

**CONSUMERS
AND
PROFESSIONALS**

EVALUATE

**LONG TERM CARE IN BROOME
COUNTY**



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NEW YORK STATE OFFICE FOR THE AGING IN
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DEPARTMENT OF HEALTH**

CONSUMERS AND PROFESSIONALS EVALUATE LONG TERM CARE IN BROOME COUNTY



This project relates to the data collection goal of NY Connects to examine the overall impact of entry points to long term care from a variety of community viewpoints.

Submitted to
Broome County CASA

by

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SECONDARY REVIEWERS FOR FOCUS GROUP DATA

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**FOCUS GROUPS CONDUCTED WITH BROOME COUNTY
LONG TERM CARE AGENCIES**

Broome County Adult Protective Services (APS)
Broome County Coalition for Home Health Care
CASA
Extended In-Home Services Elderly Program (EISEP)
Family & Children's Society
Greater Binghamton Health Center
Lourdes at Home Coordinators
Lourdes Hospital Discharge Planners
Lourdes Primary Care Associates
Mental Health Association of the Southern Tier (MHA
ST)
Southern Tier Independence Center (STIC)
United Health Services Primary Care at Wilson Square
Willow Point Nursing Home Admissions Coordinators

**FOCUS GROUPS CONDUCTED WITH BROOME COUNTY
CONSUMERS OF LONG TERM CARE SERVICES**

Caregiver Chat Group, Caregiver Services, Broome County Services, Office for Aging
Mental Health Consumer Advisory Board
Southern Tier Independence Center Parent Group

**LONG TERM CARE SERVICES RECEIVED BY SURVEYED
BROOME COUNTY CONSUMERS**

Binghamton General Hospital Transitional Care Unit
Broome County Department of Social Services (DSS)
Broome County Office for Aging (OFA)
CASA
Consumer Directed Personal Assistance Program of the Southern Tier Independence
Center
Early Childhood Intervention Program of Broome County
Home Community Based Waiver (Southern Tier Independence Center)
Interim Healthcare
Link-To-Life (Home Emergency Alarm Response)
Staffing

Consumers and Professionals
Evaluate Long Term Care in Broome County

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INTRODUCTION

As the designated Point of Entry (POE) to long term care services, Broome County Community Alternative Systems Agency (CASA) has worked toward empowering individuals to make informed choices and to streamline access to long term care services. Today, long term care services embody an expanded array of in-home, community-based, and institutional programs designed to assist not only the elderly, but individuals of all ages.

In October of 2006, the New York State Office for Aging and the New York State Department of Health made funds available to counties to develop coordinated systems of Information and Referral for long term care. These points of entry (POE) to long term care serve consumers regardless of age, income and resources, disability, or payer. Counties were classified into two groups depending on their existing infrastructure. Group A counties had a structure/system in place that will allow NY Connects to start functioning on a limited basis early in the contract period. Group B counties were in the planning stages of design and development of a NY Connects program. Broome County CASA was funded as a Group A county since it had already established a multi-dimensional long-term care information, referral, assessment, and case management program.

As an already established county, Broome proposed to enhance their current system by looking at five primary programmatic thrusts.

- Transition the current CASA Advisory Board to the Long Term Care Coordinating Council
- Conduct an inventory of current on-line and hard copy long term care resources available in the community
- Educate both consumers and professionals via media and a variety of community forums
- Conduct consumer and professional focus groups
- Evaluate and assess the impact of NY Connects

This document is a report on the results of the last two program goals. To achieve these initiatives, work began in February, 2007, to identify consumer and professional entities for the focus groups and to design and pilot test the semi-structured interview question and answer format. Questions for the consumer telephone and face-to-face surveys were also designed. All formats were piloted and revised. The Long Term Care Coordinating Council provided feedback to these activities as did members of its Evaluation Subcommittee and members of the Coalition for Home Health Care. The first focus group with professionals was conducted April 3, 2007 and subsequent consumer and professional groups met over the next five months with the last group held August 6, 2007. Individual interviews with consumers were also conducted during this time period. Transcripts of the focus groups were reviewed by the evaluation consultant and themes extracted. A group of secondary reviewers then read the transcripts and extracted themes that were verified and validated for the final report. Themes were also extracted from consumer survey data by the project evaluator.

METHODOLOGY

Approach

In order to meet the project goals, the evaluation work plan was grounded in the principles and practice of participatory evaluation and utilized techniques associated with formative (ongoing) and summative (terminal) evaluation. Ethnographic methodologies included:

- Focus groups using a semi-structured interview format with consumers and professionals;
- Face-to-face and telephone interviews with long term care consumers that also used a semi-structured interview format;
- Informal discussions with health care providers in a variety of clinical and community agencies; and discussions with relevant partnership groups including the Long Term Care Coordinating Council and the Coalition for Home Health Care.

The evaluator conducted focus groups at agency and consumer locations designated by each group so as to insure maximum comfort with the environment. A statement indicating the purpose of the focus group and participants' individual rights was read prior to each group. Focus groups ranged from 40 to 90 minutes in length with an average of 60 minutes. All focus groups were conducted from April through August, 2007.

Over 20 long term care community agencies were represented by the more than 90 professionals who participated in the focus groups. The focus group responses were recorded using a micro-cassette digital tape recorder, and later transcribed verbatim and completely by Reporters Transcription Center, a division of Czrenda Court Reporting, Inc. In addition, the evaluator took field notes of each focus group. Transcript data were then reviewed by the evaluator using the Collaizi (1999) method for qualitative thematic extraction. A secondary group of four reviewers with expertise in long term care, blinded to the evaluator's analyses, also reviewed the transcripts and identified and extracted themes. The two sets of themes were then compared and those themes that were validated by both reviewers were used in the final analysis.

