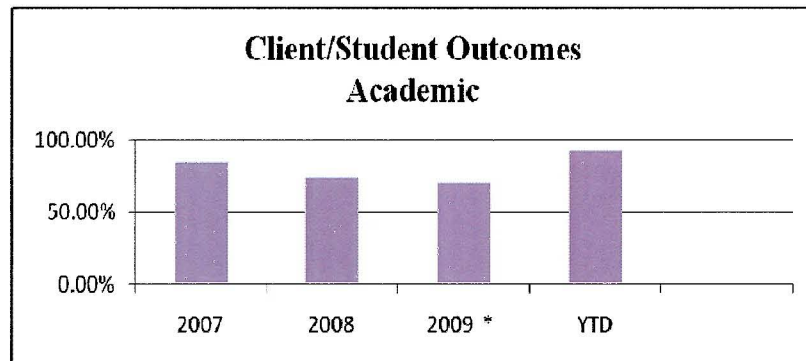
Program/Service Components

- Individual Educational Program Plans
- Adaptive Physical Education
- Transition Programs = 14-21 years
- Library/Media Support
- Adaptive Equipment
- Assistive Technology Support
- School Nursing Care
- Program Coordination
- Modality Specialities: functional curriculum based on ND State standards and holistic horticultural curriculum



Client (Student) Outcomes – Center

Outcome Area	Threshold (Target)	2007	2008	2009	Year to Date 2010 – Q1
Academic	≥65%	85	73.5	70.25	92
Communication	≥65%	84.6	62.25	45	82
Motor	≥65%	89	48	50.5	86
Vocational	≥65%	92.75	91.5	45.75	100



*Affected by flood related evacuation (91 days)



Community Services

In-Home Supports
Day Supports
Outcomes
Market Demand
Costs

Community Services

Program Description - In-Home Supports:

- In-Home Support services within the family home

Licensure/Accreditation:

- ND Department of Human Services/Developmental Disabilities Division Provider as a Center for Medicaid Services (CMS) Waiver Program

Recipient:

- Children and young adults, birth – 21 years of age, with intellectual and developmental disabilities including those with medical fragility and behavioral challenges or children at risk for developmental delay. May serve adults, ages 21 years and older.

Program/Service Components:

- Adaptive Daily Living Skills
- Behavior Supports
- Community Access
- Recreation/Leisure
- Communication
- Adaptive Equipment Support
- Assistive Technology Support
- Coaching and Mentoring for Caregivers
- Program Coordination

Program Description – Day Supports:

- Day supports within the community

Licensure/Accreditation:

- ND Department of Human Services/Developmental Disabilities provider as a CMS waiver program

Recipients:

