Broome County CASA

BROOME COUNTY CASA
NY CONNECTS
CHOICES FOR LONG TERM CARE

Annual Report 2008

Table of Contents

TABLES

DIRECTOR'S MESSAGE

To: County Executive Barbara J. Fiala

On behalf of the staff of Broome County CASA and the people we serve, it is with great pleasure that I submit the 2008 Annual Report.

Health care reform has once again emerged on the political radar screen. Those of us "in the trenches" realize that true reform is long overdue. Medicaid expenditures related to home care are on the rise. Home care serves an increasingly younger population as well as meeting the growing needs of frail elders over the age of 80. Both of these populations have significant challenges in remaining independent due to disabling conditions. The NYS Budget for the 2009 – 2010 fiscal year, calls for two demonstration projects that have the potential to eliminate county involvement with the personal care program by creating Long Term Care Assessment Centers.

In response to the Governor's budget proposals, the CASA Association of New York State has written a white paper encouraging the state to "look before they leap." Too many people still think of home care and long term care as programs for the elderly. However, the current generation of elders is the healthiest and wealthiest in the history of the world! They neither need nor seek care in the numbers expected. So we need to ask what does the current home care population look like? Under what circumstances do they receive care? What types of disabilities do they have? Are their informal supports adequate? How many years do they receive home care?

The best way to address the needs of this population is to understand who is being served. Therefore I have included the Executive Summary of The CASA Association Paper, "A Call to Action," as part of this report. Full copies of the paper can be viewed on Broome County CASA's web page at www.gobroomecounty.com.

People are living longer with chronic conditions that impact their ability to manage their day-to-day lives. CASA staff is continually challenged to assist the people we serve to be as independent as possible. Broome County CASA has a statewide reputation for long term care service delivery. I am proud of the work the staff does on a daily basis to assist many of the most vulnerable people in our community to live lives of dignity.

Respectfully submitted,

Michelle M. Berry

EXECUTIVE SUMMARY

Governor Paterson's 2009 - 2010 Budget proposes to create Long Term Care Assessment Centers and remove the personal care program from county operations. The Community Alternative Systems Agency (CASA) Association of New York State believes that effective reform requires a better understanding of who is being served in Medicaid home care programs and the current role that counties play in home care. County government in New York State (NYS) has historically been designated by the state to assess for and authorize a range of Medicaid funded long term care services. Counties play an integral role in the delivery of the Personal Care Services Program (PCSP), the largest Medicaid personal care program in the United States. Counties are also involved in authorizing and coordinating the delivery of the Long Term Home Health Care Program (LTHHCP), the Consumer Directed Personal Attendant Service (CDPAS), Personal Emergency Response Systems (PERS), as well as other community based programs.

There have been significant changes in the population served in the program since its inception in 1965, including an increase in the level of care needed in the home and an increase in the number of people served who are under the age of 60. These changes, along with an emphasis on keeping people at home, have increased the cost of service. Counties have experienced these changes and have critical information that is important to acknowledge in the effort to reorganize long term care in NYS.

As a national leader in home care, New York State has the opportunity to construct meaningful long term care system-wide reform. A partnership between the state, the local districts, consumers and providers will result in the development of an effective and efficient system that provides quality care. NYS is diverse and it is important to recognize that local resources are either available or limited by the nature of the communities served.

In restructuring home care, the CASA Association of New York State suggests the following recommendations be taken into consideration.

1. **The goals and measurable expected outcomes of long term care need to be clearly defined for all Medicaid funded care.**

2. **The New York State departments of Health, Aging, Mental Retardation and Developmental Disabilities and Mental Health oversee a myriad of community based programs. These agencies must align their vision, culture and philosophies.**

3. **Data on long term care needs to be collected, analyzed and widely disseminated and examined before making any changes to the current system.**

4. **Revise the NYS Personal Care Service Program regulations (NYCRR 505.14) to clarify the allowed Medicaid funded care a client can receive.**

5. **Provide substantive and ongoing training to those administering all Medicaid home care programs and to State Fair Hearing staff**.

6. **Provide substantive and consistent public education/orientation to households applying for in-home care on their rights and responsibilities in relation to the program's services.**

7. **Create the resources and tools needed at the local level for service provision, including the development of a standardized assessment tool.**

8. **Create a state service corps for aides working in either home care or in nursing homes to broaden the available pool of workers.**

9. **Once the state has created the mechanisms and the tools to move the system forward, create opportunities that allow counties to cross county lines to consolidate the intake and assessment process for Medicaid funded care. Naturally occurring market areas could share program administration and delivery.**

Restructuring Medicaid Home Care in New York State: A Call to Action discusses the above recommendations in depth. The paper also examines the long term care environment we currently operate in, the lessons we have learned, myths surrounding care in the home, the barriers and obstacles we have encountered and the following notable trends:

1. The Personal Care Services Program serves an increasingly diverse and younger population.
2. People spend a significant portion of their lives in receipt of long term care, making numerous care transitions, all of which require planning.
3. NYS operates NINE Medicaid Waiver Programs, creating a complex environment in leading to consumer and provider confusion as to who qualifies for what service, why, when and how.
4. As people with chronic conditions live longer, the stress on informal caregivers increases and may prevent them from providing needed support to consumers.
5. There is a shortage of aides in upstate NY. The challenging conditions they work in and the lack of transportation for them further decreases the pool of workers.
6. One of the most prominent myths is that home care is always less expensive than Nursing Home care.

The members of the CASA Association of NYS serve on the 'front lines' of home care and have witnessed major changes in the needs of the target population as well as in the demographics of that population. We support the need to reorganize the community based long term care system. We are ready and willing to work with all partners in long term care system reform.

MISSION AND PURPOSE STATEMENTS

MISSION: To serve as a central access point for assessing long term care needs of individuals and families to promote maximum independence and optimal use of available community resources.

