CASA Association of New York State
Presents:

Restructuring Medicaid Home Care
in
New York State:

A CALL TO ACTION

Winter 2009

TABLE OF CONTENTS

Executive Summary

Governor Patterson’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.

Introduction

The state and federal government appear to be on the verge of real health care reform. The New York State CASA Association, an association of New York State counties that have CASA's or CASA like structures, supports efforts to redefine and reorganize our system of health care and long term care in particular. After decades of organizing and delivering personal care aide services, we have information that is valuable in determining the changes needed.

The current system of care delivery was influenced by the passage in 1965 of the Medicare and Medicaid amendments to the Social Security Act. In 1965 Medicare and Medicaid addressed the needs of elders without health insurance, the disabled and poor women and children. Medicare addressed the acute care medical needs of those over the age of 65 and Medicaid addressed the acute care medical needs of the poor. Medicaid was expanded over the years to include coverage for people with chronic conditions, a far larger and more diverse population than the program was originally intended to serve.

County government in New York State (NYS) has historically been designated by the state to organize and provide a range of long term care services. Counties play an integral role in assessing for and authorizing 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 Program (CDPAP), Personal Emergency Response Systems (PERS), the Assisted Living Program (ALP), the Care at Home program (CAH), Private Duty Nursing (PDN), Managed Long Term Care (MLTC), and provide Patient Review Instruments and Screens for Nursing Home placement and entrance into some waiver programs.

In January of 2006 NYS provided Medicaid relief to counties by capping the costs for administering the program. Counties still contribute a substantial portion of tax revenue to Medicaid, yet the growth in the local share is now predictable. Counties continue to have a vested interest in program delivery to ensure that the care needs of the most vulnerable members of their communities, people with disabilities and the frail elderly, are met.

There have been significant changes in the population served in these programs since 1965. The changes have increased the level of services needed and therefore the cost of service. Counties, in experiencing these changes, have developed expertise in service delivery and can therefore provide critical information that is important to acknowledge in the effort to reorganize long term care in NYS. The purpose of this paper is to:

- Share our collective insights in the delivery of home care in New York State.
- Highlight the changes in the population being served.
- Make recommendations for reform.

The CASA Concept

In 1983 the then New York State Department of Social Services, on the recommendation of the Long Term Care Systems Development Project, coordinated the effort to establish the Community Alternative Systems Agency (CASA) demonstrations in nine counties across New York State including New York City. This was an attempt to "reduce the rate at which long term care expenditure is increasing by substituting personal care where less costly, for institutional placements" (CASA Operations Manual, 1983). The emphasis of the CASA demonstrations was on keeping people at home, not merely for cost containment, but also because "people are happier, and the quality of their lives [are] generally enhanced when they are able to live within the familiar surroundings of home and neighborhood" (CASA Operations Notebook , The CASA Concept, 1983).

In 1983 the growth of the elder population in need of long term care was projected to "increase within the most vulnerable age group, those 75 years and older, or 10% by 1990" (CASA Operations Manual). It was thought that due to this increase in the older population "it is obvious that the demand for long term care services will continue to grow" (CASA Operations Manual).

The population estimates made in 1983 in regard to the growth in personal care estimated the need for care among those 75 and older. Since 1983 there has been an expansion in New York State of younger disabled adults accessing the personal care aide program through waiver programs and through State Plan services. Along with this increase NYS is facing the aging of the baby boomers; the need for care for them and for the younger population will have a dramatic effect on the need for services in our state.

Personal Care: No Longer Only for the Elderly

While care of the elderly remains a significant portion of community based Long Term Care (LTC) services, four general trends have emerged to create the current LTC climate and escalating costs.

- One is the advancement in medical technology that has led to better trauma care. Young adults now survive spinal cord injuries and babies born prematurely, with disabling conditions, survive into childhood and beyond.

- Second is the increase in physical disability among people younger than 65. 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.”

- The third general trend impacting community based LTC is the disability rights movement. Disability advocates for children and adults have been active across New York State and the nation in the past 20 years. Disability advocates like Justin Dart, Jr., co-founder of the American Association of People with Disabilities, were instrumental in advocating for the first President Bush to pass the Americans with Disabilities Act in 1990. By the end of the decade the US Supreme Court issued the Olmstead decision. Also the past 20 years has seen the growth in Medicaid waivers for special needs populations such as the Traumatic Brain Injury (TBI) program, Care At Home (CAH), Home Community Based Waiver (HCBW) and the Long Term Home Health Care Program (LTHHCP), and all roads for people with disabilities are leading home, not to institutionalization.

- The fourth trend in long term care is de-institutionalization, and the rapid move from an institutional based system of care to a community based system of care.

