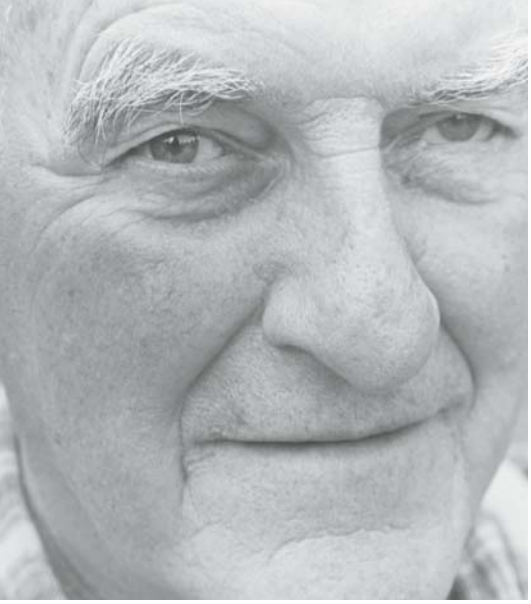
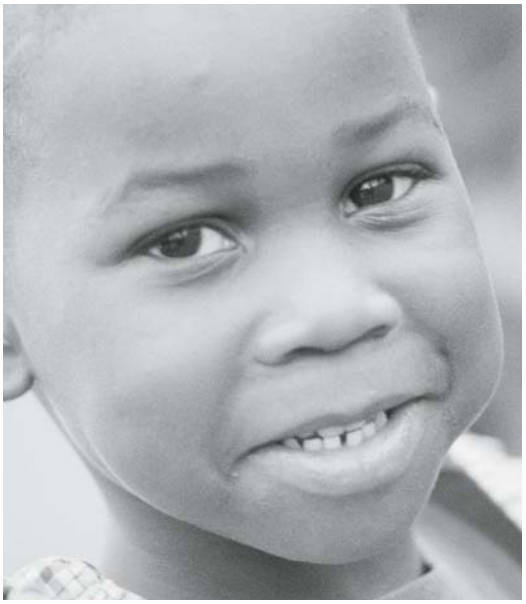


Feasibility Study: Peer Support for the Elderly Transitioning from Nursing Facility Care to Community Care

prepared for

Georgia Department of Human Resources
Division of Mental Health, Developmental Disabilities, and Addictive Diseases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Comments by individuals who have made a transition from an institutional environment to a community environment are contained throughout this report. Their comments are printed without attribution to protect confidentiality.

"When I think of the word peer support, it means someone who has been through or is going through what I am about to go through and who knows the ins and the outs, the do's and the don'ts, and they can help me and alleviate any misgivings I might have about making the move."

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Introduction

In July 1999, the United States Supreme Court issued the Olmstead v. L.C. decision, affirming that under the Americans with Disabilities Act (ADA), unnecessary segregation of individuals in institutions may constitute discrimination based on disability. Subsequent to this ruling, states must now administer programs, services, and activities "in the most integrated setting appropriate to the needs of qualified individuals with disabilities (Georgia Department of Human Resources, 2002)." The Centers for Medicare and Medicaid Services (CMS) responded to the Olmstead decision, in part, by sponsoring the Real Choices System Change Grant program, which provides funding to states to support the development of programs for people with disabilities or long-term illness (Georgia Department of Human Resources, 2002, Centers for Medicare and Medicaid Services).

According to CMS:

"On May 22, 2001, CMS invited proposals from States and others in partnership with their disability and aging communities, to design and implement effective and enduring improvements in community long term support systems. Grant applications were due in July 2001. These grants are intended to foster the systemic changes to enable children and adults of any age who have a disability or long term illness to:

- Live in the most integrated community setting appropriate to their individual support requirements and their preferences;
- Exercise meaningful choices about their living environments, the providers of services they receive, the types of supports they use and the manner by which services are provided; and
- Obtain quality services in a manner as consistent as possible with their community living preferences and priorities.

In this invitation, States and other eligible entities competed for four different types of grants:

- "Nursing Facility Transitions" grants: To help States transition eligible individuals from nursing facilities to the community. Two types of grants were offered: State Program grants to support State program initiatives; "Independent Living Partnership" grants to select Independent Living Centers (ILCs) to promote partnerships between ILCs and States.
- "Community-integrated Personal Assistance Services and Supports" grants: To improve personal assistance services that are consumer- directed and/or offer maximum individual control. Personal assistance is the most frequently used service that enables people with a disability or long term illness to live in the community.
- "Real Choice Systems Change" grants: To help design and implement effective and enduring improvements in community long term support systems to enable children and adults of any age who have a disability or long term illness to live and participate in their communities.
- "National Technical Assistance Exchange for Community Living" grants: This national technical assistance initiative will provide technical assistance, training, and information to States, consumers, families, and other agencies and organizations."[1]

[1] Complete information may be found at http://www.cms.hhs.gov/systemschange/backgrnd.asp.