PURPOSE: CASA will provide comprehensive assessment, care planning and case management services based on client need, regardless of age or income, and with consideration for the personal wishes of clients and their families. CASA will seek to assure that all services are designed to assist clients to live as independently as possible. CASA, in partnership with the consumer, family and provider community, will assist individuals in determining how best to use available resources in coordinating care that meets their needs in a dignified, individualized manner.

The three principle outcomes to be achieved through our central access point:

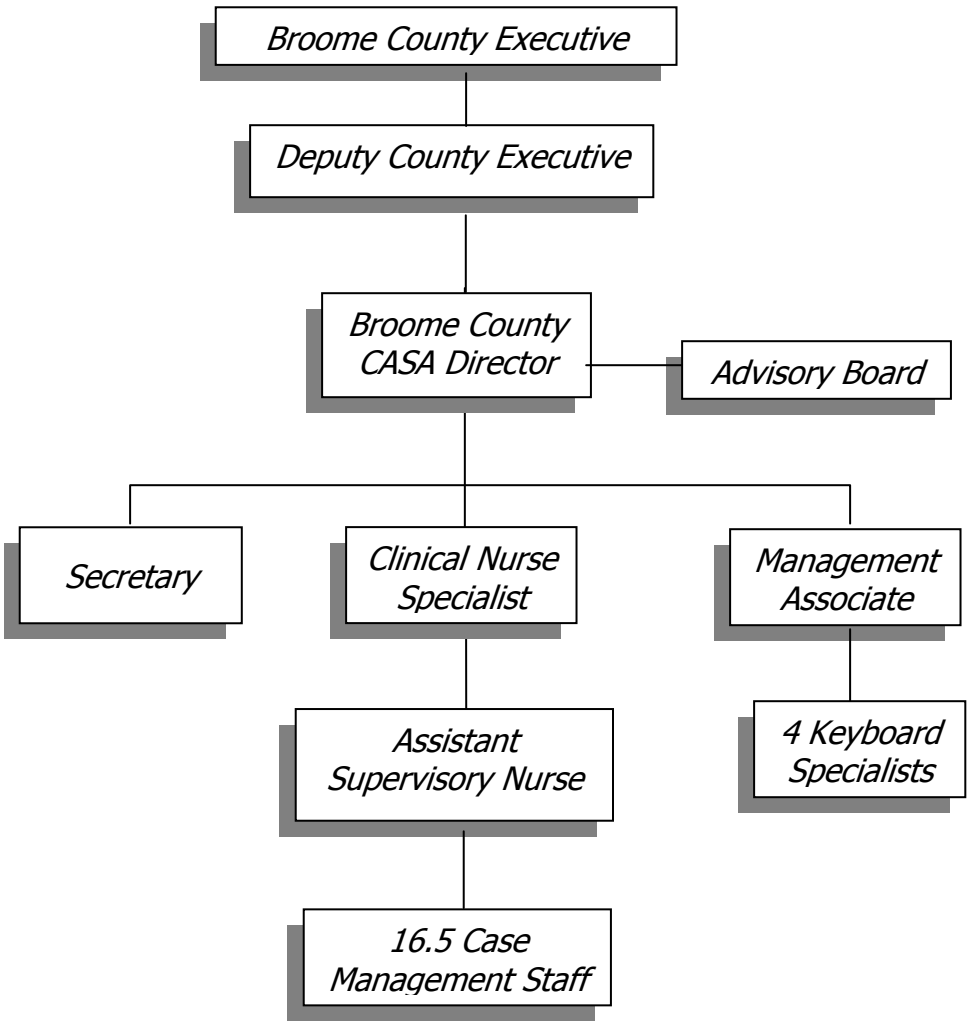
- Improved quality of life for the chronically impaired and their informal supports based on informed choices.
- Efficient, cost-effective long term care system that recognizes constraints and avoids unjustified expenditures.
- Effective coordination among service providers to meet the challenges of serving people with chronic conditions and disabilities by recognizing the value and worth of each type of service and their contribution to the overall quality of consumer care.

BUDGET AND STAFFING

Broome County CASA's approved operating budget for 2008 was $1,968,012.

The majority of the CASA operating budget is reimbursed by Federal and State Medicaid administrative dollars.

In 2008, CASA employed 26 staff members.



PROGRAM DESCRIPTION AND FUNDING

Broome County CASA began operations in 1983. "If CASA is to manage effectively, it is essential that potential long term care clients be promptly identified; that those for who community based care appears a viable option be thoroughly assessed; and that CASA ensure that, wherever possible, the long term care system is accessed at the appropriate points. None of these functions can adequately be performed at a distance. In short, each CASA will need to become that partnership between government and providers envisioned by the New York State Long Term Care Systems Development Project; and each of the CASAs will need to intervene, directly and indirectly, in the long term care system to ensure the availability, accessibility and delivery of long term care services in the most appropriate and cost efficient manner possible." (CASA Operations Notebook, NYS DSS 1983.)

- **CASA serves people with chronic disabilities OF ALL AGES.**

- **CASA receives 200 new referrals every month.** In 2008, CASA received 2,530 referrals for people in need of long term care.

- **CASA is the gatekeeper for those in need of long term care.** CASA assesses clients to determine their level of care and makes referrals to the appropriate programs and services.

- **CASA staff performs numerous functions:**

    1. Pre-Admission Program Assessments
    2. Medical Eligibility (level and locus of care determination)
    3. Case Management
    4. Data Systems
    5. Long Term Care Systems Planning and Development

- **Because of our planning function, CASA has developed innovative programs and services.** Broome County CASA began operating a Nursing Home to Community program in 1996 and the In-Home Mental Health program in 2001.

- **During the 1990's we were mandated by New York State to create new methods of service delivery to include new populations needing care,** primarily children and young disabled adults. We accomplished this with no new staffing.