Over 40 consumers including mothers of young children participated in the evaluation. The total consumer group was comprised of approximately 35% young adults, 30% middle-aged adults, and 35% elders. They provided input through focus groups, telephone surveys and face-to-face survey interviews. The same statement of informed consent used in the professional focus groups was read to the consumer participants prior to the interview. Respondents contributed their ideas and opinions with the semi-structured interview questions used as a guide. Consumer interviews ranged from 30 to 90 minutes in length with the average interview about 40 minutes in length. Recurrent themes that emerged from the consumer data were tabulated and integrated with information from the professional groups.

Study Participants

Study participants included a cross-section of professionals and consumers associated with the provision and use of long term care services in Broome County. A collaborative methodology was utilized to identify participants. Input from CASA administration and staff, discussions with members of both the Long Term Care Coordinating Council and the Coalition for Home Health Care, provided additional selections. After conducting a number of focus groups, it became apparent that mental health needs associated with long term care could not be ignored, so additional focus groups were held with the Mental Health Association of the Southern Tier (MHAST), the Mental Health Consumer Advisory Board, and the Greater Binghamton Health Center staff. CASA staff nurses provided consumer names from their caseloads, and with the consumers' permissions, were then contacted by the evaluator. Other consumers were identified through informal conversations with health care providers in the community and were contacted and interviewed in the same manner. All the consumers and community agencies that were approached agreed and were willing to participate in the study.

Analysis

Analysis consisted of: (1) thematic extraction of field notes by the evaluator, (2) qualitative analysis using extracted themes according to Collaizi (1999), which consisted of thematic extraction by the evaluator followed by thematic extraction by a group of secondary reviewers blinded to the results of the first extraction. Themes identified in the final analysis were those identified both by the evaluator and the secondary reviewers. In addition, Michelle Berry, CASA Director, acted as consultant to the evaluator for interpretation and validation of the final results.

This qualitative analysis of data represents the viewpoints of individuals who consented to participate and is not a random sample of the total population of professionals and consumers in Broome County. Therefore, results can not be generalized to the larger population. However, the recurrent themes selected for this report were voiced by a majority of the individuals queried, and these themes were validated by both the evaluator and the group of secondary reviewers lending an additional level of objectivity to the report.

Through the semi-structured interview format, using questions specifically designed to provide data for this report, a designated focus for the analysis emerged. At times, participants strayed from the specific questions, most often, skipping to questions about facilitators and barriers to long term care in Broome County early in the discussions. When this happened, the evaluator listened to the discussion and recorded comments in the field notes, and later, brought the group back to the specific questions when it seemed comfortable to do so. Regardless of where the group took the discussion, all questions were eventually addressed. The use of a semi-structured interview format allowed for more meaningful input since participants could share their personal experiences with the long term care system. In all cases, the evaluator was impressed

by the willingness of participants to elaborate on both the strengths and limitations of the current system while also making excellent suggestions for the future.

RESULTS

Results will be summarized using concept headings that emerged from the focus group and survey data. Recurrent themes with examples to support the themes are provided.



ENTRY AND TRANSITION POINTS FOR LONG TERM CARE IN BROOME COUNTY

Professional Viewpoints

Professionals identify CASA as the point of entry for long term care in Broome County and emphasize that it serves both consumers and providers. Anyone, regardless of age or income, can call CASA for information and referral, assessment, determination of eligibility for a variety of programs, plan of care determination and coordination, and continuation and follow-up over time.

In addition, there are **many other entry points** to long term care in Broome County. People may be identified as needing information on long term care at their physician's office or the hospital. They may ask neighbors for advice or call local home care or human service agencies. It is agreed that there are numerous entry points into the system. NY Connects is a program to streamline information across settings and make consumers in particular aware of where they can call if they need information.

Entry points cited by focus group participants were **multiple and varied**. **More than fifty entry points** were identified **depending on the mission and focus of the long term care organization and the services each provided**. Agencies that had **broad and diverse purposes and goals** tended to have **more entry points**, while agencies that had a more **narrow focus had fewer**. However, whether the agency was large or small, the number and kinds of entry points remained **varied and unique**. **Many service providers viewed CASA as Broome County's central POE** as is evidenced by the number and kind of referrals they receive. For example, CASA nurses receive referrals from acute care institutions, nursing homes, clients themselves, neighbors, home health care agencies, primary care physicians, caretakers, Adult Protective Services (APS), mental health providers, the Southern Tier Independence Center (STIC), Office for Aging, the Family & Children's Society, and a host of other private and not-for-profit providers. Providers refer clients across the lifespan to CASA as is evidenced by the fact that children and youth account for approximately 15% of their current referrals and this number continues to grow.

Events that could lead to entry into the system might include **an acute crisis situation** such as an automobile accident leading to traumatic brain injury or, **exacerbation of a chronic illness** when a family is no longer able to care for their loved one with dementia at home. **A change in status for the family or caregiver network** can create a "ripple effect" expanding the number of persons affected by the change. If the client and family have multiple long term care needs, the **number and kind of services they require can expand**. Some consumers such as those with mental illness may not be receiving the services they need and deserve because of **the voluntary nature of these services**.