Georgia's Real Choice Systems Change Grant

Over the past four years, Georgia has received a total of $3,319,319 Federal dollars under the Real Choice System Change Grant; $1,027,211 in 2001 for Nursing Facility Transition; $1,385,000 in 2002 (see below); and $907,108 in 2003 to support the Independence Plus Initiative and Quality Assurance and Quality Improvement in Home and Community Based Services. Additionally, in 2004, Georgia's Department of Human Resources, Department of Community Health, and Department of Community Affairs applied for Real Choice System Change grants to support Housing Transition programs and initiatives.

The goals of Georgia's 2002 Real Choice Systems Change Grant were defined by a stakeholder group including consumers, family members, representatives from state organizations, service providers, and advocacy groups. Six project goals were developed to support Georgia's grant proposal:

- A medication certification program;
- A direct care staff initiative;
- An evaluation of a supported housing demonstration pilot;
- *A transition program that builds upon a model peer support program;*
- Improvement in communications policies, procedures and practices of state agencies involved in long-term care service delivery; and
- Development of a regional access system for mental health and developmental disabilities services (Georgia Department of Human Resources, 2002).

Georgia's peer support projects are focused on four key areas; (1) training peer support specialists within a hospital environment and improving support for peer support specialists, (2) peer support for developmental disabilities, (3) peer support for physical disabilities, and (4) exploring the feasibility of peer support for the elderly.

The Rationale for Peer Support: A Literature Review

The promise of positive outcomes through peer support has achieved acceptance in recent years and has been recommended for persons undergoing life crises and to promote social integration in the general population (Pillemer and Suitor, 2002). Peer support is a cost-effective, self-help model that, through the encouragement of others who have shared disabilities and experiences, assists individuals with disabilities establish independence and community-integrated living (Georgia Department of Human Resources). Peer supports lend unique insight and provide direct services designed to assist consumers in regaining control over their own lives and control over their recovery process (Sabin and Daniels, 2003). Research findings generally underscore their positive contribution, particularly in old age (Litwin, 1998).

Through the evaluation of social support programs, researchers have underscored the positive outcomes associated with utilizing a peer support model. Sourtzi, Amanatidou, and Velonakis (1998) concluded from their examination of the Senior Health Mentoring Program (which integrated the use of peer volunteers in promoting healthy nutrition for the prevention of cardiovascular disease in the elderly) that volunteer peer educators were notably effective. Klein, Canaan, and Whitecraft (1998) examined a peer support program for individuals with severe mental illness and substance abuse disorders and found that mentally ill individuals that are connected with volunteer friends reported higher levels of satisfaction with their support services, less loneliness, and increased self-esteem. Furthermore, the study concluded that pairing a peer social supporter with a "Friends Connection," (2) reflected positively on both system outcomes and perceived quality of life. Klein, Cnann and Whitecraft (1998) also found that teaming professional and peer paraprofessional helpers may enhance the high-risk client's service use by motivating them to seek and remain in formal outpatient treatments and informal support groups.

The involvement of consumers in the role of service providers has become increasingly popular, particularly among mental health agencies (Mobray, Moxley, Thrasher, et al. 1996). Klein, Cnaan, and Whitecraft (1998) find "experiential similarity," or, having undergone the same stressful transition, critical to improving quality of life and customer satisfaction among mental health clients receiving assistance from volunteer or non-professional helpers. Inclusion of consumers as mental health workers can increase the sensitivity of programs and services for recipients given that consumers are capable of relating to clients' problems, and developing high levels of trust and rapport (Mobray, Moxley, Thrasher, et al. 1996). Georgia's Certified Peer Specialists (CPS) Program, an example of a peer support model of consumer control, recruits individuals who can offer such shared experience to help meet customer objectives and preferences (Sabin and Daniels, 2003).

It is important to recognize the inherent value that peer support programs provide to social support services for elderly populations. Through the process of giving and receiving support from others, peer support allows individuals to increase their self-esteem and skills and achieve their own level of independence (Georgia Department of Human Resources). This reciprocity has been found to correlate with a range of important outcomes among older adults including life satisfaction, happiness, and self-esteem (Litwin, 1998). Krause (1999) explains that older adults who are

[2] Originally established in 1989 as part of Pennsylvania's Community Support Program (CSP) and funded with Philadelphia State Hospital closure funds, the Friend's Connection is a supplemental rehabilitation intervention that provides one-to-one support and "clean and sober" recreational activities for dually diagnosed individuals (Klein, Cnaan, and Whitecraft, 1998).

embedded in active social networks tend to enjoy better physical and mental health than do elderly people who do not maintain strong ties with others. Establishing social support programs for the elderly may be particularly important given that a significant proportion of elderly people do not maintain meaningful social ties with others (Krause, 1999).

Considerations for Peer Support Programs for the Elderly

Given the heightened expectations for individuals serving as peer support specialists to educate and provide leadership, those best suited to function as peer educators should possess experience in formal or informal leadership and/or educational roles (Sourtzi, Amanatidou, and Velonakis, 1998). Furthermore, the recruitment of peer support volunteers should be focused on persons that exemplify positive attitudes (Sourtzi, Amanatidou, and Velonakis, 1998).