CASA PROGRAMS AND PARTNERSHIPS

- Personal Care Aide
- Shared Aide
- Consumer Directed Personal Assistant Program
- Long Term Home Health Care Programs
- Nursing Home to Community
- Nursing Home Placement
- Private Duty Nursing
- Family Homes for the Elderly
- Medical Day Care
- Assisted Living Programs
- Care At Home
- Home Community Based Waiver
- In-Home Mental Health Program
- Partnership with Tioga County DSS
- Personal Emergency Response Systems

CASA PROGRAMS

CASA operates AND/OR authorizes Medicaid payment for the following programs, which are MANDATED by the state of New York.

1. PERSONAL CARE PROGRAM

This program operates under three models: traditional **Personal Care, Consumer Directed Personal Assistance Program, and Shared Aide**. Between these three models, Personal Care serves 490 clients on a monthly average.

- The Personal Care Program represents the largest Medicaid home care program in the state, as well as in the United States.
- In New York State, personal care is a billion-dollar program.
- CASA assesses every person receiving personal care on a bi-annual basis.
- CASA develops a care plan for every person in the program on a bi-annual basis.
- CASA authorizes the Medicaid payment and coordinates the care with the assistance of seven contracted licensed nursing agencies and the Southern Tier Independence Center (STIC).
- 47% of the people receiving this service on a monthly basis are less than 60 years old.
- Beginning in the early 1990's, the Personal Care Program became available to developmentally disabled children and adults via the Home and Community Based Waiver programs and the Traumatic Brain Injury program.

2. LONG TERM HOME HEALTH CARE PROGRAM

This program is referred to as the "Nursing Home Without Walls Program." It provides a higher level of nursing case management and assessment than the Personal Care Program. There are two providers in Broome County that service approximately 175 clients on a monthly basis. CASA assesses and authorizes the Medicaid services for these clients and is the number one referral source for both programs.

3. ASSISTED LIVING PROGRAM

There are four providers of these residential care programs in Broome County with a total of 105 beds, approximately one-third are Medicaid recipients. CASA assesses all clients, private pay or Medicaid, who want to access the program and authorizes payment for Medicaid residents. Assisted Living supports seniors in need of long term care, but not infirmed enough for skilled nursing care.

4. MEDICAL DAY CARE

Susquehanna Nursing Center operates the only Medical Day Care Program in Broome County. CASA assesses and authorizes the care for all Medicaid clients served by the program.

5. PRIVATE DUTY NURSING

CASA assesses and authorizes all Medicaid private duty nursing cases in Broome County for an average of 20 clients per month. People in receipt of this care are mainly children with high tech nursing and intense nursing management needs.

6. CARE AT HOME

CASA provides assessment and Medicaid payment authorization to this program designed to serve children.

The goal of every CASA assessment is to develop the best care plan, at the least cost for all payers, whether private pay or Medicaid.

Combined with the referrals we receive on a monthly basis, CASA staff manages approximately 1,100 clients per month.

CASA PARTNERSHIPS

During CASA's existence, we have worked with many community agencies to implement new programs in an effort to better manage long term care Medicaid expenditures. Programs that have resulted in these partnerships are as follows:

1. FAMILY HOMES FOR THE ELDERLY

One provider coordinates approximately 20 private homes and serves an average of 35 clients on a monthly basis. CASA determines eligibility and authorizes the Medicaid payment for clients served in this program. The program is operated by Family & Children's Society and is the most successful program of its kind in New York State.

2. NURSING HOME PLACEMENT

CASA assesses residents in the community who are in need of nursing home care and assists the families in accessing care. CASA also generates a waiting list of those waiting for placement and forwards the list to nursing homes on a weekly basis. This process is unique to Broome County CASA.

3. NURSING HOME TO COMMUNITY

This effort is a model program for the state and nation. Since 1996, Broome County CASA has assisted over 4,500 people achieve nursing home discharge.

4. IN-HOME MENTAL HEALTH PROGRAM

Broome County CASA recognized the need for greater management of psychotropic drugs in home care. Community Mental Health Reinvestment money was obtained by Family & Children's Society to assist people in their homes stay on their medication regime. There are no Medicaid dollars involved in the delivery of this service, yet it has the potential to save Medicaid dollars by assisting clients in managing their care.

5. PARTNERSHIP WITH TIOGA COUNTY

Broome County CASA entered into a partnership with Tioga County DSS in 1998 to review their residents for post-hospital care who are served by Broome County hospitals. We receive $20 for every case we review on Tioga County's behalf.

2008 HIGHLIGHTS

1. NY CONNECTS

In October of 2006 the NYS Departments of Aging and Health provided financial assistance to counties across New York State to create or support long term care points of entry or NY Connects. CASA, in partnership with the Broome County Departments of Aging and Social Services, is the designated NY Connects partner in Broome County. CASA has been functioning as a point of entry for long term care in Broome County for over 20 years. The support provided by the state for NY Connects has allowed us to enhance our information and referral services and educate both the public and provider community on the benefits of having one place to call for information on long term care.

The year 2008 represented the second full year of operation under the NY Connects "banner." One of the goals of the NYS Departments of Aging and Health is that every citizen in New York State comes to recognize the NY Connects logo and what it stands for.

2008 was also our first full year of collecting data for NY Connects on the types of calls we receive from people looking for information on long term care options. The story the data tells supports the concept of having one place to call that specializes in providing unbiased information to the community. While there are many entry points into the system, only CASA has the expertise and the depth of knowledge to discuss all programs available to the public for long term care. In 2008 CASA intake staff made over 4,000 suggested referrals to over 150 community organizations such as Faith in Action, home care agencies and care facilities. Our system also tracks over 100 topics related to long term care. In 2008 our intake nurses made reference to those categories over 11,000 times. Topics discussed range from food pantries, to eye care, legal services, and finances.

In 2007, our first year of funding from NY Connects, Kathleen Colling, Ph.D. RN, conducted focus groups of both professionals and consumers to determine what their impression was of the current long term care system and how it might be improved. These focus groups are summarized in the report "*Consumers and Professionals Evaluate Long Term Care in Broome County*" and can be accessed at www.gobroomecounty.com/casa.