Personal Care: The Role of the County

Counties, both those with and without CASAs, have historically played a major role in all Medicaid community based long term care programs in New York State and perform the following functions:

- Determine Medicaid eligibility.
- Assess for and authorize Medicaid payment for the Personal Care Service Program (PCSP), the Long Term Home Health Care Program (LTHHCP), Consumer Directed Personal Attendant Program (CDPAP) and Personal Emergency Response Systems (PERS).
- Assess for and authorize or coordinate Medicaid payment for the Assisted Living Program (ALP), the Care at Home program (CAH), Private Duty Nursing (PDN), and Managed Long Term Care (MLTC).
- Provide Patient Review Instruments and Screens for Nursing Home placement and entrance into some waiver programs.
- Provide case management.
- Work in partnership with stakeholders, providers and consumers to ensure service availability.
- Engage in local system and policy development the most recent example: implementing NY Connects.

From determining Medicaid eligibility to authorizing personal care, district staff has developed expertise in long term care and is knowledgeable about **all** programs, both Medicaid and non-Medicaid, offered in the community. They work as partners and problem solvers with **all** stakeholders, providers and consumers to develop a **comprehensive** plan of care. These partnerships and familiarity with the players in other local programs leads to more effective and efficient service delivery.

It is with the knowledge and expertise developed and evolved over 30 years of assisting county residents of all ages in navigating the often complex delivery systems that make up community based long term care in NYS that we will discuss:

- **Recommendations**
- **Case Management**
- **Trends in Personal Care**
- **Lessons Learned**
- **Barriers and Obstacles**
- **Case Studies**

Recommendations

As a national leader in home care, New York State has an opportunity to construct meaningful long term care system wide reform. The NYS CASA Association suggests the following recommendations be taken into consideration. To create the most effective and efficient quality care system it is important for the state, the local districts, consumers and providers to work as partners recognizing that local resources are either available or limited by the nature of the communities served.

1. **The goals and measurable expected outcomes of long term care need to be clearly defined for all Medicaid funded care. The continuum of care includes State Plan Services, Waiver Programs, Assisted Living Programs and Nursing Homes. Evidence-based means of achieving goals and measurable outcomes need to be researched and developed for the entire continuum.**

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.** Conflicting values and practices among state agencies are reflected at the local level. NYS offers very generous state plan services, as well as services provided by the State Office for the Aging and nine waiver programs. The regulations governing these programs are derived from the differing philosophies of these competing state agencies. Do we respond to peoples' needs or wants? Are Medicaid dollars to be used to address medically related conditions or to meet people's need and desire for socialization? Personal Care Service Program regulations were designed to address the need for basic task related care due to disabling physical conditions; the program is also accessed by those with disabling mental health conditions and developmental disabilities.

3. **Data needs to be collected, analyzed and widely disseminated**. Before creating any new system of care the state needs to take a step back and collect some statistics on who is being served and how. As noted in the Governor's budget, "Fewer people are getting services, but the cost per person is rising sharply due to the increased level and costs of the services provided."

    - What are the current administrative costs of operating the Medicaid personal care program via a county system of service delivery?
    - What are the projected administrative costs for operating the Medicaid personal care program via non-governmental agencies?
    - Who is being served?
    - What types of chronic conditions do they have?
    - What are the services they are receiving?
    - How many programs are people participating in (HCBW, TBI, CAH, NHTDW, OMRDD, PCSP, PDN)?

- Are services being duplicated?
- Do the services conflict?
- What types of outcomes can we expect for the money we are paying for the care?
- What is the average length of stay in Medicaid Personal Care Programs?
- How often do consumers transition between care sites?
- How does the need for care change over time?
- How many have a diagnosed mental health problem?
- How many have drug and alcohol problems?
- How many are developmentally disabled?
- What is the range of ages of people in the Personal Care Program county by county?
- What impact has the introduction of waivers had on Medicaid personal care (state plan) expenditures?
- Where does the money go?
- Who benefits from the system in its current form?
- Who resides in the households of people receiving personal care?
- What are the average hours of service delivery per week? By program? By disease process? By age category?

There are many unanswered questions when it comes to Medicaid personal care in NYS. Without an understanding of who is currently being served and how the population has changed and will change over the years, it is difficult to determine how best to restructure the system.

4. **PCSP Regulatory Reform.** The regulations governing personal care services (505.14) emphasize that services are provided to assist people with personal hygiene, nutritional and environmental tasks. These services are related to a medical condition and physician orders must be obtained to verify that the person needs care. The regulations provide little guidance in determining the number of hours of care a person might receive, particularly in the case of disabled children, and have never been revised to include Consumer Directed Care. In fact, in NYS there is essentially no limit on the number of personal care hours a person might receive. The NYS Personal Care Services regulations need to be revised 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**. Personal care services, operated by local social service districts or local Offices for Aging, are woven into the fabric of their communities. If the program is not delivered “consistently throughout the state” it goes beyond districts “not cooperating.” Staff works on complex social problems presented by consumers by accessing the local resources which are often unique to each community and limited by the availability of local resources. The PCSP, the largest home care program in the United States, offers absolutely no training from the state level to the local level. At a minimum, a training program that addresses the need for consistent assessments should be offered on an annual basis in regard to: assessment, care planning, and case management.