A 1996 survey of 400 agencies offering supported housing to persons with severe mental illness reported 38 percent of employed mental health customers as paid staff (Mobray, Moxley, Thrasher, et al. 1996). This statistic indicates that administrators and clinicians may ultimately need to integrate adequate training and organizational development to enhance the effectiveness of peer support programs (Sabin and Daniels 2003). Organizations must contribute to the development of not only those who receive services from their peers, but also the consumers who assume the roles as workers (Mobray, Moxley, Thrasher, et al. 1996). Pillemer and Suitor (2002) suggest that multiple structural mechanisms must be in place to enable positive outcomes and add that peer support alone, without other interventions, will offer limited benefits.

Employees filling peer support roles face unique stressors, which, if not addressed appropriately, may limit their ability to be effective (Mobray, Moxley, Thrasher, et al). It is possible that consumer workers may suffer resentment or distrust from non-consumer staff fearing job displacement, experience problems with role definitions and boundary issues, or have difficulty relating personally to other workers (Mobray, Moxley, Thrasher, et al. 1996). In summary, it is important to clearly define roles for incumbents of peer support positions, as vaguely defined roles can create considerable ambiguity, role conflict, role strain, and personal stress (Mobray, Moxley, Thrasher, et al. 1996).

Mobray, Moxley, Thrasher, et al. (1996) also emphasize the value of increasing the understanding of how role innovation impacts consumer-workers. Consumers who take on new roles as peer support specialists often redefine themselves through the discovery of new personal capacities, skills, strengths, and the establishment of new employment and career vistas. Community support systems should be cognizant of the need to potentially redefine program mission and goals, human resource development systems, career development ladders, and performance compensation policies. The stress for consumer workers may be too high without a reconfiguration of organizational supports for this type of innovation (Mobray, Moxley, Thrasher, et al. 1996).

An Overview of Peer Support Programs

As policymakers and stakeholder groups consider the efficacy of peer support programs for the elderly, it may be helpful to take note of the following list of unique community programs that have been successful in integrating a peer support component:

Alpha One Independent Living Center – Home to the Community

In 1995, a demonstration grant was awarded to the Alpha One Independent Living Center in Portland, Maine through Robert Wood Johnson Foundation's Building Health Systems for People with Chronic Illness program. The main objective of this project was to improve the quality of life and health status of non-elderly adults with a range of disabilities by enabling 40 nursing home residents, age 18 to 65 to transition to the community. During the four-year project, Home to the Community (HTC) assisted 56 nursing home residents in identifying their goals and strategies for living independently. Of those 56 residents, 25 left nursing homes and returned to living in the community (Chaney and Croke, 2003).

Fairhill Center

Cleveland's Fairhill Center for the Aging is now home to 17 organizations that collectively and collaboratively offer a comprehensive network of health and social services to the elderly. Together they provide everything from clinical health evaluations to adult day care and caregiver support groups to health promotion activities. Elderly neighborhood residents serve as volunteers for both Fairhill and its tenant organizations. This array of services is often referred to as an "elder care network, " providing senior centers, churches, meals-on-wheels providers, caregiver respite programs, congregate care facilities, senior advocacy organizations, and hospital outreach programs. Peer volunteers assist in the provision of such social services as "grandparents raising grandchildren," offered by Fairhill's Intergenerational Resource; and a hot line for the Alzheimer's Association. About 1,500 of Cleveland's elderly have participated in these programs over the past year (Strenger, 1995).

Georgia's Certified Peer Specialist Program

In October 2001, Georgia's Department of Human Resources received a grant from the Substance Abuse Mental Health Services Administration, Center for Mental Health Services to support statewide consumer training of peer specialists. The Certified Peer Specialist project is now administered through the Georgia Mental Health Consumer network, in collaboration with the State Office of Consumer Relations. Certified Peer specialists are responsible for the implementation of peer support services, which are Medicaid Reimbursable under Georgia's new Rehab option. One critical component of their training is the provision of peer support in institutional and community-based settings such as hospitals, peer centers and community support teams. As of March 2004, there were a total of 191 Certified Peer Specialists filling roles in the public mental health system (Georgia Certified Peer Specialist Project, 2004).

Georgia's Maintain Independence and Employment Program- Infrastructure Grant

The Medicaid Infrastructure Grants program sponsored by the Centers for Medicaid and Medicare Services (CMS) enables states to build needed systems to help people with disabilities purchase health coverage through Medicaid. Grant funds assist employers with accessing disabled workers seeking employment, training staff in new employment possibilities, improving transportation, and other supports for people with disabilities, and outreach and training programs targeted at consumers using a peer support model (Ellington).

Pennsylvania Transition to Home (PATH)
The Pennsylvania Transition to Home (PATH) project is designed to assist people in the transition from nursing homes into the community and help policymakers learn about perceived or real barriers that nursing home residents face when considering alternatives to living in a nursing home. Specifically designed to work with nursing home residents to help them move into the community, PATH offers a Transition Coordinator to provide support and guidance, information and referral, assistance in finding housing or modifying an existing home, connections to community services such as peer support, assistive technology, home modifications, household tasks, and community integration (Pennsylvania Department of Aging).