Since the concept of long term care now embraces both children and adults, **the number and kind of entry points has increased dramatically in Broome County.** This has led to **challenges regarding capacity for many organizations,** such as mental health services for adults and children and adult protective services. In Broome County, providers have developed **good relationships with each other** both formally through **partnerships and coalitions,** as well as personally from many **years of working together.** While professionals have a good understanding of the goals and missions of community agencies in general, the constantly **changing long term care marketplace and its relationship to NY Connects** has resulted in the **need to be immediately updated once these changes occur.**

Points of transition along the long term care continuum often represent a change in status that can necessitate **movement forward or backward on the continuum.** For example, a nursing home resident can move forward by returning home to the community, or a medical emergency such as a heart attack can move a client from stable status at home to an unstable situation in acute care. Here, **the knowledge base of each long term care provider** is critical to successful transitions. Whether a crisis or a more chronic situation, **transitions involve many professionals and caregivers** whose ability to communicate with each other is important. **Transitions can be problematic** to professionals when the client resists making the transition, or when the transition can not be made due to lack of capacity of the agency responsible for accepting the client. **Entry and transition points are critical events in long term care and can be pivotal events that govern the success or failure of these experiences.**

Summary
Entry and Transition Points Cited by Professionals

- **Number and kind of entry and transition points has increased**
- **Entry and transition are key pivotal events affecting outcomes**
- **Need up-to-date knowledge of community resources**
- **Communication among professionals key to success**



ENTRY AND TRANSITION POINTS FOR LONG TERM CARE IN BROOME COUNTY

Consumers' Viewpoints

Consumers' responses regarding **points of entry and transition** are **varied and multiple**. They note that entry to and transition along the long term care system can depend on **their health problems** as well as the **mission and focus** of the long term care organization and **the services each provided**. Entry points to long term care services are sometimes **well defined**, for example, at Early Intervention Team services for infants with disabilities and CASA for adults with physical disabilities. At other times, consumers found it **difficult to find an entry point** that provided comprehensive services and this made it necessary to search for additional entry points so that comprehensive care could be given. For example, when the consumer's health declined and palliative care was indicated.

Provision of long term care is governed by **long-established agency protocols** based on state regulations. Agencies work hard to assess consumers in a timely fashion, however, at times, consumers have to wait **longer periods of time**, and this can be problematic. If the long term care agency lacks capacity to provide services, consumers become frustrated **and resume their search** for other assistance. **Transition points** in care for consumers are often **problematic due to access issues, age restrictions for programs, and complex federal or state regulations**. Consumers **rely on information from a number of sources**. Sometimes they prepare for transitions on their own, in **anticipation** for what might come in the future. At other times, they **rely upon professionals** to assist with transitions. Consumers often **communicate with peers** through support groups or **Internet chat rooms** to widen their scope of information especially if they are not satisfied with the answers they receive from service providers.

Transitions, for consumers, are often accompanied by **strong emotions, uncertainty, frustration, and anxiety**. Even if the transition is positive, for example, a disabled child entering school, the **changes in the long term care routine that transitions necessitate, often have the potential for family coping to be stretched to its limit**. While transitions may have been routine for the professional, they represent major changes for the family who may need to **make adaptations in their routines and adjust to new caregivers**.

Summary
Entry and Transition Points Cited by Consumers

- **Multiple and Varied**
- **Points can be both well defined, or difficult to locate**
- **Access problems, age restrictions, regulations, and other stressors may impact coping**
- **Multiple information sources are used**



TIMING AND DELIVERY OF INFORMATION

Professionals' Viewpoints

The timing and delivery of information at entry and transition points along the long term care continuum is dependent on the **professional's assessment of consumer status** at that point in time as well as the **amount and type of information** that is appropriate given the circumstances. Professionals also begin to **anticipate** what might occur later on at specific points and use their **judgment based on experience** with similar cases to determine the **amount and type of information that is given**.

Assessment of consumer receptivity for certain information can also be a determinant. For example, if a consumer is showing resistance to assistance, CASA nurses might just let the person know that there is a system available to help them and give information on accessing the system when they are ready. Since CASA nurses **meet consumers face-to-face** and are able to establish working relationships with them, information can be given over time, when consumers are receptive.

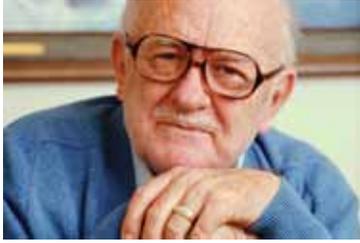
Professionals are **discrete** in their questioning about sensitive issues such as personal income, and also **utilize existing data bases** that are available to them. In those cases where **community agencies can share information from electronic data bases**, the necessary processes to insure prompt care are facilitated. Sometimes health care agencies **differ in their interpretation of HIPAA regulations** and **when information can not be shared**, planning for care can become more difficult.

System delivery "glitches" can occur and might inhibit how information is delivered and shared. Issues may arise between the Office of Mental Health and the Office of Mental Retardation and Developmental Disabilities over case jurisdiction. In another example, when the consumer reached a certain age, changes had to be made in programmatic support in order to insure continuity of services. Sometimes certain regulations might inhibit sharing of information, but the overall goal continues to be service delivery that is seamless and uninterrupted.

Summary

Timing and Delivery of Information Cited by Professionals

- **Dependent on assessment of consumer status and receptivity**
- **Timing of information delivery is critical: how much and when**
- **Face-to-face communication with both consumers and professionals enhances relationships**
- **Development of shared data bases is needed**
- **HIPAA interpretations can affect timing of information**



TIMING AND DELIVERY OF INFORMATION

Consumers' Viewpoints

The process through which consumers are engaged in order to receive reliable information might well be described as a **“difficult journey”**. Despite numerous attempts by long term care providers to make information available, consumers report **significant problems in accessing and using information**. Consumers, especially parents for their children and children for their aged parents, are key players in the information acquisition search. Sometimes entry into the system can be mandated by the specific age or health problem of the participant. Lourdes hospital High Risk Birth Clinic serves infants and their families while the Office for Aging serves seniors.