6. **Provide substantive and consistent public education/orientation to households applying for in home care on their rights and responsibilities regarding the program's services.** Very few households have any experience in directing the work of others in their home. This can lead to underutilization of the personal care aide, or in placing unreasonable demands upon the aide. Statewide orientation of the consumers of personal care and their family members can help reinforce a strength based approach to designing and executing a care plan, and set clear expectations for performance.

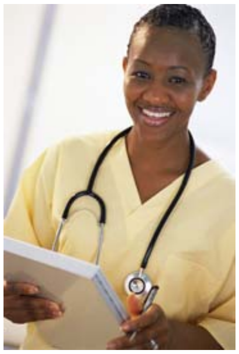
7. **Create the resources and tools needed at the local level for service provision.** We support the development of a statewide assessment tool. NYS also needs to provide the resources at the local level to efficiently and effectively deliver home care. Housing stock in NYS is aging and often not accessible. The state should promote development of new housing that emphasizes livable components. Localities are essential in collecting data on client characteristics, outcomes and expenditures; however they are woefully lacking in computer resources.

8. **Create a state service corps for aides.** Unless and until aides are paid a decent living wage with benefits, we will always have problems recruiting and retaining aides. If the state and federal governments continue to allow profits to go to agencies without paying the work force, then a service corps for aides should be created. This could be tied to college education tuition forgiveness. College students could work during the school year and summers or even full time after college for a year or two to pay back their college loans. This would be one way to expose young adults to health professions or social work.

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.** Counties could create MOUs with neighboring counties to share resources in program administration and delivery. These collaborations will depend on the counties involved; those that can benefit due to their geographic or regional situations. There are counties throughout the state with urban cores that act as market centers to neighboring rural counties. These **naturally** occurring market areas could form consortiums to partner in the delivery of service.

In support of these recommendations, the NYS CASA Association will use the rest of this paper to describe the environment we currently operate in, the lessons learned, barriers and obstacles and case studies.

Case Management



Case management, defined as “a collaborative process of assessment, planning, facilitation and advocacy for options and services to meet an individual's health needs through communication and available resources to promote quality cost-effective outcomes” ("What is a case manager?" 2008) is a central part of the requirements of the Personal Care Service Program (PCSP). It is essential in the current complex care environment to assist consumers to access quality cost effective care.

Case management is **not** a discrete billable service in the PCSP; however, as outlined in NYCRR Title 18 regulation 505.14, the local social services district professional staff is to actively perform case management functions. The district staff must:

- Assess the consumer’s physical capabilities, environment and mental health status and develop a comprehensive plan of care to meet their needs.
- Negotiate care with informal caregivers.
- Establish linkages with other community agencies.
- Monitor the effectiveness of the plan of care and adjust as circumstances change.

The people served in the PCSP live in poverty, manage multiple chronic conditions, increasingly spend a significant portion of their lives in receipt of services and are often perplexed by a system that is increasingly complex. While the delivery of basic physical care was the intent of the PCSP, people’s ability to remain independent in their homes depends just as much on their ability to manage the day to day business of living. PCSP caseworkers are not just coordinating the aide service needed to address physical care needs. Every PCSP caseworker who walks through the door increasingly finds themselves having to manage a wide range of social problems. These problems, ranging from utility shut offs to elder or substance abuse, must be addressed to create a stable and safe environment for the home care workers and the consumers.

While home care has become more complex, there has been a trend to move away from case management to “service coordination.” Service coordinators encourage consumers to access services on their own. While many consumers are capable of performing this function on their own, those who aren’t capable, or choose not to, are often at a loss of where to turn.

Some of the difficulties that are faced by the local district staff include:

- **People in the PCSP often live in households with more than one person**. When this occurs, the PCSP caseworker needs to negotiate a plan of care that only addresses the needs of the recipient. Due to current regulations, a Personal Care Aide cannot provide maintenance for the entire household. In these situations the PCSP caseworker must make referrals on the consumer’s and the family’s behalf to other agencies that might be able to assist with care for family members such as child care. These problems exist with all age groups but are more complicated in situations with young families.

- **It is not unusual for people in the PCSP to have anywhere from 2 to 4 "case managers."** These "case managers" tend to 'case manage' only the services provided within the program they represent, such as the Traumatic Brain Injury Program or the Home and Community Based Waiver program. The local district staff must oversee all of the services provided in order to prevent duplication of and/or conflict between service goals and payment sources.