Senior Companion Program (SCP)
Operated by the city of Phoenix Senior Services Division, the Senior Companion Program is a volunteer program that enables primarily low income persons, age 60 and older, to provide personal assistance and peer support for activities of daily living. The clients are usually home bound with physical and/or mental health limitations and often at risk of being institutionalized. In 1998-1999, Senior Companions volunteered 85,290 hours in the city of Phoenix, serving 525 seniors with companionship, letter writing, personal care and grocery shopping (City of Phoenix Human Resource Department).

Nursing Home Transition Initiative-Wisconsin
Sponsored by the Health Care Financing Administration (now CMS), this state-based grant program assists individual states in developing process and infrastructure changes to transition from nursing homes to the community. The Wisconsin Department of Health and Family services is conducting the Wisconsin homecoming project, which would be a collaborative effort to coordinate state and local resources for the purpose of providing relocation services to nursing home residents who chose to receive home and community-based long-term care services. This project will also improve opportunities for all persons with substantial disabilities to live out of nursing homes. Elderly persons and persons with disabilities will be engaged in volunteer and paid roles to identify and support individuals who wish to relocate (Johnson).

Ongoing Peer Support Research Projects
Examining ongoing research projects relevant to peer support for the elderly illuminated the scarcity of current research on this topic. Listed below are two such research projects:

"Comadre A Comadre" A One-on-One Peer Support Project for Hispanic Women with Breast Cancer
Sponsored by the Susan G. Komen Breast Cancer Foundation, the overall goal of the proposed "Comadre A Comadre" project is to plan, implement, and evaluate a culturally appropriate, one-on-one peer support intervention for newly diagnosed Hispanic women with breast cancer and their families in Albuquerque New Mexico. Recruited participants, including post-treatment Hispanic breast cancer survivors and family members or friends of post-treatment survivors will lead cancer support groups. The goal is to improve the psychosocial adjustment of Hispanic women with breast cancer by increasing social and practical support and, thereby, ultimately improve quality of life (Saavedra).

Cuidando con Confianza (Caring with Confidence)
Sponsored by the Administration on Aging, Cuidando con Confianza is being conducted in Pima County Arizona to develop, test, and implement an effective, culturally appropriate, and acceptable family caregiver support model for culturally defined communities. This project will provide services including peer support groups, workshops and training on care giving techniques, community resources, and social activities (Wagner).

On Going Real Choice Systems Change Grant Projects Incorporating Peer Support
Georgia is not alone in its efforts to explore peer supports for the elderly who are transitioning from nursing facilities back into the community. In an effort to understand other states' efforts, Real Choice Systems Change grantees who indicated any peer support component within an overall project were contacted. The results of those inquiries are detailed in the tabled below.

State	Grant Year	Intended Population	Setting
Utah	2002	Children, their parents, adults of *any age* with disability or long-term illness	Not specific to NF
Wisconsin	2001	*Any person* with a disability or long-term illness residing in a NF	NF transition
Washington	2001	Individuals *under 65* living in NF	NF transition
New York	2002	*Individuals with DD* transitioning from ICF; *any age or disability* transitioning from NF to community	ICF and NF transitions
Connecticut	2001	*Any person* with a disability or long-term illness residing in a NF	NF transition
Maryland	2001	*Persons with disabilities* living in NF	NF transition
Utah	2002	*Individuals of all ages with significant disabilities* living in nursing facilities	NF transition
Alabama	2001	*People with disabilities,* some of whom are elderly	NF transition
New Hampshire	2001	*Persons with mental* illness in a nursing facility	NF transition
West Virginia	2001	*Persons of all ages with disabilities* in a nursing facility	NF transition
California	2002	*Native Americans and Hispanic individuals with cognitive, mental/emotional, physical, hearing, vision and multiple disabilities*	NF transition
New Jersey	2002	Individuals *under 65* living in NF	NF transition

The Decision Matrix

After reviewing current literature, a Stakeholder Advisory Group (SAG) was convened on April 20, 2004 to begin deliberating the feasibility of establishing a peer support program specifically for elderly individuals who desired to transition from facility based care to community based care. The process was designed to be iterative, and after the first stakeholder meeting, a decision matrix was developed to explore the following dimensions:

- **Peer Definition**: Who exactly would qualify as a peer? Did a peer need to be someone over the age of 60 to align with the Older Americans Act, or could a peer be defined simply by virtue of a shared experience?
- **Model**: What sort of model would a peer support program for the elderly be built on? Would peers be volunteers or paid staff?
- **Funding**: If such a program were enacted, how would it be funded? What is the possibility that Medicaid would reimburse such services?
- **Structure**: Would the program be housed in an independent non-profit or within a government agency?
- **Need**: Are we certain there is a need for peer support targeted specifically to elderly individuals?