From these focus groups we learned that consumers access the long term care system through multiple and varied entry points. Consumers reported that they value a team approach to care and find having to repeat the same information to numerous providers cumbersome. As a result of these findings we developed a tool for consumers to utilize in communicating with their providers. The tool, *My Little Book…A Health Diary* was developed and published in 2008 by Action for Older Persons.

The purpose of the book is to assist people in keeping track of their medical information and to share that information with all of their providers. A CASA nurse assists consumers with filling in the book and will continue to provide guidance in 2009 as we try to establish a profile of who is most likely to utilize the book in managing their medical care.

2. NURSING HOME TO COMMUNITY

Nursing Home to Community remains a touchstone for Broome County CASA. In learning more about other areas of the nation where similar programs have developed, it must be noted that CASA developed this program in 1996 by reorganizing existing resources. We did not receive any grant dollars as have other agencies, or any additional operating dollars. We recognized the need in our community for this activity in the early 1990's and by 1996 began by servicing two out of nine skilled nursing facilities. Today we serve all nine skilled nursing facilities in Broome County and in 2008 we received 679 referrals and assisted in coordinating discharges for 475.

3. CLIENT PROFILES

In 2008 the CASA staff continued the tradition of purchasing Christmas gifts for the neediest on the caseload. Each nurse put the names of their candidates in a hat and four names were drawn. These are the profiles of the people chosen. (The names have been changed.) These profiles are a reflection of the people we serve and the magnitude of, not just their need for home care, but their need for human contact and the basic necessities of life.

Raymond and Tara

My clients, Raymond (father) and Tara (daughter), were chosen for the CASA Christmas basket.

Raymond is 80 years old and lives with his wife Milly, his adopted foster child Tara (31), and his granddaughter Mary (14) (daughter of their other adopted foster child).

Raymond has been receiving home care since 2005. He survived prostate cancer, but still has other chronic health problems, including chronic, severe pain.

Tara was admitted to home care this month. She was born with Spina Bifida and a Chiari Malformation (a structural malformation of the cerebellum). She has been very independent most of her life and even earned a degree from Broome Community College. Last year, however, she suffered some severe complications due to her Spina Bifida and now needs bimonthly nursing visits.

Raymond and Milly are of very modest means, but are giving people who took in two foster children years ago. They later went on to adopt these foster children. They knew the challenges they would face with both of their foster children, but didn't anticipate Raymond's health problems. Finances have been very tight for the last several years. Milly still works part time cleaning at the school. The work is difficult for her at her age. They rent their old farmhouse at a reduced rate from the Baptist Church. Last year they ran out of food and fuel. They utilize food pantries and HEAP, but still have trouble getting by. They fear what will happen this year if fuel prices are even higher than last. Despite dire circumstances, the family finds strength in each other and is very resilient and upbeat.

The family would appreciate anything at all, even basic household items. Tara's list includes anything purple! She wears petite and medium clothes. Raymond is in need of pajamas and large sweatshirts.

Robert and Diane

My clients, Robert and Diane, were chosen for the CASA Christmas basket. They receive home care and are in very poor health.

Diane is 62 years old with poor cardiac-respiratory status. She is in need of a heart transplant but she has declined one, so her prognosis is limited. She has a myriad of health problems including, obesity, insulin dependent diabetes and arthritis. Her activity tolerance is poor and she requires oxygen at all times. At 5' 10", she weighs 245 pounds. She enjoys word search puzzles and is in need of basic items such as socks, soap, slippers and sweat shirts.

Robert is 64 years old and was diagnosed with cancer last year, with metastasis to brain, liver and lungs. He also has Rheumatoid Arthritis with chronic pain. His prognosis is limited and this will most likely be his last Christmas. He continues to go for chemo treatments weekly. He is losing weight, and is now about 145 pounds and 5' 9" tall. He is in need of clothes that fit due to the weight loss: socks, underwear, sweat shirts, hats, gloves and he wears suspenders.

Jane

Jane is a 65 year old obese woman with diabetes, anxiety disorder and agoraphobia. She has bilateral upper extremity tremors and this makes it hard for her to read or do any type of craft projects. She lives alone, as her husband died unexpectedly in 2005. Sadly, just two days ago, her sister died. She has only one cat now that she loves dearly. She has few household items or furnishings. She has a mental health caseworker.

The landlord had to remove the rugs and linoleum from the apartment because at one time the couple had 11 cats and the flooring became soiled. The floors are bare wood and unfortunately, a strong cat urine odor lingers in the apartment despite the dedicated cleaning efforts of personal care aides. The cat is compliant with litter box use.

Jane wears size 2x or 3x. She could use a warm sweater or sweatshirt and sweatpants. Her shoe size is 8. Warm socks or washable slipper sox with grippers on the bottom would help to keep her warm in the winter. She enjoys watching television. A warm throw for her couch or some pillows for the living room would be used often. Her kitchen lacks basic household items such as dish towels, dish cloths, dish pan, dish scrubber. She could use a new tea pot or a small crock pot. She likes to heat up canned soups such as cream of mushroom or tomato or beef stew.

She has incontinence issues and uses many washcloths. New towels, washcloths, a shower curtain, washable bath mats, a new toothbrush, shower soap or gel, and dental floss would be appreciated. She likes stuffed animals.

Her mental health caseworker is arranging for her to get a new full mattress and box spring. A heavy duty plastic mattress protector, sheets, pillow cases, a blanket or bed spread would help to brighten her bedroom. A sturdy TV tray for the living room would give her some place to eat her meals, as she does not have a kitchen table or chairs. Gel room deodorizers might help with the lingering odors.

Jane has so little and I'm sure that any gift that you can share with her would brighten her holidays. Thank you in advance for your thoughtfulness.