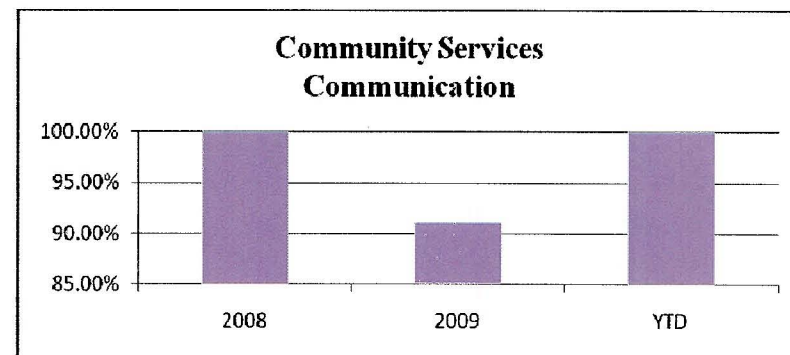
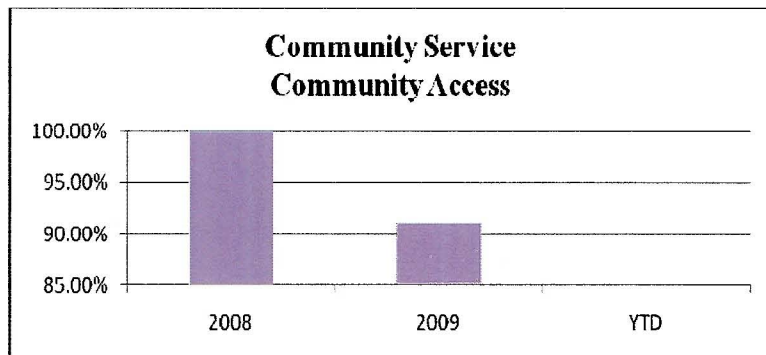
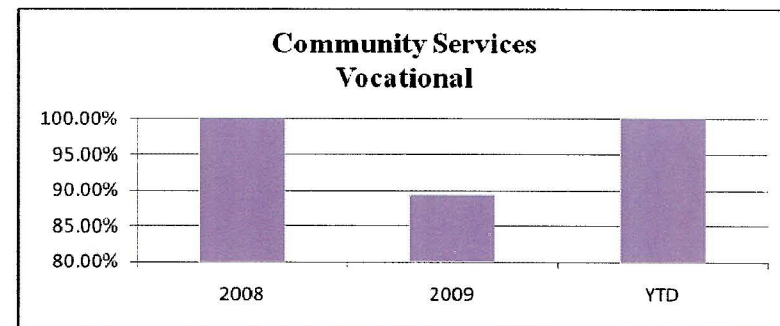
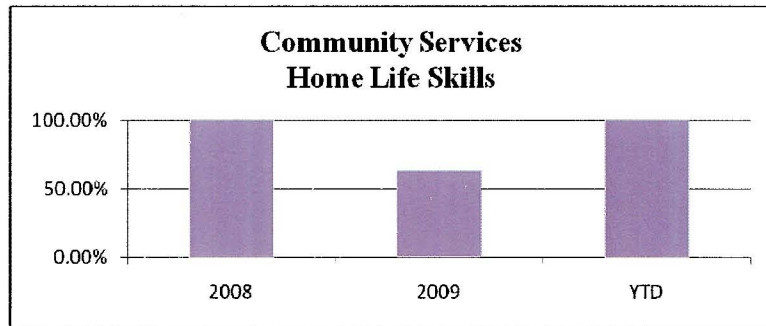
- Adults, 21 years of age or older, with intellectual and developmental disabilities including people with medical fragility and behavioral challenges