Peer Definition

PEER AGE

After considerable deliberation at its first meeting, the SAG decided that the age of a peer support specialist for the elderly should be aligned with the federal Administration on Aging (AOA) definition of 60 years or older for several reasons. First, a peer support program for individuals with mental health issues already exists in Georgia and is currently seen as a national model. It does not define a specific age, but the majority of peer support specialists within mental health are working age. Second, the Real Choice Project also contained components that were developing peer support programs for persons with physical and developmental disabilities. The group felt that in order to distinguish this program from others, the ideal candidates should be 60 years old or older.

At the second SAG meeting, peer age again provoked a lively conversation because of two additional inputs: the ready availability of disabled peer support specialists who had also made a transition from a nursing facility to the community and the concern of the availability of a large enough pool of older individuals who had both completed a nursing facility transition and who were willing and able to serve as a peer support specialist. The discussion concluded that, at a minimum, a peer support specialist for the elderly should have the shared experience of having made a previous nursing facility transition regardless of the age of the individual. The concern of peer support supply will be addressed later in this report.

> **Criteria: AGE – A peer support specialist for the elderly should ideally be age 60 or older, but age will not be a restriction as long as the candidate has the minimum of a shared experience of completing a nursing facility transition his or herself.**

PEER RELATIONSHIP

The question of whether or not a peer support specialist for the elderly should be allowed to be a relative of the individual supported was initiated at the first SAG meeting. Cliff Burt, with the Georgia Department of Human Resources' Aging Division, suggested that the SAG review a report on the Family and Friends project to gain insight into both the population a peer support program might serve and the relationships among caregivers and those for whom care is given. Mr. Burt also recommended that the group review an evaluation of Georgia's self-directed care program. A synopsis of that report is included at the end of this report as Appendix B.

At its second meeting, the SAG agreed that whether or not a peer support specialist should be allowed to be a family member depended largely on whether or not the program (ideally) would be staffed with paid or volunteer peer support specialists. The group felt that if a volunteer model was envisioned (see below), it did not matter if the peer was a relative.

> **Criteria: RELATIONSHIP – Paid peer support specialists for the elderly should not be a relative of the person being assisted.**

PEER SKILLS

The initial discussion around desired peer skills and possible, ideal candidates elicited the following list of characteristics:

- Trained Ombudsmen
- Someone who may have made the transition already
- Individuals from older worker programs
- Care coordinators from the AAAs
- Retired professionals

The introduction of positions from existing state programs triggered a discussion on whether or not the position we were envisioning already existed in some form within the current state aging and disability service delivery systems. While it was acknowledged that using a person such as a trained Ombudsman or care coordinator might violate the criteria that peer support specialists have shared experience, it was decided that a review of current job descriptions across a variety of aging and disability services programs might give insight into the skills one would desire a peer support specialist to have. A comparison of five such job descriptions is included as Appendix C.

Although the SAG determined that there was overlap between required skills, education, and experiences of certain state program personnel and what was envisioned for a peer support specialist of the elderly, it decided the descriptions reviewed did not address the unique insights that a peer could bring to the process. Therefore, the overlap of duties was not viewed as a reason to abandon the concept of peer support for the elderly. From the job descriptions, however, the SAG was able to agree that a peer support specialist of the elderly should be trained and certified, which would require adequate funding for that purpose. It was felt that, based on experiences with other peer support programs, training and certification instills pride and ownership of the position, establishes a level of quality control, and positions it more appropriately for potential funding. The SAG also agreed that the peer support specialist should possess teaching skills that can be transferred to the individual being supported and be a non-professional who is a member of the community.

Criteria: SKILLS – The peer support specialist of the elderly should receive training and certification in peer support and should be a non-professional community member that possesses teaching skills that can be transferred to the individual being supported.

Model

The SAG quickly dealt with whether a peer support specialist of the elderly should be paid, volunteer, or a hybrid patterned after the Long-term Care Ombudsman program where Ombudsmen are both paid and volunteers. After reviewing the literature, including summaries of the Cash and Counseling Demonstration, and drawing on their own anecdotal experiences, the SAG agreed that paid peer support specialists would be more committed, have more pride in their positions, and be more reliable. Additionally, several SAG members saw paid peer support as an opportunity for employment of individuals who may find it difficult to find employment in the traditional employment market. Exceptions to this philosophy would be made to allow for the employment of individuals who may be on Social Security and must carefully monitor the amount of extra income they earn outside of their benefit dollars.

Criteria: MODEL – A peer support for the elderly should be staffed by paid, trained, and certified peer support specialists.

Funding

At the outset, it was impressed upon the SAG that this particular project was a feasibility study – not a planning or implementation study. Therefore, there was never intended to be future funding automatically attached to the project if the SAG decided that peer support for the elderly was feasible. At the group's first meeting, Larry Fricks, from the Georgia Department of Human Resources' Mental Health, Developmental Disabilities, and Addictive Diseases division, described the program he pioneered – peer support for individuals with mental health issues. Mr. Fricks explained that the model is built on the concept of evidence-based practice and recovery from disease. Therefore, he was successful in getting authorization for Medicaid reimbursement for peer support based on the concept that peer support aids in recovery and results in lower cost to the state and federal governments.