- **Upstate counties serve an annually increasing percentage of people younger than 60 years of age in the PCSP.** Throughout the state, the percentage of the young and disabled adults served in the PCSP ranges from 20% to 50% of the total monthly caseload. These are NOT people with developmental disabilities; they are physically disabled from a myriad of maladies or misfortunes. Often these disabling conditions are far more complex and require more service provision than those of today's elders. Along with their physical disabilities, many have mental health and alcohol and drug abuse problems which often cloud their ability to make choices.

- **Care transitions**. The transitions of care, from home to hospital to nursing homes and back home, require planning and coordination. Often it is the local district staff that coordinates these transition meetings as any changes need to be reflected in the consumer's plan of care.

- **Available programs change depending on available funding.** A program may end and no longer be available to the consumer. The local district case worker must then assist the consumer to access the needed service in another program. This requires the specialized **local** knowledge of the worker.

These are but a few of the difficulties involved in case management for and with the consumer. These services are provided by the local district or CASA staff as part of the PCSP, not as a separate billable service.

Trends in Personal Care

As stated before, Community Based Long Term Care Services in New York State are extensive and complex. The New York State Personal Care Assistance Program is the largest Medicaid personal care program in the United States. Besides this program, there are nine Medicaid waiver programs plus the Private Duty Nursing program.

There have been many suggestions to streamline these programs. One recently proposed by the Berger Commission, NY ANSWERS, suggested eliminating all of the waivers and creating a single agency for assessing and authorizing long term care services. The second proposed by Governor Paterson in his 2009-2010 state budgets is the creation of “Long Term Care Assessment Centers.” While everyone agrees that the system is too complex as it stands, there is no agreement on how to change the system to make it more efficient, while delivering cost effective and efficient quality services.

Whatever reform outcomes are ultimately established, the following trends should be taken into consideration:

- **The PCSP serves an increasingly diverse and younger population**. These people will spend a significant amount of their natural lives in receipt of Medicaid long term care services and often have complex needs.

- **NYS operates NINE Medicaid Waiver Programs**. These programs are designed to address specific populations: LTHHCP, TBI, CAH I, II and VI, OMRDD HCBS Waivers, OMH, NHTDW and Bridges to Health. While these programs can all stand on their own merits, the fact that there are nine of them adds to consumer and provider confusion as to who qualifies for what service, why, when and how. Due to the specificity of each program, we are still left with consumers not meeting the criteria and “falling through the cracks.” Lastly, many of these programs access the PCSP for the hands on care that they don’t provide, thus leading to the multiplicity of case managers, and increased use of state plan services.

- **Transitional care.** People both under and over the age of 60 requiring care to manage chronic conditions will make numerous transitions between hospital, rehabilitation center, nursing home and the community. State investment in the development of electronic medical records would provide many efficiencies in transitional care.

- **Caregiver stress.** Informal caregivers, the providers of the vast majority of service, often are working and raising families, while trying to care for aging parents, disabled spouses or children with disabilities. With people living for so many years with chronic conditions, the stress on these caregivers will continue to mount and may prevent them from providing needed support to consumers.

- **Working conditions for aides providing personal care can be challenging.** Licensed Home Care Service Agencies are finding it difficult to find aides who will stay in situations that offer significant challenges. These include homes where people have hoarded so many things you can barely turn around, homes where people involved with consumers may be actively dealing in drugs or drinking to excess, or consumers who engage in sexual harassment or have poor interpersonal skills.

- **Aide shortage.** There is a shortage of aides in upstate NY and a high turn over rate. Pay and benefits are poor and many aides lack transportation to get to their jobs. These circumstances contribute to what is rarely discussed, the social problems that the aides bring to the work place. Aides often need to have the reinforcement of case management themselves or job coaches to learn basic work skills such as the importance of showing up and being on time.

- **NYS 2009-2010 Budget** is calling for the phasing out of 6,000 skilled nursing beds in NYS, the expansion of Medical Day Care, Certified Home Health Agencies, and Assisted Living Programs.

- **NY Connects: Meaningful informed choice:** Choice is a “buzzword” in health care reform. However, we are consistently dealing with consumers who are at a loss as to how to evaluate the choices before them. Consumers need help sorting through the complex myriad of health care choices before them. Whether it is assistance in choosing one of the over 50 Medicare Part D plans offered in NYS, or choosing a waiver provider, we often find “consumers” frustrated by the task. NY Connects is a response to consumers need for unbiased information on long term care in their community.

- **Health Literacy**. Health Literacy is key to making informed choices. Health literacy is defined in *Healthy People 2010* as: "The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions." Health literacy is not simply the ability to read. It requires a complex group of reading, listening, analytical, and decision-making skills, and the ability to apply these skills to health situations. With the move towards a more "consumer-centric" health care system as part of an overall effort to improve the quality of health care and to reduce health care costs, individuals need to take an even more active role in health care related decisions. To accomplish this people need strong health information skills or someone to assist them in interpreting the options.