Program Service Components:

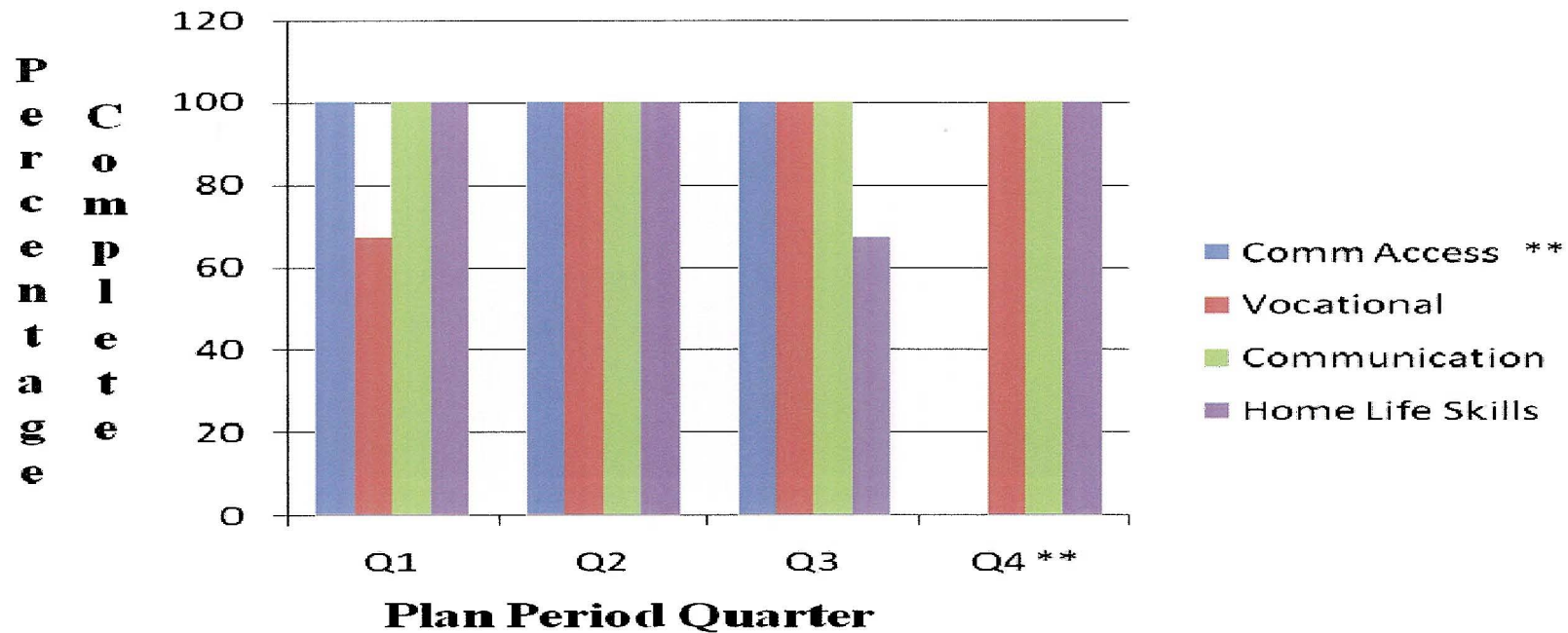
- Adaptive Daily Living Skills
- Behavioral Supports
- Community Access
- Recreation/Leisure
- Communication
- Assistive Technology Support
- Adaptive Equipment Support
- Vocational Experience
- Coaching and Mentoring