The SAG agreed that while advances have significantly improved the quality of life of elderly individuals, recovery from old age is unlikely. However, it was indicated that this concept of peer support might be somewhat like care coordination, in that it aids an individual in connecting to services, encourages the delivery of care in the least restrictive setting, and would most likely result in reduced cost due to de-institutionalization. Grant funding was also considered, but it was acknowledged that grants do not make for a sustainable funding stream, and no SAG member was interested in creating a new program that may have to be eliminated due to the exhaustion of grant funds. Grant funds, however, were not eliminated as possible pilot project support.

Criteria: FUNDING – A peer support program for the elderly should not be created until sustainable funding is secured for such a purpose. Funding peer support through Medicaid as a form of care coordination should be explored further.

Structure

Similar to the job description discussion, the SAG was not interested in creating an independent 501(C)(3) for peer support if it could be built upon or incorporated within existing state supported programs. Local Area Agencies on Aging (AAA) were considered, as they have responsibility for covering the entire state through 12 regional agencies. Centers for Independent Living (CIL) were also considered because of their experiences with the disabled community, their locations around the state, and their previous experience with peer support programs. Ideally, a peer support program for the elderly might be best housed within an Aging and Disability Resource Center – an entity being created in Georgia through federal grant funding and that is intended to be a "one stop shop" for aging and disability information and referral.

> **Criteria: STRUCTURE – A peer support program for the elderly should be incorporated into an existing state program that has statewide coverage. It should not be a stand-alone 501(C)(3).**

Need

Late in the SAG's deliberations, a concern about the need or demand for and supply of peer support specialists trained for the needs of the elderly was identified. Previously, the SAG had targeted several needs that might be met by peer support specialists for the elderly: help with making the transition from institutional care to community care, care giver respite and/or support, and untangling bureaucratic snafus, among others. While it was agreed that the specialist's purpose could be well-defined, it was not known if there was a sufficient number of individuals in the community who had already made the transition and who were willing to help others if such a program were to be created.

Initial data from the Georgia Department of Human Resources' Aging Services Division's Community Care Services Program showed that in FY04, program staff helped transition 81 individuals with an average age of 73. Seventy-two percent were female. The Centers for Independent Living reported helping transition 44 individuals with an average age of 55. Forty-four percent were female. Other estimates of individuals with the potential for transition have ranged from 150 to 5,000.

It was decided that in order to gain a better understanding of the challenges individuals face in transitioning, their willingness to serve as peer support specialists to others, and what they might have to offer other individuals as peer support specialists, the project would interview individuals who had successfully made the transition from institutional care to community-based care.

In November 2004, both CCSP and DisABILITY Link were contacted to determine their interest in interviewing clients they had assisted in transitioning. For logistical reasons, CCSP did not participate; however, DisABILITY Link was successful in recruiting four Centers for Independent Living (DisABILITY Link in Atlanta, BAIN in Bainbridge, Walton Options in Augusta, and Disability Connections in Macon) to assist the study staff.

An interview protocol was developed that addressed basic demographics, transition experiences, challenges, willingness to serve as a peer support specialist, and what individuals might offer others who are considering a transition. Protocols were submitted to and approved by both the

Institutional Review Boards at the Georgia Department of Human Resources and Georgia State University. Representatives of the CILs were trained on the protocol by project staff, and no compensation was offered those who agreed to be interviewed. Interviews were conducted in person by CILs staff and audio recorded in addition to written notes being taken. Project staff at no time came in contact with the interviewees and has no indication of their identities.

Centers for Independent Living conducted the following number of interviews:

- DisABILITY Link: 24
- Disability Connections: 10
- BAIN: 5
- Walton Options: 4

  Total **43**

Of those interviewed, the average age was 53, and the median age was 54. Forty-four percent were female. The average number of months that elapsed from the time they decided to transition to the time they actually transitioned was seven, and the median was four. Those who were transitioned cited the following challenges in planning to leave the institution:

- Housing 20
- Paperwork, bills, etc. 7
- Arranging services/care plan 6
- Waitlist for the waiver 3
- Finances 2

"The main thing was getting out from over there – just getting housing."

"Well my first challenge for getting out of the nursing home was dealing with the facility. They did not want to let me go, because I was a paying customer."

"The worst challenge that I had with the whole thing of being in the nursing home at the time was to get a chair, my own chair. They didn't give me a chair. They did not want to let me have a chair. When I did get a chair, I had to go through other people to get it."

"I hit a wall so many times, I thought my head was going to explode, but I just kept on trying and trying."

"I didn't have any money to pay a deposit. I didn't have any money to pay my first months rent. I couldn't even make an application, because they cost $30 to $35. I didn't have any money."

The types of problems experienced in planning a transition seem to fit well with the role envisioned for a peer support specialist for the elderly. Several of those interviewed stated they could help identify housing for individuals, and two actually offered a place to live. First-hand experience with paperwork snafus might smooth the path for those who have existed within a system that previously did not demand they be involved in their own care.