Issues to Confront: The Myths of Home Care

CASA Association members recognize the need to join the state and nation in reforming our systems of care. To that end, we would like to share our observations and insights.

1. Home Care is always less expensive than Nursing Home Care. In fact this is often not the case. While home care is the 'right' thing to do if people want to remain in their homes, when you consider all of the public benefits and services Medicaid personal care recipients are receiving, care for an individual at home can far exceed the cost of the care of an individual in a nursing home. In addition, addressing the challenges of coordinating and managing these services in the home is also costly.

2. A program with an aggregate budget will decrease the cost of care. Recently advocates have touted the "aggregate cap" method of personal care budgeting as the panacea to the rising costs of personal care. The decrease in cost is seen only in the total amount budgeted for the program. If several "high cost" individuals are in the program others will need either to be left out of the program or have their services reduced. This may leave many consumers without care or with limited care.

3. Traditional fee for service care is always more expensive than managed care. As ideas emerge to place personal care under the auspices of a managed care entity, we would encourage the state to look at what has happened to the Medicare program as they moved away from traditional fee for service. "Instead of paying private plans less than traditional Medicare, in the belief that they could find innovative ways to cut costs and improve care, we are now paying them significantly more." *NYT editorial July 14, 2008, "Medicare's Bias"*.

4. Personal care can be guaranteed. There are unrealistic expectations placed on the provision of personal care as it is currently configured. The delivery of personal care is dependent on a limited pool of personal care workers who are poorly paid. As low wage workers, they have a myriad of problems such as transportation or finding child care. If they call in sick to work or cannot service a client on a particular day, it is often hard if not at times impossible for the agency to replace that worker for the day. Even with the advent of consumer directed care, care cannot always be guaranteed.

5. Long Term Care is just for the elderly. As the number of people of all ages with chronic disabilities has grown more prevalent, long term care has expanded to serve people in all age groups. The two fastest growing groups of people in receipt of LTC are elders over the age of 85 and young adults between the ages of 40 to 60.

6. All people are capable of managing their own care. Many people need assistance in accessing and managing their care since the system as it stands is complex. People often need to work in partnership with informal care providers or case managers in order to manage their care.

Lessons Learned: Case Management and Personal Care

Lessons Learned: 1. Local knowledge of services is key to good care planning and case management.

New York State is geographically and ethnically diverse. The ability to concentrate services in a neighborhood in Buffalo does not exist in Essex County where neighbors can live miles apart. While New York City (NYC) has a large personal care aide work force, upstate New York is experiencing the worst crisis in securing personal care aide workers in years.

New York City has public mass transportation, while aides in suburban areas, rural areas and upstate cities do not have access to public transport on the scale it is available in NYC. Even if the aides have access to public transportation in Buffalo or Syracuse, often the consumers don't live on the bus route, thus creating a barrier to service provision.

Programs available to assist people in the community differ from county to county. Programs that provide home repairs, food, transportation, coats for the winter time or air conditioners for the summer are operated by a variety of local non-profit agencies across the state. Knowledge of these programs is essential to care plan development.

Lessons Learned: 2. Care provision is best done in partnering.

No single agency can deliver services alone. All agencies need to work in partnership. Consumers served by the waiver programs are entitled to access the PCSP, making it necessary for the agencies and consumers to work closely together in establishing and maintaining the best plan of care. This can be difficult because both the county and the waiver provider are governed by different state agencies with differing philosophies of care. OMRDD focuses on what consumers "want" and DOH regulations governing personal care are based on what the consumer "needs." Service plans need to be coordinated with other providers when people transition between the hospital, psychiatric facility, nursing home and the community. As previously noted, it is not unusual for a consumer to have more than one case manager or "coordinator." People attend all kinds of programs and therapies outside of the home as well as receive personal care in the home.

Lessons Learned: 3. A consumer's circumstances on paper can appear vastly different than what is taking place in actuality.

A consumer with severe disabilities might be living in very nice surroundings with a good support system and a mentally healthy outlook. This person might require less care than what a paper review might indicate. The only way to know these things is to meet the consumer and see where and how they live, and to know the community they live in. This helps ensure that limited resources for care provision are distributed in a manner that is most useful to the recipients.

Lessons Learned: 4. Staff must be continually educated on programs available.

An assessment requires knowledge of the available resources in the community. Since Medicaid is the payer of last resort, it is important that case managers know of all the services available in the community when developing a plan of care. Over time some community programs may disappear, while others start up. In one community an individual started the *Beds for Kids* program out of the back of a truck. He accepts and distributes beds to those children in need and their families. Educating case management staff on these **local** programs is essential to good case management.