Cynthia

My client, Cynthia, was chosen as one of our CASA Christmas recipients. She is 59 years old and has been diagnosed with Obsessive Compulsive Disorder, Schizophrenia and physical diagnosis of Scoliosis and Osteoarthritis. She has no family and her main social contacts are with the CASA nurse, her home care aide and adult protective. She is a very simple person of simple means, but I know that receiving these gifts will be a big deal for her.

Cynthia could use a small decorated Christmas tree to brighten her apartment. She enjoys word search puzzles (large print) and is learning to knit and crochet. She loves clothes and could use a sweater, socks, gloves, winter hats and sweat shirts. She really loves jewelry, silver especially, rings, bracelets, and beads. Cynthia loves to look at fashion magazines and would appreciate a calendar with German Shepherds or Poodles.

TRENDS IN LONG TERM CARE (LTC)

In order to understand the factors that have contributed to the increase in the number of hours of service delivered by the Personal Care Program, as well as an increase in the number of people served under the age of 60, it is important to acknowledge the following national trends.

- Decrease occupancy in nursing homes
- Increase in Medicaid spending on home care services
- Decrease in disability rates of elders
- Increase in disability rates of young adults
- Increase in public policy initiatives around the issues of deinstitutionalization and disabled rights: Olmstead, New Freedom Initiatives, Medicaid Buy-In
- Growth in Medicaid Waivers
- Advances in medicine enable people to live longer: traumatic brain and spinal cord injuries, developmental disabilities, advances in cancer treatment and most obvious, how HIV/AIDS has quickly become a chronic disease due to drug therapy.
- National Public Radio (NPR) reported on February 13, 2004, that "Social Security Disability Insurance is one of the government's costliest social programs; it is more expensive than welfare. It costs more than unemployment insurance and it's bigger than the earned income tax credit for low-income workers. In fact, it costs more than those programs combined, and it's growing rapidly."
- NPR continued to report: "There are nearly six million Americans under the age of 65 on the Social Security disability rolls. The yearly cost of their income and Medicare health benefits is more than $100 billion. Every payday you and your employer together contribute nearly two percent of your wages to pay the cost of SSDI. That's double the rate 20 years ago."
- For people who receive SSDI benefits, the return to work rate is about 2/10ths of one percent, or close to zero!

Disability and Obesity

The Rand Corporation Research Brief Series 2004, titled *Obesity and Disability, The Shape of Things to Come,* reported the following key findings:

- Obesity in the U.S. population has been increasing steadily over the last two decades – and severe obesity is increasing the fastest.
- Obesity is linked to higher health care costs than smoking or drinking.
- Obesity plays a major role in disability at all ages.
- The cost consequences of disability among the young could swamp recent Medicare and Medicaid savings stemming from increasingly good health among the elderly.

Other findings noted in the report:

- The fastest-growing group of obese Americans consists of people who are at least 100 pounds overweight.
- Individuals 100 pounds overweight increased from 1 in 200 adults in 1986 to 1 in 50 adults in 2000.
- Weight has a dramatic effect on people's ability to manage five basic activities of daily living: bathing, eating, dressing, walking across a room, and getting in or out of bed.
- If historical obesity trends continue to 2020 the number of residents in U.S. nursing homes would likely grow 10-25 percent more than historical disability trends predict.

This chart represents the number and percentage of people assessed in 2008 for any OFA In-Home Services Unit program or CASA assessment.

BODY MASS INDEX (BMI) BY AGE GROUP

Age Groups	BMI > 30	Total Assessments	% BMI > 30
18 – 49	54	137	39%
50 – 54	35	69	51%
55 – 59	39	81	48%
60 – 64	66	103	64%
65 – 74	124	289	43%
75 – 84	107	439	24%
85+	42	431	10%
TOTAL	467	1,549	30%

The National Long Term Care Studies

A National Institute of Health news release in December of 2006 noted the following: "chronic disability among older Americans has dropped dramatically, and the rate of decline has accelerated during the past two decades, according to a new analysis of data from the National Long-Term Care Survey (NLTCS). The study found that the prevalence of chronic disability among people 65 and older fell from 26.5 percent in 1982 to 19 percent in 2004/2005. The findings suggest that older Americans' health and function continue to improve at a critical time in the aging of the population."

The analysis also showed that from 1982 to 2004/2005:

- Chronic disability rates decreased among those over 65 with both severe and less severe impairments, with the greatest improvements seen among the most severely impaired. The researchers note that environmental modifications, assistive technologies and biomedical advances may be factors in these declines.

- The proportion of people without disabilities increased the most in the oldest age group, rising by 32.6 percent among those 85 years and older.

- The percentage of Medicare enrollees age 65 and older who lived in long-term care institutions such as nursing homes dropped dramatically from 7.5 percent to 4.0 percent. The emergence of assisted-living options, changes in Medicare reimbursement policies and improved rehabilitation services may have fueled this decrease in institutionalization.

As researchers continue to study the data some interesting trends are beginning to emerge that beg more questions as to how to assist people with chronic disability.

- The majority of the decline occurred in the Instrumental Activities of Daily Living (IADL) category. Tasks included in this service category are: money management, grocery shopping, laundry, and housekeeping.

- Nearly all IADLs declined over the period, but the most dramatic change was a 3.7 percentage point drop in help with money management during the period of time 1984 to 1989 when Social Security direct deposit became the norm.

- This raises the question whether IADL declines reflect improvements in health or improvements in the physical environment.

- In three activities of daily living (bathing, dressing, getting in and out of bed) an increasing percentage of elderly manage these activities with use of equipment in combination with formal or informal care.

- By modifying the environment an elder lives in (housing, location of services, equipment), can we impact their ability to remain independent longer?

While it has been interesting to follow the NLTCS and their findings on an aggregate decrease in disability in the 65 and older population, a public policy alarm must be sounded in regard to obesity and its potential impact on disability rates for both adults under the age of 60 and for this population as they approach their golden years.

The gains in decrease in rates of disability among the 65+ age group could rapidly be eroded by the increase in disability among those less than 60 years of age.