Ninety-eight percent of those asked said they would be willing to serve as a peer support specialist for the elderly if Georgia created such a program. Many were very enthusiastic in their eagerness to participate, including those 80 years old and older. When asked what type of assistance they thought they could provide from their own experiences, interviewees listed the following:

- Shared experience; someone to talk to: 15
- Information and referral: 13
- Support; counseling: 8
- Help with paperwork and ID cards: 3
- A place to live: 2

"It is building a community. What I mean by building a community is to communicate with others. Helping them to get out of the facility would be a joy of mine. It would make me happy, if I could just get one person to come out like I did, to let them see how it feels to be back out in the community with other people. How I feel about being out in the community, it gives me a sense of being amongst others and belonging, not just being by myself."

"I have been there. I did that. It felt good to get out of the system. Do I enjoy being out of the system? Yes I do. Would I enjoy helping someone else to get out? Yes I would. Would I be there as a peer supporter? All the way."

"If I could help anybody with what I have gone through, the things that I have learned, I would pass it on to them with no problem."

"If you talk to anybody who can understand what you are going through, how to do it, you cannot ask for anything better."

Again, the services interviewees felt they could offer those considering a transition matched well with what the SAG had determined might be the greatest needs.

> **Criteria: NEED (Supply/Demand) - There is sufficient need for a peer support program targeted to elderly individuals. Peer Support Specialists would serve as educators/information providers, friendly visitors, transition problem solvers, and someone on the other end of the phone when the individual who has transitioned has questions that need to be resolved.**

Conclusions

Based on literature review, interviews with experts in the filed, interviews with other states' program directors, facilitated discussion, and interviews with individuals who have made the transition in Georgia from institutional care to community-based care, the Stakeholder Advisory Group has determined that a peer support program for the elderly is feasible based on the following program criteria:

> **Criteria: AGE – A peer support specialist for the elderly should ideally be age 60 or older, but age will not be a restriction as long as the candidate has the minimum of a shared experience of completing a nursing facility transition his or herself.**
>
> **Criteria: RELATIONSHIP – Paid peer support specialists for the elderly should not be a relative of the person being assisted.**
>
> **Criteria: SKILLS – The peer support specialist of the elderly should receive training and certification in peer support and should be a non-professional community member that possesses teaching skills that can be transferred to the individual being supported.**
>
> **Criteria: MODEL – A peer support for the elderly should be staffed by paid, trained, and certified peer support specialists.**
>
> **Criteria: FUNDING – A peer support program for the elderly should not be created until sustainable funding is secured for such a purpose. Funding peer support through Medicaid as a form of care coordination should be explored further.**
>
> **Criteria: STRUCTURE – A peer support program for the elderly should be incorporated into an existing state program that has statewide coverage. It should not be a stand-alone 501(C)(3).**
>
> **Criteria: NEED (Supply/Demand) - There is sufficient need for a peer support program targeted to elderly individuals. Peer Support Specialists would serve as educators/information providers, friendly visitors, transition problem solvers, and someone on the other end of the phone when the individual who has transitioned has questions that need to be resolved.**

The SAG also suggests that the state of Georgia pursue a planning grant prior to attempting to implement such a program statewide, examine the possibility of partnering with an existing peer support program, and budget for program evaluation from the beginning.

“Like the first day I was here, I woke up and sat out here. I was looking around and thought, what in the world am I doing? I thought did I make a mistake? No, I don't think so.”

Appendix A

Stakeholder Advisory Group

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Cliff Burt	Georgia Department of Human Resources, Aging Division
Alan Goldman	Georgia Department of Human Resources, Aging Division
Doris Jones	UHS-Pruitt Corporation
Betti Knott	Georgia Department of Human Resources, Real Choice Systems Change Grant
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Appendix B

ASSESSING GEORGIA'S SELF-DIRECTED CARE PROGRAM

Purpose: Evaluation Study designed to assess Georgia's Self-Directed Care Program

Funding: Grant award to Georgia Division of Aging Services in 2001 by the Administration on Aging (AoA). Provided through the National Family Caregiver Support Program through Title IIIE of the Older Americans Act

Method of Evaluation: Five Area Agencies on Aging (AAAs) were selected to participate as demonstration projects in the development of self-directed care program for aging adults in Georgia:

- Legacy Link, Inc. (Legacy Link, n = 23)
- Southwest Georgia Council on Aging (SOWEGA, n = 37)
- Central Savannah River Area Agency on Aging (CSRA, n = 42)
- Heart of Georgia Altamaha (HEART, n = 48)
- Southern Crescent Area Agency on Aging, n=0
  Total n = 128

All except Southern Crescent were included in this evaluation. Over the course of 16 months, telephone interviews with 128 self-directed caregivers from these four AAAs were performed using a modified version of the Caregiver Support and Satisfaction Survey. (This can be viewed at www.gpra.net.) These responses were compared with responses from 1,301 caregivers participating in the Performance Outcomes Measurement Project (POMP), an initiative formed to meet the accountability conditions of the Government Performance Measurement Act (GPRA). The 1,301 POMP caregivers were sampled from six states, Florida, Illinois, Indiana, New York, North Carolina, and Georgia (n=372).