At other times, consumers of all ages engaged in **“persistent exploration.”** This includes computer searches and multiple calls to providers in order to figure out how best to enter the system. Consumers of **mental health services reported that initial entry into the system was fraught with problems**. However, **once “in” the system, services become more accessible**. Serious problems emerge when entry into the system is made difficult for consumers. This may occur when **age restrictions** for schooling for children with disabilities occurs. Legislative mandates such as **income level may limit or prohibit services**. Some consumers report that they are still in a quandary over where to turn for information since, despite efforts to obtain necessary information, they remain confused over the appropriate entry point.

Consumers of all ages also use a **variety of approaches** to obtain information including **computer searches, calls to providers, asking other peer consumers, speaking with family members, the local newspaper, newsletters, caregiver retreats, using support groups, directly approaching professionals, and reading research studies**.

Information is provided in a **variety of forms** including **verbal exchanges, pamphlets, on-line chat rooms, web sites specific to medical conditions, educational booklets, and through attendance at support groups**. In one case, the health care provider had not identified the child's problem and it was only through the parent attending a support group that her child received the necessary assessment that identified the problem. The Caregiver Chat Group also provided information about a variety of long term care services available to elders.

When consumers are in an emotional crisis, they are **not ready to receive information**. They recount poignant personal stories of being left alone when they needed the support of professionals. Some consumers feel that professionals each wanted a “piece” of their children and **no one was caring for them in a holistic manner**. The need to know the **identity and role of each provider** and how each one of them **fit into the treatment plan** was important. They reported that it is still like a **“maze”** to find services and that talking with professionals requires “decoding”.

Consumers find information difficult when it **doesn't "connect to anything else."** They wanted to know how one program interfaces with another and how it fits into **"the big picture"**. One consumer had been to several lawyers and had still not deciphered her parent's financial problems. Consumers also want to be recognized **as important members of the "team"**; they want to **have input into the treatment plan and to have the ability to make mid-course corrections in the plan** as time goes on.

The **attitudes and communication skills of health care providers** was especially important in the **person-to-person delivery of information**. Consumers report that some providers totally disregarded their feelings, treating them or their child **"just as a disease"**. Other providers were described as judgmental, ignorant, unfeeling, or rude. Some totally disregarded the physical state of the client when giving information, for example, giving information when the client was in a highly anxious state. **The timing and delivery of information is also key**. Consumers are not ready to receive information while in crisis, but information can be helpful after encouraging the consumer to express feelings and concerns. The **use of abbreviations, or terms that are not readily understandable, are points of difficulty**. **Lack of explanations and the failure of information to connect with other issues** in care were often mentioned as problematic.

Parents see themselves as **advocates** for their children just as caregivers of elders do. Consumers of all ages report continual searching for information as time passes and needs change. They report wanting to **"be prepared"** for transition meetings for their loved ones. They emphasize the need to **"read" continuously** to acquire information **about new programs and initiatives**. In one case, after an initial evaluation was done and the need for a specialized provider was identified, it became evident that this type of **provider was not available in the community**. This led to frustration and disappointment. One consumer pointed out that information should **be delivered on an individual basis**, in that each consumer is ready to receive it at different points in time. The need to **standardize forms** between agencies to avoid repetition and to make information and plans **available in written form** was emphasized.

Although some consumers feel that the information they receive has been given in a **timely fashion, others disagree**. Some feel that physicians are **reluctant to make an early diagnosis of a disability**, especially for a child, preferring to refer the child out of town to another physician. Parents may view a latent diagnosis as detrimental in that therapies are not received early enough. One consumer said that the physician just **"came and went"** and was disappointed that information from this provider was lacking. Some consumers engage in **"anticipatory planning"**, for example, consumers with family members who have chronic conditions or terminal illnesses. In these cases, information is **sought early in the illness trajectory** so that preparations could be made well in advance of any crisis that might occur. Consumers **use support groups** to gain knowledge from others who have gone through similar experiences in order to be better prepared for the future.

Consumers demonstrate **more confidence** in accessing information and making contacts as time passes and they become more familiar with the system. They learn what specific agencies to call, if they need an **advocate or an exception to a regulation**. They investigate services on their own or use support groups to get additional information. Consumers acquire a certain comfort level in navigating the system and became **“system savvy”** over time.

Consumers use **support groups, workshops, conferences, personal contacts with professionals, Internet information, acquaintances, family members, friends, therapists, and specialists to acquire information specific to transitions.**

When asked about what information was easiest and most difficult to find, one consumer reflected the opinions of many others when she said, **“Nothing was easy to find”** and **“You really are lost in the beginning”**. Many consumers go directly to CASA for help especially when **nursing services at home are required**. Service coordinators who provided information about the **Home and Community-Based Waiver programs** assist consumers who appreciate this information. Information shared by peers and through **support groups** makes information-gathering less difficult.

Consumers say that the **results of current research** regarding their health problems can be a challenge. This is especially true for parents of disabled children as they transition between programs. As consumers progress along the long term care continuum, **information about managing transitions** becomes more difficult to find. **Information on specific specialists**, knowing who was “good” and “knowing where to go”, as well as having information on a **specific “timetable” for transitions** can be problematic. One consumer mentioned that if she had not been a “reader”, she would not have known about a certain program because the agency working with her at the time wasn’t aware of it.