Lessons Learned: 5. The care needs of consumers have become more complex.

As noted, throughout the state, younger persons and disabled adults now make up one fifth to one half of the personal care caseload. These consumers often present with multiple problems, sometimes the least of which are their physical care needs. If people have mental health or drug and alcohol problems, live in unsanitary environments, are without running water, have inadequate heating/cooling, multiple animals, or refuse to take medications and/or follow the plan of care the provision of service can be a challenge. All of these factors can lead to informal and formal caregiver burn out.

Lessons Learned: 6. Social and economic issues can have a major impact on care planning.

One issue complicating the delivery of personal care is the lack of affordable accessible housing throughout NYS. High rents, increasing costs for food and clothing and the current economic climate make it difficult for informal providers of care and therefore make case management for consumers even more complex.

Barriers and Obstacles to Community Based LTC Service Provision

1. Aide Shortage: The number one barrier to service provision in upstate NY is the personal care aide shortage. Aides are notoriously low paid. With the recent surge in gas prices, agencies upstate noted many aides leaving this line of work. Many experienced aides have been forced to move to other lines of work to increase their income.

2. Difficult to serve: In every county, providers and district staff work in partnership with the consumers to coordinate care. Young adults with disabilities have the potential to spend a significant portion of their lives in receipt of personal care. The complexities that their home lives can present often make it necessary to change provider agencies. It is not unusual for counties to rotate agencies or use a combination of agencies in order to coordinate care for "difficult to serve" consumers, especially those with a high number of hours.

3. Cultures: This not only refers to ethnic groups, but can include rural versus urban as well. Consumers living in rural areas are often reluctant to allow others to assist them and may not even acknowledge that they have a problem. Those with different upbringings/religions will only allow what their culture will permit. Case managers need to have the knowledge gained from working with many clients to be of the most assistance with the most sensitivity.

4. Location: It is not only difficult to serve consumers in outlying areas; consumers in urban areas who don't live on a bus line often cannot find care. Licensed agencies strive to hire people in hard to serve locations. Aides often don't want to travel far between cases since they are not paid for travel time. Aides can accept jobs at will.

5. Transportation: Transportation is probably the most frequently cited barrier or obstacle by both consumers and providers. Public transportation can be difficult to access for both helpers and consumers and routes are limited.

Conclusion

The CASA Association of New York State recognizes the need for long term care reform. The system was originally designed to serve an elder population at the end of their lives. Since the inception of the Personal Care Service Program in New York State, the population being served has changed drastically. However, the regulations governing the program have not adequately addressed the change in the population. An argument can be made that the growth in the waiver programs was a direct result of the perceived inability of the Personal Care Service Program to address the needs of a younger disabled population. Yet, access to the Personal Care Service Program for waiver participants is often the key to living independently in the community.

Therefore, we strongly encourage the state to begin the process of long term care reform at the state level. This would involve reviewing all of the long term care programs offered by the state and coordinating and streamlining the governing values, vision, regulations and philosophies of all home care programs in NYS to meet the needs of both the consumers and the taxpayers. Once this has been accomplished, the state and the local districts need to work as partners to create the most effective and efficient quality care system.

Case Studies

Assessment and case management are ongoing and evolutionary, needs change often and care plans have to be adjusted. The following case studies are presented to illuminate the aspects of care we have discussed.

"Ben"

"Ben" is six foot six inches tall and weighs 400 pounds. He is in his late thirties and resided in Broome County upon initial evaluation for personal care services. Four years previous he had been diagnosed with cancer of the brain and spine, received chemo and was in remission. After the break up of his marriage he moved in with his mother who found it difficult to work full time and care for him. Due to the lack of other informal support, CASA suggested he apply for the TBI waiver program so he would be able to remain in a home setting with formal support. However, while waiting to be admitted to the program he was hospitalized.

Following that hospitalization, he moved out of his mother's home into an apartment in a rural area. He was now enrolled in the TBI program and received personal care aide service twice a week. His CASA nurse visited monthly.

His care was complicated by conflicting reports of bizarre behavior, family disputes over the correct course of action, financial problems with unpaid bills and regular communication from the licensed agency attempting to provide the now one hour daily seven days a week service.

CASA coordinated assistance from adult protective and the local mental health crisis intervention team. Ben's bizarre behavior manifested itself in his refusal to empty bottles that he was using as a urinal. He lined up these bottles in the living room, making it increasingly difficult for anyone to work in that environment.

His mother though concerned was unable to assist. The TBI program was unable to maintain a plan of oversight and discharged the client, and the PCA/ CDPAP, the most long serving and stable of all services, could not continue as no one wanted to work in the home.