Increase in Disability Rates Among the Young

47% of people served by CASA in the 2008 total unduplicated Personal Care caseload were less than 60 years old.

The Rand Health Study in 2003 found that the number of people ages 30-49 who were disabled in their ability to care for themselves or perform other routine tasks increased by more than 50 percent from 1984 to 2000.

For people ages 30-39, the number reporting disabilities rose:

- 118 per 10,000 people in 1984
- 182 per 10,000 people in 1996

For those ages 40-49, the numbers rose:

- 212 per 10,000 in 1984
- 278 per 10,000 in 1996.

In addition, researchers found smaller but still significant increases for those ages 18-29 and those ages 50-59. In contrast, disability declined by more than 10 percent for people ages 60-69.

Researchers found that the only trend to account for this increase in young disabled adults that increased proportionally to the increase in reported disability is the increase in obesity found in the U.S. population over the same period.

Increase in Public Policy Initiatives to Address the Young Disabled

The disability rights movement is the next civil rights movement.

U.S. Supreme Court Olmstead Decision 1999

This decision is in response to two developmentally disabled individuals in Georgia who wanted to leave the institution they were in and live in the community. The Supreme Court found the state in violation of these individuals' rights under the Americans with Disabilities Act, and ruled that:

"States are required to provide community-based services for persons with disabilities if treatment professionals determine that it is appropriate, the affected individuals do not object to such placement and the state has the available resources to provide community-based services."

The New Freedom Initiative

As part of a nationwide effort to remove barriers to community living for people with disabilities, President Bush announced the New Freedom Initiatives in 2001.

Goals:

- Increase access to assistive and universally designed technologies;
- Expand education opportunities;
- Promote homeownership;
- Integrate Americans with disabilities into the workforce;
- Expand transportation options; and
- Promote full access to community life.

Ticket to Work and the Work Incentives Improvement Act

Medicaid Buy-In permits Medicaid eligible disabled individuals to work without the loss of their Medicaid benefits. Designed for people between the ages of 16 to 65, people with disabilities can retain their attendant and health care coverage under Medicaid while working and earning as much as $45,000 per year. At some point, CASA staff will be assessing people with disabilities in the work place to authorize aide service during hours of work.

Outcomes Achieved/Outcomes Expected/Effectiveness

CASA strives to deliver quality Medicaid home care services in the most cost effective manner.

- Personal care aide (PCA) services can be delivered with both quality and cost efficiency.
- CASA constantly adjusts hours of service as client needs change.
- We open and close clients to different programs as needs change. For instance, since taking over the Private Duty Nursing Program in 1998, we have decreased the number of billable hours to Private Duty Nursing (PDN) by over 20% per week.
- Many of the same clients in PDN now receive service from a Consumer Directed Personal Assistant (CDPA).

History of PCA Billable Hours

- Billable hours to personal care in 1991 were 198,316.
- The ages of those served in personal care at that time was 80% over the age of 60 and 20% under the age of 60.
- We instituted shared aide and took a more task-based approach to delivering PCA services in the 1990s, thus impacting billable hours downward.
- PCA billable hours were at their lowest in 1998 at 127,039.
- See **Major Program and Performance Measures (page 23)** to review PCA billable hours over the past four years.

Increase in PCA Billable Hours

- CASA serves an increasingly younger and severely disabled population.
- Consumer Directed has enabled clients to fill more authorized hours of personal care.
- Consumer Directed has enabled us to move clients from the high cost of Private Duty Nursing to the lower cost CDPAP.
- Our average length of stay in the program has increased.
- Shorter nursing home stays may contribute to longer lengths of stays in the community.

The programs CASA administers are **mandated** by NYS and CASA's operating expenditures are funded by Medicaid administrative dollars.

COMPARISON OF AGES OF CLIENTS

Age Range	Total Referrals in 2008	Total Unduplicated Count (PCA)* in 2008	Total Unduplicated Count (LTHHCP) in 2008
21 & under	23	88	0
22 – 24	7	6	0
25 – 29	9	20	1
30 – 34	5	14	3
35 – 39	21	24	2
40 – 44	30	26	9
45 – 49	51	45	7
50 – 54	88	59	17
55 – 59	118	66	26
60 – 64	107	77	23
65 – 69	133	63	22
70 – 74	215	63	32
75 – 79	322	58	29
80 – 84	451	59	42
85 & over	950	72	57
TOTALS	**2,530**	**740**	**270**

Note the following:

- 14% of total referrals are less than 60 years old.
- 55% of total referrals are 80 and over.

- 47% of active PCA recipients are less than 60 years old.
- 18% of active PCA recipients are 80 and over.

- 24% of LTHHCP clients are less than 60 years old.
- 37% of LTHHCP clients are 80 and over.

*PCA includes: Traditional Personal Care, Shared Aide, and Consumer Directed Personal Assistance, and Home & Community Based Waiver.

MAJOR PROGRAM & PERFORMANCE MEASURES

PROGRAMS	2005	2006	2007	2008
PCA Hours Billable to Medicaid	206,497	212,548	206,803	188,610
Shared Aide Sites	18	18	18	18
Client Referrals (Total)	2,509	2,324	2,372	2,530
AVERAGE CASES MANAGED/MONTH				
Personal Care:				
• Traditional	143	131	155	173
• Shared Aide	212	211	191	171
• Consumer Directed Personal Assistance Program	150	169	168	167
SUBTOTALS	505	511	514	511
Long Term Home Health Care Program	228	211	180	182
Nursing Home Placement	112	112	80	74
Family Homes for the Elderly	36	39	37	35
Assisted Living Program	31	25	26	27
Care At Home	9	7	7	7
Home & Community Based Waiver	48	49	51	56
Nursing Home to Community	271	288	221	253
Golden Days	14	16	17	23
Private Duty Nursing	29	25	23	21
Case Management only	322	331	317	345
Traumatic Brain Injury*	0	0	7	12
TOTALS	1,605	1,614	1,480	1,546
Personal Emergency Response System	207	212	228	231
PRIs Completed/Reviewed	332	319	398	388
UNDUPLICATED COUNT				
Personal Care Programs	742	731	770	740
Long Term Home Health Care Programs	325	280	241	270

* Prior to 2007, these numbers were not tracked.