Client Outcomes – Community Services

Program Goal Area	Threshold (Target)	2007	2008	2009	Year to Date 2010 – Q1
Community Access	≥75%		100	91	NA
Vocational	≥75%		100	89.3	100
Communication	≥75%		100	91	100
Home Life Skills	≥75%		100	63	100
Comments: All clients met their objectives in the 4 quarter of their plan. There were no clients with community access objectives ending in the 4 th quarter of their plan.					



Community Services Outcomes



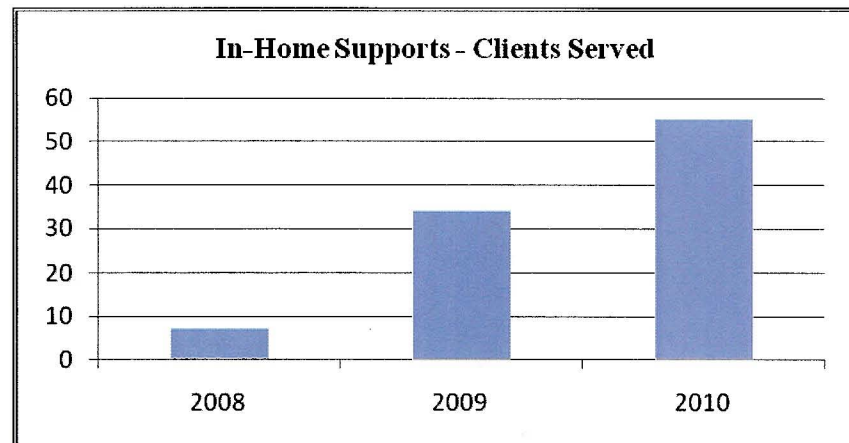
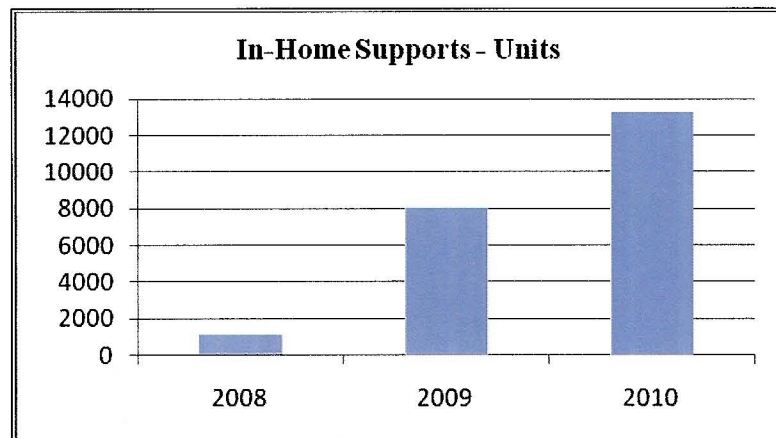
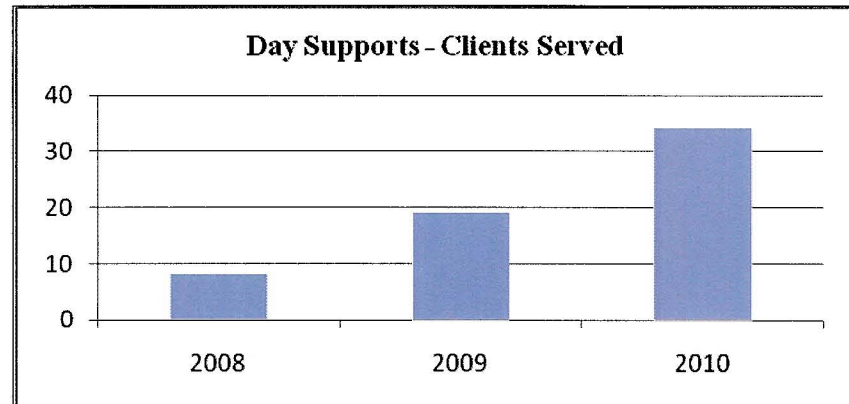
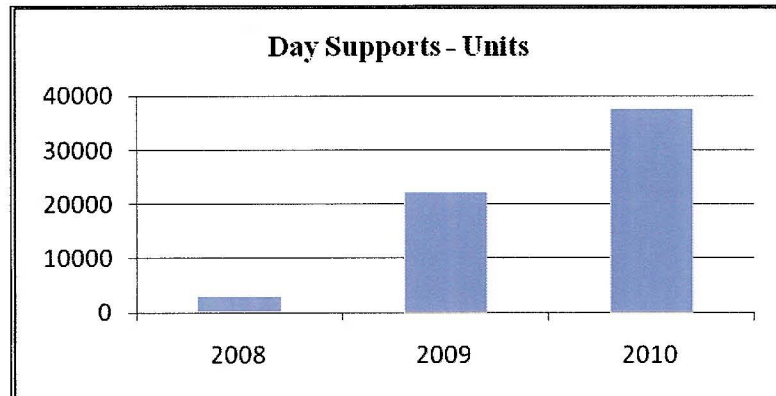
**** Community Access** – There were no clients in quarter 4 with a community access goal.