Consumers emphasize that even with good information, “in the beginning” of their long term care journey, they are **overwhelmed** and **are not as quick to use the information**. Later, once **“in the right place” to receive information**, consumers are able to initiate responses necessary to act on the information they had received. In some cases information was presented in a usable form, in others, for example, **physician’s orders, it was difficult to understand**. Consumers feel that knowing what to do is easier if it is presented in a **“timetable” form** indicating what comes next as time goes by. One consumer, who was not able to use the Internet, continued **to rely on information from professionals** to direct care. **“Learning the ropes” of accessing information** and navigating the long term care system is an important **developmental task** for consumers. Consumers are ready to receive information **“once we get our feet on the ground.”** In one case, this was three to six months after the initial crisis, for another, it was immediately. Readiness to receive information seems to **occur on an individual basis** and is **dependent upon the degree to which the individual and family are under stress**. One consumer emphasized that early decisions had to be made by family members, and later, **once the consumer’s**

condition had stabilized, decisions were made by the individual. When points on the long term care continuum change rapidly, for example, as infants with disabilities move through developmental tasks, **parents need information in order to anticipate changes as well as when the actual changes occur.** When **consumers attend support groups,** and **peers “tell their stories,”** consumers report readiness to listen, for example, when peers say, “Here’s what I do,” consumers find this very helpful.

Summary
Timing and Delivery of Information Cited by Consumers

- **Individualize according to how consumer or caregiver is coping**
- **Connect information to other sources and release in a timely manner**
- **Standardize data gathering forms**
- **Use variety of information formats**
- **Treat family members like they are team members, value their input**
- **Support groups and peers are valuable sources of information**
- **Confidence of consumers to discern information increases over time**



FACILITATORS AND BARRIERS TO CARE

Professionals' Viewpoints

Facilitators for initial entry points transitions, are numerous. **Professional relationships develop between community agencies** over time and these relationships assist in managing care delivery. For example, in 2007a homecare agency closure necessitated coordination to insure continuous care for consumers. CASA staff worked diligently with other agencies to transfer clients so that their **care was seamless, professional, and uninterrupted. Membership in Partnerships and Coalitions** also provide monthly updates so that each agency can feel more connected. In addition, **when agencies can share elements of their databases and agree on HIPAA interpretations, care is facilitated.** These types of information sharing mechanisms enhance cooperation between agencies.

Good interpersonal skills enhance the provision of care. When consumers and professionals work in partnership, entry into the system and transitions become positive. The **person-to-person contact** (professional with consumer) is viewed as essential to provision of care. For CASA nurses, the **ability to visit the home and work with the consumer and family to assess and plan for future care** is a great facilitator. Family dynamics can also create some issues, for example, when adult children distrust each other and can not agree on a plan of care for an elderly parent. **When the consumer, family, and professional agree on the plan of care and are committed to it, services can be delivered in a timely manner.**

Many **community agencies are viewed as facilitators** by consumers who have had positive relationships with them. **Eligibility** in certain assistance programs such as Medicaid can also be a facilitator as is the **ability to qualify** for other federally and state-supported programs.

Entry points and transitions are accompanied by **stressors** for both caregivers and consumers and can be seen as **barriers. Paperwork, approvals, timetables, financial criteria, present and anticipated needs, and a host of other factors** could be barriers to care. Certainly the **mission and philosophy** of each agency can be both a facilitator and barrier. If philosophies of consumer care are similar, fewer barriers to care exist. But if an agency's **philosophy of care differs from another, barriers might result.** For example, providers must operate under specific regulatory guidelines that might necessitate adjustment of advocates' expectations for care.

Lack of knowledge about specific services between and among agencies and consumers was viewed as a barrier. One professional recounted a call from another agency regarding a specific service for a consumer. It was the view of this professional that the service could have been provided by the agency making the call. In another case, a consumer asked for long term care services when the agency could only provide short term or interim care.

Misperceptions about roles can also be problematic. For example, consumers might not fully grasp **the goal of eventual self-care** after being in a dependent role. Sometimes consumers who are discharged from the nursing home setting after a long period of residency may have difficulty in directing their own care once they are back in the community.

Differing perceptions of need between long term care agencies may be problematic. During the performance of a consumer assessment, professionals can differ somewhat in how they view the needs of the client. In any case, examiner bias can occur in any setting, resulting in inconsistencies in interpretation of need.

As younger and younger persons with disabilities enter the long term care system, roles of caregivers can become blurred. Long term care systems were designed with the frail elderly in mind. People under the age of 60 often have different household compositions than elders whose families have left the home. Bringing an outside person or entity as a helper or case manager into any household is challenging, yet when extended family members are involved, **caregiving responsibilities between the agency and the traditional caregivers in the household can be confusing until specific roles are negotiated.**

Agency value systems and assessments can differ at times resulting in different perspectives regarding consumer care. Medical professionals, may use a different set of guiding principles than do advocacy professionals. When this happens, efforts to find a “common ground” through reconciliation between value systems can result in greater understanding of perspectives and approaches.

Lack of certain professional practitioners in the community such as pediatric neurologists, developmental pediatricians, geriatricians, Medicaid dentists, and psychiatrists are seen as a barrier. **Lack of capacity**, especially within the mental health system, is problematic. For example, it might take several months to receive care by a psychiatrist or mental health counselor. **Lack of trained home health aides to help with consumers of all ages** has remained a problem as has the **lower salaries** for these workers. **Medication oversight for seniors** is also mentioned as a need by providers in primary care settings.