In the end it was the CASA nurse/case manager who persisted and the client was involuntary admitted to a local psychiatric ward. After months of treatment Ben was discharged to an adult care facility in a neighboring county.

Ten months later his previously uninvolved stepmother removed him to care for him at her home with consumer directed care approved by Broome County. Assessment visits were provided by Cortland County. The arrangement lasted eight months before Ben was evicted.

Ben now lives with his father outside of Broome County with TBI waiver services and state plan consumer directed services of twelve hours a day. He requires two people to assist with transfers, requires regular wound care and continues to slowly deteriorate.

While the TBI program is now primarily responsible for overseeing his care, the provision of his care would not be possible with out the consumer directed program. Broome County CASA authorizes the care, reviews the paperwork and regularly communicates with workers where he currently resides, as well as the TBI program case manager and the Broome County DSS who certifies him for Medicaid.

This is not an isolated case but one that illustrates the continuity a PCSP Case Manager brings in monitoring in and out of county care provided by multiple programs and "coordinators of care" during a younger disabled client's lifetime.

"Jared"

"Jared" is a 43 year old man with quadriplegia and mental illness who lives alone in senior apartments outside of Ithaca. He has two teenaged children who he rarely sees and limited family connections. He is reliant on his motorized wheelchair for mobility and is able to transfer himself in and out of bed when he is feeling well. He needs personal care, mobility assistance, medication assistance, bowel care, meal prep, along with housekeeping, shopping and laundry assist.

Last year Jared's paranoia exacerbated to the point where he was dismissed by his physician and his home care services, leaving him unable to function at home. He was transported to our local hospital and after a lengthy stay on the "swing unit" was eventually transferred to a nursing home that could provide for his care, outside of our local community.

It was Jared's wish to return to his apartment. In order to support his desire to return home, his long term care case manager and adult protective worker arranged for a discharge planning meeting at the nursing home to discuss what Jared would need to safely return home. They also discussed the facility's difficulties in managing Jared's behavior, and shared their experiences on how best to work with him.

Following the discharge planning meeting and the development of a care plan to return home, facility staff reported improved cooperation in working with Jared and as a result they were able to work with Jared on his plan to return home.

The case manager from Tompkins County arranged for Jared to take a day trip (150 miles each way) back to Ithaca to set up primary care with a new physician. When the local CHHAs refused to provide care for him due to his history of difficult behavior, his case manager developed a plan of care that included private duty nursing, personal care services, personal emergency response, and home delivered meals. She worked with Jared's support system to make certain he had a reliable back up plan. Once primary care was established and new homecare staff located, Jared returned home to his apartment where he remains today.

Without the persistent collaboration of Jared's Tompkins County case manager with the other players in this case, he would still be living in a nursing home against his wishes. The current cost of his homecare is less than $3,000 per month which is less than half of the cost of his care in the nursing home.

"Paul"

In the summer of 2006, Paul was paralyzed in a diving accident. The accident left him a quadriplegic. After spending time in a rehabilitation facility and a nursing home he expressed his desire to die. He refused all care at the nursing home and was admitted to the hospital. In the hospital he also refused care. His mother, Helen, who was diagnosed with lung cancer, decided to take him to her home. Paul was discharged with ***Hospice*** *and the* ***Consumer Directed Personal Care Aide Program (CDPAP).*** *His sister became his consumer directed aide. Also residing in the home was Paul's disabled father and his brother Kevin.*

Kevin is 40 years old and profoundly mentally retarded. Kevin is fed with a stomach tube. He is unable to swallow food normally due to the potential that he will choke. He cannot walk and is transferred from bed to wheelchair by a lift. Kevin is in the ***HCBW*** *program from* ***Delaware Association of Retarded Citizens (ARC)****. ARC provides a service coordinator once a month and 30 hours of personal care. In addition to this he receives 35 hours of consumer directed care per week. He smiles and makes guttural sounds. He has a toy that he loves, which with the touch of one button on the front plays music. He is capable of using this toy. The family is poor and live in a rural area.*

Paul went home before Christmas 2007. A makeshift "hospital area" was set up in the large kitchen. The district staff wanted to provide Christmas presents to the family and were given the following ideas from Helen: towels and washcloths, men's flannel pajamas and thermal tops, baby lotion, shampoo, bed sheets, CDs of children's' songs, or books with a button to press to make sounds. They anticipated it would be Paul's last Christmas.