Vocational – One client did not make progress in quarter 1 of plan due to medical reasons.

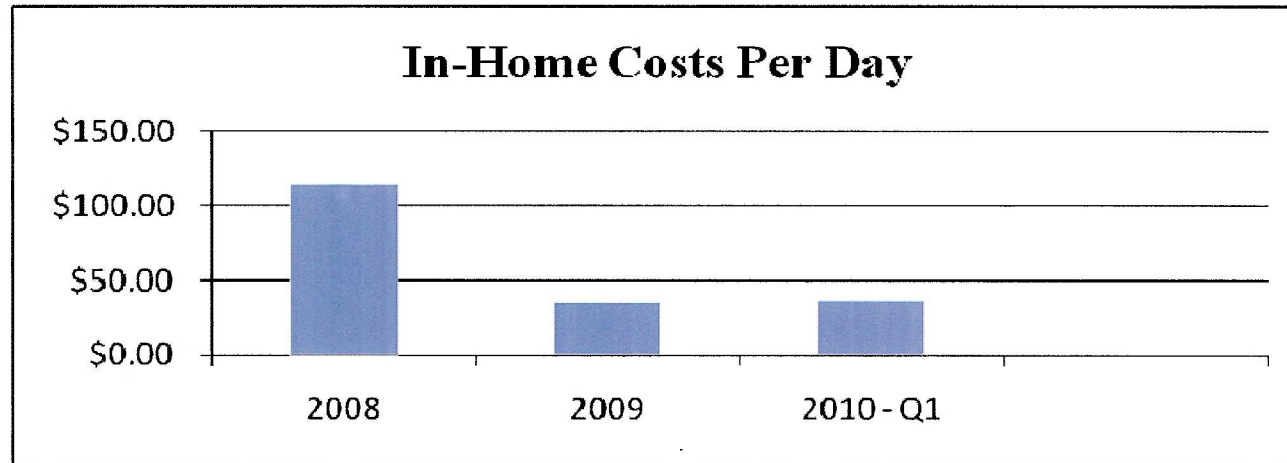
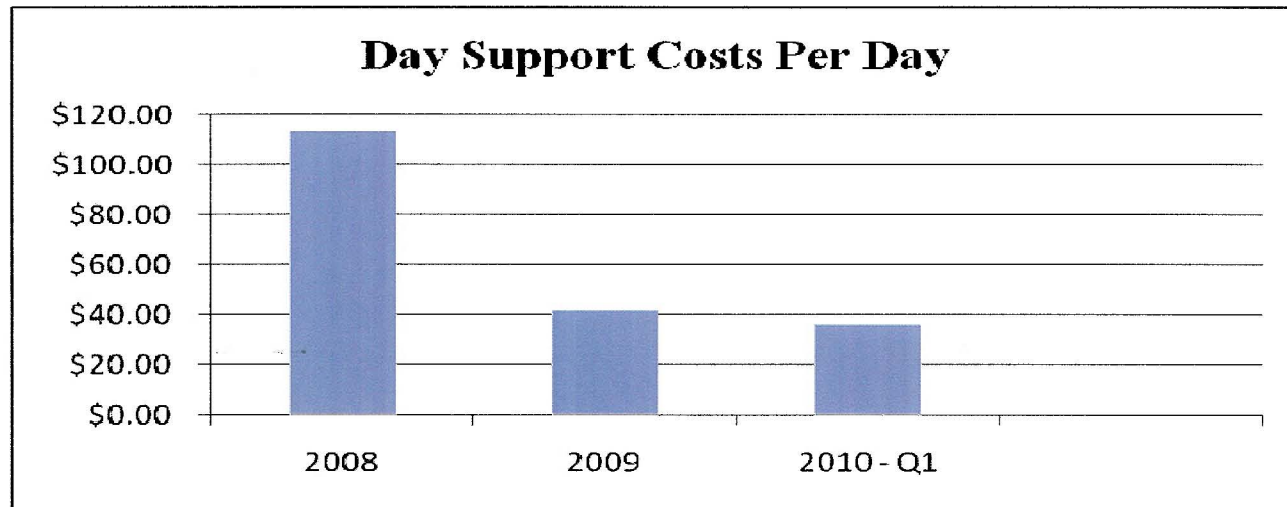
Communication – All clients met their communication objectives.

Home Life Skills (ADLs) – One client did not make progress quarter 3 due to equipment change.

Community Services – Market Demand



Cost Per Day





Outreach Services

Conferences/Workshops

Program Descriptions
Recipients
Programs/Services

Outreach Services – Evaluations and Consultations

Program Description:

- Evaluations/consultations within a home, community or school setting.

Recipient:

- Children and young adults, 6-21 years of age, with intellectual and developmental disabilities including those with medical fragility and behavioral challenges or children at risk for developmental delay. May serve adults, age 21 year and older.

Program/Service Components:

- Speech/Language
- Motor/Mobility
- Functional Vision Adaptations
- Alternate Augmentative Communication
- Dysphagia
- Assistive Technology
- Adaptive Equipment Support
- Relationship Development
- Vocational and Job Interests
- Education/Academic
- Sensory Integration
- Nursing Consultation
- Adaptive Daily Living Skills
- Behavioral Support
- Community Access
- Recreation/Leisure

Outreach – Conferences and Workshops

Program Description:

- A variety of conferences, workshops and module training sessions are developed and presented regarding latest tools for working with autism, adaptive and assistive technology, behavior supports and communication.

Attendees:

- Professional in the field of disabilities, families and Anne Carlsen Center staff.

Subject Areas:

- Autism
- Sensory Issues
- Applied Behavioral Analysis (ABA)
- Diet and Nutrition
- Assistive Technology
- Visual Supports
- Social Relationships
- Literacy
- Family Supports
- Positive Behavior Supports
- Communication

Recreation – Social Life

Program Description – Camp Grassick

- Provide week long camping experience (overnight and day options)

Recipients:

- ND Children, age 14-21 with intellectual and developmental disabilities

Programs:

- Technology and the Arts
- Recreation/Leisure

Outreach – Conferences