Summary
Facilitators and Barriers Cited by Professionals

Facilitators

- **Collaborative relationships**
- **Partnerships and Coalitions**
- **Agreement on Plan of Care**
- **Positive Communication**

Barriers

- **Regulatory constraints**
- **Transition stressors**
- **Differing provider goals**
- **Misperception of roles**
- **Differing perceptions of needs**
- **Lack of specialized practitioners**



FACILITATORS AND BARRIERS TO CARE

Consumers' Viewpoints

Consumers acknowledge that **compassionate and supportive approaches** by professionals **greatly facilitate care**. When professionals are **knowledgeable about services** and outline the steps to service provision, consumers are more confident. Providers who recognize the stressors **associated with prolonged caregiving roles** are viewed more positively. In instances where the long term care system can be **flexible and allow for self-determination by the consumer** and when professionals **incorporate the family into the plan of care and treat them as a "team member,"** family members come away with increased confidence in their role as caregivers.

Barriers occur when consumers **are unable to locate the services of specific professionals locally**. These include but are not limited to: psychiatrists, child psychiatrists, child psychologists, developmental pediatricians, geriatricians, pediatric neurologists, pediatric physical therapists, pediatric occupational therapists, rehabilitation specialists, and educators for children with special needs. Consumers also mention the need for local primary and secondary school systems to **provide educators skilled to handle the special needs of children with behavioral problems, autism, mental retardation, and other neurological disorders**.

Many consumers talked about not being able to find information on **specific health problems and medical centers where specialized procedures could be performed**. Although Internet information was available, navigating it was sometimes difficult. Consumers wanted information to be **"linked"** to other essential pieces of information so that it was easily understood and navigated. They wanted to know **how each program was "linked" to another and then, linked to them**. **Web-based information in a central repository** that provided information on how to access professionals in out-of-town locations when one was not available locally, would be helpful.

Confidentiality issues could sometimes **prevent access to good information**. **Restrictions imposed and misinterpreted**, such as the HIPAA rules and regulations, while providing privacy, can become a burden for consumers as they add another "layer" of paperwork. Multiple forms for information release and other paperwork can delay necessary referrals and consultations and can be stressful for consumers. In certain situations, as with adults suffering from mental illness, **HIPAA regulations** are viewed as positive since they protect privacy.

Barriers to the provision of assistance include consumer reports of having **to wait long hours** to be seen by professionals, and at times, being told that the professional would be late or would not be coming at all. Some parents were given information around

classroom aide requirements for their child, but this was followed with the statement that **no aides were available**. Parents completed paperwork to apply for programs and then were told that the school did not have any personnel available to implement the program. Sometimes parents were asked to choose programs for their child **but lacked the information** about the programs and could not make an appropriate choice.

Summary Facilitators and Barriers Cited by Consumers	
Facilitators	Barriers
<ul style="list-style-type: none">• Knowledgeable, supportive providers• Flexibility to accommodate needs• Team approach to care• Comprehensive information sources	<ul style="list-style-type: none">• Lack of specialized practitioners• Regulatory restrictions• Lack of provider capacity• Communication problems• Limited access to information



DUPLICATION OF INFORMATION AND SERVICES Professionals' Viewpoints

In general, professionals feel that there is **very little duplication**, if any, of information and/or services. They are more likely to mention gaps in services, rather than duplication. Consumers may be receiving care from several agencies but efforts are made to collaborate rather than duplicate services. Sometimes services from several agencies are necessary to cover consumer needs but **each agency makes their own contribution rather than duplicating**.

Professionals feel that use of **computer data bases** can assist in service coordination. CASA and Office for the Aging are developing a shared data base that will allow each agency to view some data elements of consumers served by both agencies.

One area where duplication might occur is in the assessment protocols used by each agency. Professionals emphasize that each assessment protocol is unique to each agency and necessary so as to gather information that would allow the agency to achieve its individual mission. However, **duplication of some assessment questions does occur**. When possible, agency personnel **time their home visit to coincide with other involved agencies** so that the consumer does not have to repeat information.

Summary Duplication of Information and Services Cited by Professionals

- **Very little duplication**
- **Coordination between agencies prevents duplication**
- **Recognize need for shared computer information systems**



DUPLICATION OF INFORMATION AND SERVICES

Consumers' Viewpoints

Some consumers feel that it is **helpful to have information repeated** especially if the original information has been given during a stressful time. Forms that consumers have to **repeatedly complete** with the same information are viewed as problematic. Consumers often handle information in unique ways in order to facilitate care. For example, one consumer provided a detailed history of a family member's problem printed in bold type, and sent it to a consulting physician one week prior to their visit. Consumers voice their concerns with having to fill out lengthy paperwork. One said, "**They don't realize how much energy and work goes into having to answer those questions.**"

Consumers **do not feel that long term care services are being duplicated** in Broome County. As with professionals, consumers are more likely to identify service gaps when the topic of duplication is discussed.

Summary

Duplication of Information and Services Cited by Consumers

- Duplication of services is not viewed as a problem
- Having to repeat the same information to numerous providers is a problem
- It is helpful to hear about services multiple times



COMMUNITY SERVICE GAPS

Professionals' Viewpoints

Gaps in providing long term care are **many and varied** depending on the **agency mission and role** in the community. Lack of reliable **transportation** individualized to fit the needs of both children and adults meant a gap in services for many.