PERSONAL CARE AIDE BY LEVEL OF CARE

Program	PCA Level I*		PCA Level II*		Totals
Personal Care Aide	111	*42%*	154	*58%*	265
Shared Aide	129	*49%*	132	*51%*	261
Consumer Directed Personal Assistance Program	26	*13%*	177	*87%*	203

* See Page 25 for description of PCA Level I and Level II.

Personal Care Aide: Levels of Care

Personal Care Aide services can be accessed in three main standards of operation:

- *Personal Care Aide (PCA):*
  CASA assesses, authorizes and case manages services to individual consumers and contracts for the services through traditional licensed care agencies. Service is billed in one hour time increments.

- *Shared Aide (SA):*
  CASA assesses, authorizes and case manages services for consumers who live in clusters that allow CASA to authorize care for many consumers delivered by one agency. Each agency aide is able to serve more clients in shorter periods of time by being centralized in one area and/or building. Aide time is billed in 15-minute increments instead of hourly.

- *Consumer Directed Personal Assistance Program (CDPAP):*
  CASA assesses and authorizes care for self directing consumers who hire their own aides and manage their own care.

Care Plan Development

Within these categories of care, CASA works with the consumer to determine a care plan that best meets the consumer's needs. CASA builds the care plan around three basic questions:

1. What are you able to do for yourself?
2. Who is helping you now?
3. How do you maintain your maximum level of independence?

While cost of care is a factor in all of our care planning, it is not the overruling or overriding factor.

Determining Need for PCA Level I or PCA Level II

CASA works with the consumer to determine the type and amount of home care needed: hands off (PCA I) or hands on (PCA II) care, or a combination.

- **PCA Level I:** These are services that are referred to in the vernacular of long term care and aging as "Instrumental Activities of Daily Living" (IADLs). They include shopping, housekeeping, laundry, assistance with bill paying, and other essential errands.

- **PCA Level II:** These services are called the "Activities of Daily Living" (ADLs). They include bathing, dressing, grooming, toileting, transferring, assistance with walking, feeding, and meal preparation.

Which level of service a consumer receives is based on the three questions asked above, as well as the consumer's desire, determination, or physical need for the service.

Many of our PCA Level I clients could use assistance with Level II tasks as a result of their physical limitations, yet due to their desire to remain as independent as possible, they prefer that we take care of the PCA Level I tasks while they take care of their bathing and grooming needs.

2008 DMS-1 SCORES BY PROGRAM

DMS-1 Score	CASA Case Management		Traditional PCA		Shared Aide Program		Lourdes LTHHCP		Ideal LTHHCP		CDPAP		PDN		TOTALS	
0 – 59	149	*48%*	92	*57%*	109	*66%*	20	*33%*	14	*24%*	44	*31%*	0	*0%*	428	*46%*
60 – 179	97	*31%*	48	*30%*	38	*23%*	25	*41%*	27	*47%*	35	*25%*	2	*8%*	272	*30%*
180 +	65	*21%*	21	*13%*	18	*11%*	16	*26%*	17	*29%*	62	*44%*	23	*92%*	222	*24%*
Totals	311	*100%*	161	*100%*	165	*100%*	61	*100%*	58	*100%*	141	*100%*	25	*100%*	922	*100%*

0 – 59	Indicates a need for a minimal amount of service, much of it related to housekeeping and chores.
60 – 179	Referred to as the Health Related level of care and at this level people begin to need personal care assistance.
180 +	Referred to as the Skilled Nursing level of care and often indicates a high level of physical disability or related inability to care for oneself due to dementia.

PRIMARY DIAGNOSIS OF CLIENTS

Ages 22 – 59		*60 Years & Over*		*Combined Age Groups*	
Nervous System Disorders*	65	Cardiovascular Disease	60	Nervous System Disorders*	86
Mental Health Disorders	27	Hypertension	55	Cardiovascular Disease	75
Musculoskeletal Problems & Injuries	19	Diabetes	48	Diabetes	66
Diabetes	18	Respiratory/Pulmonary Disease	44	Hypertension	59
Cardiovascular Disease	15	Mental Health Disorders	28	Mental Health Disorders	55
Respiratory/Pulmonary Disease	10	Musculoskeletal Problems & Injuries	23	Respiratory/Pulmonary Disease	54
Congenital	10	Arthritis	23	Musculoskeletal Problems & Injuries	42
Cancer	7	Nervous System Disorders*	21	Arthritis	26
Obesity**	5	Cancer	10	Cancer	17
Infectious Immune Disorders	5	Digestive System Disorders	7	Digestive System Disorders	11
Digestive System Disorders	4	Obesity**	4	Congenital	10
Genitourinary System Disorders	4	Sensory	3	Obesity**	9
Hypertension	4	Genitourinary Systems Disorders	2	Sensory	7
Sensory	4	Skin Disease	2	Infectious Immune Disorders	7
Arthritis	3	Infectious Immune Disorders	2	Genitourinary System Disorders	6
Skin Disease	2	Miscellaneous	11	Skin Disease	4
Miscellaneous	6			Miscellaneous	17
	208		343		551

* Nervous System Disorders have a potentially high impact on the ability to perform ADL's and IADL's.
** Obesity is not often listed as the primary diagnosis.