However, Paul had a change of heart once he returned home. He decided to accept care, start eating again, and agreed to have his infected wounds treated. He was eventually discharged from Hospice care and continued to receive 63 hours per week of Consumer Directed Care from two providers. One of whom was his sister who was also raising his two young sons. In addition he received nursing and Home Health Aide services from a ***Certified Home Health Agency (CHHA)****. Everyone who saw him could not believe he was the same person.*

Paul was able to remain home until Christmas of 2008 when he passed away at the hospital. Helen's lung cancer continues to advance. In the past she accepted intermittent CHHA assistance but now refuses. She spends approximately two weeks out of every month in the ***hospital****. Yet, she is the "glue" that continues to hold the remaining family together and at home. When Helen dies care coordination will continue for Kevin as he will require case management for the rest of his life.*

"Ellen"

In December of 2004 Ellen was 65 years old. She just finished treatment for endometrial cancer. Despite the weight she lost during treatment, she still weighed 250 pounds on her 5 foot 3 inch frame. The weight loss created a problem with excess skin, which impeded her ability to walk. She was also diabetic, had a history of depression and was transferred from the hospital to a nursing home for rehabilitation after fracturing her leg. Ellen is married and has one daughter.

Ellen was referred by the nursing home to the local PCSP program in December of 2004. She was discharged home just before Christmas, but within 24 hours she was back in the hospital and was discharged back to the nursing home.

Before a second discharge to home could be attempted she was readmitted to the hospital. From the hospital she was transferred to another nursing home where her daughter worked.

At this point, she refused all attempts at rehabilitation, even refusing to get out of bed. However, an initial care planning conference was held with the PCSP staff, Ellen, her family and the facility staff. The family was informed that Ellen is eligible for spousal impoverishment Medicaid so she can opt to stay in the nursing home or receive home care. She preferred to go home and her husband and daughter supported that decision.

Yet, Ellen made no progress toward going home as she refused all attempts at rehab. The PCSP staff decided to get the input of the local Independent Living Center (ILC) to see if they could motivate Ellen to work toward her goal of going home. The ILC was also helpful in obtaining equipment and recommending home modifications.

Another meeting was held with the ILC, Ellen and PCSP. The home care agency that was originally involved in her care refused to take her back due to her unwillingness to care for herself in the nursing home. Ellen's daughter noted she will assist her parents at home but works full time herself and cannot be the primary support. Also Ellen's husband is very frail with a heart condition.

Once again Ellen was admitted to the hospital with a blood infection. Upon returning to the nursing home an improvement in her mood was evident. She began to work on her goal of becoming independent enough to return home.

By the following summer things began to shape up for her return home. A licensed home care agency accepted her case and she hired consumer directed aides as well for twenty-three additional hours of care per week. Due to an open wound on the perineum she was going home with a Foley catheter and was new to insulin after her last hospitalization. These requirements for care entitled her to two hours of home health aide five times a week under Medicare which the home care agency would provide in addition to the twenty-three consumer directed hours under Medicaid. Ellen continued to attempt to do more for herself and staff at the nursing home documented these efforts.

To complicate matters she and her husband were legal residents of a neighboring county. They decided to stay in the county where the nursing home was and their daughter resided. This made it necessary to coordinate services with the neighboring county's DSS.

Ellen was discharged home in the late summer of that year after being in and out of the nursing home over a period of twenty-one months!

She made a successful transition to home and has been able to remain there. This case demonstrates the complexities of the people being served in the long term care system. For Ellen to be successful at home she needed the assistance of her daughter, the PCSP, ILC, a licensed home care agency, a certified home care agency, access to durable medical equipment, and coordination of Medicaid benefits across county lines.

For many people in nursing homes, it may take months before they are stable enough to return home.

References

Case Management Society of America. (2008). *What is a case manager?* Retrieved December 31, 2008, from http://www.cmsa.org/Home/CMSA/WhatisaCaseManager/tabid/224/Default.aspx

Community Alternative Systems Agencies, Operations Notebook, NYS DSS, 1983

National Public Radio, February 13, 2004

New York Times editorial July 14, 2008, "*Medicare's Bias*".

CASA Association of New York State Member Mailing List:

Counties: Albany, Allegany, Broome, Cattaraugus, Cayuga, Chautauqua, Chemung, Columbia, Cortland, Delaware, Dutchess, Erie, Essex, Franklin, Fulton, Greene, Herkimer, Monroe, Montgomery, Nassau, Niagara, New York City, Oneida, Onondaga, Ontario, Orange, Orleans, Otsego, Putnam, Rensselaer, Rockland, Saratoga, Schenectady, Seneca, St. Lawrence, Suffolk, Sullivan, Tioga, Tompkins, Ulster, Warren, Washington, Westchester, Yates

Questions in regard to the content of this paper should be directed to:

Michelle Berry: Broome County………..607.778.2420….mberry@co.broome.ny.us
Esther Evans: Dutchess County…………845.486.2588….eevans@co.dutchess.ny.us
Carmen Hlosta: Chautauqua County…….716.753.4447…HlostaC@co.chautauqua.ny.us
Liz Norton: Tompkins County…………..607.274.5369…liz.norton@dfa.state.ny.us