The most frequently identified service gap by focus group professionals is for people with mental health issues. Identified needs include:

- **additional capacity to admit consumers in crisis to in-patient units**
- **expanded services for youth and uninsured/underinsured individuals**
- **expansion of mental health services so that consumers will not have to leave the community for care,**
- **advocate for increase of reimbursement rates to providers**
- **recruit additional mental health practitioners for adults and children**

Strategies to **improve communication** between multiple agencies serving a single consumer are often identified as important to remedying gaps in service provision. One example might be when a consumer doesn't know exactly which long term care services he or she has received. Another example involved the need for long term care providers who visit the consumer in the acute care setting to document their plan of care in the consumer's chart. Increased **flexibility** in federal and state programs especially for consumers who represent exceptions to the rules could prevent gaps, as could **need-based rather than diagnosis-based service** delivery. Service gaps exist in the provision of **Day Care and Respite** services for **children and the elderly**. **Increased capacity for agencies such as Adult Protective and the Mental Health Association of the Southern Tier** who serve highly vulnerable populations are also mentioned. **Gaps in communication** related to a plethora of data bases across agencies could be rectified by introducing some standardization between agencies or facilitating the use of a single data base for all agencies. **Expanded capacity** for community agencies regarding the **use of computers to facilitate electronic referrals** was another suggestion to improve communication.

Summary
Community Service Gaps Cited by Professionals

- **Transportation**
- **Mental Health services**
- **Communication between agencies**
- **Develop strategies to address regulatory constraints in care provision**
- **Funding of programs to reflect current community needs**
- **Investment in information technology for individual providers and the broader community**



COMMUNITY SERVICE GAPS

Consumers' Viewpoints

Consumers using services for their children who are in the long term care system are unanimous in their **frustration with the elementary school system**. They feel that services provided through the Early Intervention Program are good, but once the child is of school age, the transition is not always smooth. **Improving the communication system between the school and parents**, and improved **learning and behavioral planning** based on meetings with parents and teachers would be helpful. A **seamless system** from pre-school through high school for children with disabilities was suggested. Assessments prior to school attendance and regularly throughout the year can also be helpful. The need to expand pre-kindergarten programs for children with special needs was also noted.

Recruitment of a pediatric neurologist, developmental pediatricians and psychologists and advance practice nurses, plus pediatric low vision specialists, and behavioral specialists could help improve care. Home health care aides trained to work with children, pediatric day care, and greater respite resources for caregivers of disabled children can help in the future.

Adult consumers dealing with disabilities stress the need for **better transportation** as well as **modifications to the health care environment**. For example, local hospitals may not have examining tables for people in wheelchairs. **Lack of home health care aides**, especially on nights and weekends, remains a problem. Helping to **change attitudes, education** about newer programs, and improved knowledge about **recent developments in treatment options**, can also help to close knowledge gaps.

Consumers of mental health services see gaps in the system for the **newly diagnosed or persons in crisis**. Once admitted to the system, it becomes easier to obtain services when services are available. **Lack of a wide range of mental health practitioners** needs to be addressed as does the **development of more programs to address the transition from dependence to independence**. **Reducing the stigma of mental illness, employing peer counselors** in acute care and community agencies to mentor and advise, as well as **strengthening the peer support group** system are also areas for future service development.

Summary
Community Service Gaps Cited by Consumers

- **Transportation**
- **Transitions between community programs and schools**
- **Availability of aides for children**
- **Knowledge of treatment options outside the community**
- **Need for specialized practitioners**
- **Programs to transition all ages to independent living**

FUTURE RECOMMENDATIONS

The “Future Recommendations” Section will be organized into **three thematic areas** that emerged from the data. These are:

- **Allocation of Community Resources**
- **Community Education for Long Term Care**
- **Enhanced Communication for Long Term Care**



The first section will focus on viewpoints expressed by professionals and the second section will be devoted to viewpoints of consumers in regard to these areas.

Section One

FUTURE RECOMMENDATIONS

Professionals’ Speak

Allocation of Community Resources



Long term care providers identified additional resources that could enhance their service delivery to consumers. Several providers cite the need for **additional acute care discharge planners**. They are also consistent in their desire that better **salaries and benefits be provided for home health care aides**. Increased resource allocation to provide **transportation** for consumers especially to physician appointments would also be beneficial. Increasing agency capacity through resource allocation devoted to **updating computer and data base capability** is also cited as an important need.

Increasing mental health services for adults and children is cited as a need by both mental health providers and long term care providers. Professionals identify the need for **more acute care mental health beds** as a pressing problem. **Expansion of crisis care services** to include more precise assessments by professionally educated personnel and **better facilitated entry into mental health services** are often mentioned as critical needs. Expansion of **mental health rehabilitation programs** and more **community-based services** including the **expansion of numbers of available mental health professionals** is also frequently mentioned.

Professionals suggest that resources be reallocated in regard to various aspects of **Medicare and Medicaid**. Providers feel that, at times, reimbursement rates are not sufficient to cover their costs, and this may limit the number of consumers they can serve in their practices.

COMMUNITY EDUCATION FOR LONG TERM CARE

Professionals often discuss the need for **continual education** regarding many aspects of long term care. **Expanded definitions of long term care** to include children and young adults and **concepts associated with point of entry** are identified as needing further exploration and elaboration. Professionals are unanimous in their need to know the **latest legislative regulations** regarding such initiatives as the waiver programs, as well as the latest Medicare and Medicaid rules. Professionals recognize that their knowledge regarding the **multiple steps** from eligibility determination to service provision is critical to insure that a consumer receives the program.