REFERRAL STATISTICS

TOTAL NUMBER OF REFERRALS

	2005	2006	2007	2008
Community	1,548	1,463	1,568	1,560
Hospital	961	861	808	970
TOTALS	2,509	2,324	2,376	2,530

REFERRALS BY PAYOR SOURCE

	MEDICAID				NON-MEDICAID			
	2005	2006	2007	2008	2005	2006	2007	2008
Community	395	384	485	483	1,153	1,079	1,083	1,077
Hospital	207	171	201	246	754	690	607	724
TOTALS	602	555	686	729	1,907	1,769	1,690	1,801

HOSPITAL REFERRALS

	MEDICAID				NON-MEDICAID			
	2005	2006	2007	2008	2005	2006	2007	2008
BPC	9	0	6	1	2	0	5	0
General	42	42	69	64	105	73	94	101
Lourdes	91	61	63	89	267	266	216	290
Wilson	65	67	62	90	379	351	292	332
Other	0	1	1	2	1	0	0	1
TOTALS	207	171	201	246	754	690	607	724

COMMUNITY REFERRALS

	MEDICAID				NON-MEDICAID			
	2005	2006	2007	2008	2005	2006	2007	2008
Neighbor/Friend	4	3	11	11	7	11	15	25
Self/Family	138	111	177	156	505	502	546	594
Community Agencies	106	124	142	119	181	188	165	155
CHHA	33	34	34	56	54	30	48	45
ACF	5	9	17	11	48	56	55	39
LTHHCP	5	5	4	2	10	11	1	0
PCA Providers	4	8	5	15	13	10	8	5
Physicians	12	28	40	27	78	77	97	63
RHCF	87	62	55	86	246	194	148	151
TOTALS	394	384	485	483	1,142	1,079	1,083	1,077

NURSING HOME TO COMMUNITY PROGRAM

	Nursing Home Residents Assessed by CASA						Nursing Home Residents Discharged with CASA Involvement				
Year	Age 0-59	*%*	Age 60+	*%*	**Totals**		Age 0-59	*%*	Age 60+	*%*	**Totals**
2001	18	*4%*	432	*96%*	**450**		16	*5%*	311	*95%*	**327**
2002	35	*6%*	541	*94%*	**576**		28	*6%*	462	*94%*	**490**
2003	40	*6%*	597	*94%*	**637**		31	*5%*	539	*95%*	**570**
2004	57	*8%*	616	*92%*	**673**		62	*10%*	556	*90%*	**618**
2005	37	*6%*	582	*94%*	**619**		55	*8%*	607	*92%*	**662**
2006	56	*9%*	559	*91%*	**615**		44	*9%*	423	*91%*	**467**
2007	44	*8%*	475	*92%*	**519**		36	*9%*	372	*91%*	**408**
2008	31	*5%*	648	*95%*	**679**		23	*5%*	452	*95%*	**475**

The following table depicts the average length of stay for Nursing Home to Community Clients that were discharged back into the community during the year 2008.

Payor Source	**Number of Nursing Home to Community Clients**	**Percentage of Nursing Home to Community Clients**	**Total Days in a Nursing Home**	**Average Days in a Nursing Home**
Medicaid	37	*8%*	8,879	239.97
Medicare / Medicaid	102	*21%*	14,970	146.76
Medicare / Private Pay	285	*60%*	25,649	89.99
Private Pay	51	*11%*	6,814	133.61
TOTALS	**475**	***100%***	**56,312**	**118.55**

IN-HOME MENTAL HEALTH CARE PROGRAM

14 Active Clients

GENDER	**Number of Clients**	***Percentage***
Male	3	*21%*
Female	11	*79%*
TOTALS	14	*100%*
AGE RANGES		
Less than 60 years old	5	*31%*
60 years old and over	9	*64%*
TOTALS	14	*100%*
IS CLIENT COMPLIANT WITH TAKING MEDICATIONS?		
Yes	14	*100%*
No	0	*0%*

Activities of Daily Living

Activities	**Clients**	***Percentage***
Bathing	5	*36%*
Mobility	0	*0%*
Transferring	0	*0%*
Dressing	1	*7%*
Personal Hygiene	8	*57%*
Toileting	0	*0%*
Eating	1	*7%*

Instrumental Activities of Daily Living

Activities	**Clients**	***Percentage***
Shopping	12	*86%*
Getting to places	10	*71%*
Housework/Cleaning	13	*93%*
Meal Preparation	6	*43%*
Personal Business	10	*71%*
Telephone	0	*0%*
Medications	9	*64%*

CLIENT DEMOGRAPHICS

Our client demographics tell the following story about the people we serve in the Medicaid home care programs (Personal Care, Consumer Directed and Long Term Home Health Care).

They are overwhelmingly female.
Two-thirds of the people in the Personal Care or Long Term Home Health Care Programs are women.

Most likely they are not married.
They are either widowed, divorced or have never been married.

By virtue of the fact that they are served by Medicaid programs, they are low income. Their primary source of income comes from three government programs: Social Security, Supplemental Security Insurance, or Social Security Disability.

Ninety percent of the people we serve depend on others to transport them around town, thus the high percentage (over 90%) that require their aides to shop for them. While they report being dependent on others for transport, 10% or less report using public transportation.

Home ownership is low among the people we serve. Seventy percent of them rent or live with someone else and 50% of them live alone.

In the Personal Care Program which includes Consumer Directed Care, 47% of the recipients are under the age of 60. When combined with the LTHHCP, 40% are under the age of 60 (LTHHCP tends to care for a higher percentage of elders). However, these numbers are still high and indicate the large numbers of young disabled adults using home care.

CASA authorizes shopping and housekeeping for almost the entire population of people receiving home care from any program. Two-thirds of the population requires assistance with bathing and personal hygiene.

So who is being served in the Medicaid home care programs in Broome County? Out of the 1,011 people served in 2008, they were mostly low income women who are not necessarily elderly. They live alone, do not own their own homes and are dependent on others for transportation. The most frequently requested services are shopping, housekeeping, and personal care. Most likely they each have more than one chronic condition related to the top five diagnostic categories: nervous system disorders, diabetes, mental health disorders, respiratory/pulmonary disease, and hypertension.

2008 CASA Advisory Board Members

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