ENHANCED COMMUNICATION FOR LONG TERM CARE

Professionals recognize that comprehensive long term care can not be delivered without continuous efforts to **enhance communication** within the current network of service delivery in the county. They identify that interagency communication is often enhanced when agencies can **share various aspects of their consumer data bases**. They also recommend that agencies reach **agreement on their interpretation of HIPAA** regulations so that long term care providers are consistent in agreement as to which aspects of the data base can be shared without jeopardizing consumer privacy.

While interagency communication overall is cited as a strength of the long term care system, professionals recognize the need to **develop methods to communicate** even more effectively with each other. For example, discussions are continuing in regard to staff from outside long term care providers being able to write in the consumer's acute care chart. Providing opportunities for professionals to **communicate both formally and informally** around consumer care issues is cited as being critical to excellence in long term care. The development of **strategies for consumers** to use to enhance communication between professionals who provide their care at home can also be beneficial.

Professionals also suggest that a **community-wide information system** be established across all long term care settings. Accessing Internet technology so that all professionals and consumers can have **quick and easy access to the most recent information** about services as well as links to other pertinent data bases is often mentioned as a communication goal.



Section Two

FUTURE RECOMMENDATIONS

Consumers Speak

Allocation of Community Resources

Disparities between funding allocations to long term care agencies is sometimes difficult for consumers to understand. For example, one consumer illustrated this point by giving the example that it costs roughly one thousand dollars a day for acute stay mental health services. If three people were hospitalized in acute care for one year, that amount would exceed the entire operating budget for the Mental Health Association of the Southern Tier (MHAST) for that period of time. This consumer pointed out that since community-based care is aimed at **prevention of hospitalization** and can reduce acute care admissions, it makes sense to **direct resources to community services**, yet this was often not the case. Resources directed toward more community centered mental health services are indicated. In addition, resources that make it possible for long term care systems to integrate and collaborate toward the goal of **more holistic, consumer-centered** care, could improve the quality of care while also saving costs.

Consumers also note that in the area of mental health, when services are delayed due to long waiting lists, there is an increased potential for the client's problem to worsen. Consumers suggest that resources be directed toward the following:

- **Improvement of crisis services**
- **Improved triage at entry into the system**
- **Recruitment of additional mental health providers**
- **Additional peer counselors**
- **Additional community rehabilitation services**

Parents of children with disabilities feel that the following resources are needed for primary and secondary education:

- **Teacher education**
- **Increased appointments of special education faculty**
- **Additional teacher aides and**
- **Providing opportunities for increased teacher/family dialogue**

Consumers also suggest that additional resources be directed toward improving the **transportation** system so as to increase access to long term care services especially for consumers in the **rural areas**.

COMMUNITY EDUCATION FOR LONG TERM CARE

Consumers are unanimous in their perception that the community needs continuous education to **mitigate against the stigma associated with many long term health problems**. Greater emphasis on **the use of media** to raise awareness and understanding of such topics as caregiver stress, autism, and mental health problems would be helpful. Consumers rely on information provided by professionals and emphasize the need for professionals to engage in educational programs focused on the latest treatments and research for long term health problems. Continuing education programs that update professionals on the latest funding rules and regulations as well as the latest trends in long term care are mentioned as eventually resulting in better care for consumers.

Consumers rely on professionals for guidance in relation to financing long term care. Continuing education programs that focus on the impact of long term care on family finances with exploration of avenues to pay for this care are seen as helpful.

ENHANCED COMMUNICATION FOR LONG TERM CARE

Consumers emphasize the need for long term care professionals to focus on:

- using therapeutic **communication skills** especially during initial entry to the long term care system and at transition points along the service trajectory.
- synchronizing the **timing and delivery of information** to coincide with the consumer's coping status
- developing **multiple communication mechanisms** that enable professionals and consumers to establish productive, working relationships
- making consumers **part of the "health care team"**
- integrating consumers' **input** into the plan of care
- insuring that consumers are **"partners"** with professionals through continuous communication and collaboration.

Consumers also express the desire **for greater system communication** to insure more holistic care. One example of this was when mental health managers interfaced with practitioners in primary care and community health to coordinate medications for a client. Consumers feel that artificial barriers were created when services were "housed" in large, bureaucratic systems and that professionals needed to **work through some of these boundaries** so that consumers can receive more person and family centered care.

Consumers are definitely using the Internet, email, chat rooms, and other technological mechanisms to access and use information on all aspects of long term care. They acknowledge the need for a centralized, comprehensive data base of community resources that would be linked to other pertinent Internet sites. This **community-wide**

information system should also be linked to sites that provide information on how to access specialized physician services in out-of-town medical centers when these physicians are not available in our community.



SUMMARY

This evaluation of the long term care system in Broome County underscores the fact that this system is dynamic rather than static; responsive as opposed to stagnant; and is constantly evolving to meet the needs of consumers and their families. Evaluations such as these are integral to examining the reality of what is “now” as well as looking ahead to “vision for the future”. NY Connects and its Broome County partner agencies (CASA, Office for the Aging, and the Department of Social Services) together with other long term care agencies in the county, have created a relationship synergy that will strengthen communication among them so that future efforts to develop a community-wide information system for both professionals and consumers can be achieved.

Working together with the New York State Office for the Aging and the New York State Department of Health, Broome County long term care providers will continue to explore and refine their roles in relation to the NY Connects initiative and will emerge from these discussions with a cohesive, more effective communication system in place. Data provided in this report will form the cornerstone for future efforts to continue the search for additional resources, utilize technological advances to enhance interagency and consumer communication, and expand community education initiatives.