Research Questions and Hypotheses:

Research questions in this analysis included but were not limited to:

1) Are there important differences between the caregivers enrolled in Georgia's Self-Directed Care Program and those caregivers in the POMP sample?

2) Do caregivers participating in self-directed care programs choose a different mix of services than those clients served with traditional services?

3) Are caregivers of consumers of self-directed programs more satisfied than caregivers whose consumers receive services through traditional methods (POMP caregivers)?

4) Do self-directed care program caregivers indicate the need for as much additional information regarding programs and services as POMP caregivers?

> *Hypothesis 1*: Self-directed caregivers will need less information, because care managers mentor caregivers regarding how to find resources to meet their own individual needs.

5) Because self-directed care programs provide caregivers more control over their lives, are self-directed care caregivers more positive about the aspects of caregiving than those caregivers served by the traditional system?

> *Hypothesis 2*: Self-directed caregivers will be more positive about the "positive aspects of caregiving" questions in the survey.

6) Are there differences in the negative aspects of caregiving for these comparison groups?

Analyses:

AoA subcontracted with Westat to perform a statistical analysis of the data to address the above listed research questions and hypotheses. Two analyses were done in which Westat used t-tests to establish significant differences between the two groups:

- *Analysis 1*: Westat analyzed responses from self-directed care program caregivers (n=128) and compared them with responses from POMP caregivers (n = 1,301) who received services through the traditional service delivery system.

- *Analysis 2*: Westat analyzed responses from self-directed care program caregivers (n=128) and compared them with responses from a subset of POMP caregivers in Georgia (n= 372) who received services through the traditional service delivery system.

Findings: *Analysis 1*
Note: For both analyses, results are listed only for those tests which resulted in significant differences between the self-directed caregivers and POMP groups. Details of each analysis can be found in the original report.

- **Table 2**: Self-directed caregivers provide a higher percentage of all of the care for the care recipient than do POMP caregivers. (38.81% vs. 13.08%

- **Table 4**: Self-directed caregivers reported a higher use of adult day respite care (27.34 vs. 5.97%); individual caregiving counseling (18.75 vs. 5.16%); caregiver training or education (20.31 vs. 5.21%); and caregiver support groups (15.63 vs. 3.85).

- **Table 6**: Self-directed caregivers express the need for more case management (66.67% vs. 29.90%), homemaker services (77.78% vs. 42.49%), home delivered meals (60.61% vs. 19.49%, and individual caregiving counseling (82.61 vs. 19.29%)

- **Table 7**: Compared to POMP caregivers, self-directed caregivers need more help with medicines (39.84 vs. 17.39%); getting other family members involved in care (46.88 vs. 20.30%); respite care or adult daycare (68.75 vs. 28.11%); and money management assistance (37.50 vs. 2.48%).

- **Table 8**: Compared to POMP caregivers, self-directed caregivers reported a greater need for someone to talk to, such as counseling services and/or support groups (67.93 vs. 39.44%). Westat did not find any other significant differences regarding the need for additional information. Westat's findings support Hypothesis 1. Other than the need for someone to talk to, self-directed caregivers need less information regarding programs and services compared to POMP caregivers.

- **Table 11**: Westat found significant differences between groups for all negative aspects of caregiving except financial burden and stress. Where lower mean scores signify greater burden, compared to POMP caregivers, self-directed caregivers reported that their caregiving duties more often left them with not enough time to care for themselves (2.33 vs. 3.23); or the rest of their family (2.65 vs. 3.59); affected their relationship with other family members in a negative way (3.47 vs. 4.31); interfered with their personal needs for privacy (2.92 vs. 3.96); and created problems in their social lives (2.86 vs. 3.96)

Findings: *Analysis 2*

- **Table 12**: Compared to Georgia POMP caregivers, self-directed caregivers provided a higher percentage of all of the care for the care recipient (38.81 vs. 13.19%).

- **Table 13**: Compared to Georgia POMP caregivers, self-directed caregivers provided more ADL care (89.84 vs. 68.54%) and more help with finances (95.31 vs. 79.56%).

- **Table 14**: Compared to Georgia POMP caregivers, self-directed caregivers reported a higher use of: adult day respite care (27.34 vs. 7.35%); assistance with access to services (21.88 vs. 12.59%); individual caregiving counseling (18.75 vs. 5.09%); caregiver training or education (20.31 vs. 4.53%); and caregiver support groups (15.63 vs. 1.48). Compared to Georgia POMP caregivers, these caregivers also used less in-home respite care (44.88 vs. 68.48%); case management (42.97 vs. 64.94%); homemaker services (31.25 vs. 64.25); and home health aides (42.97 vs. 71.45).

- **Table 15**: Where lower mean scores signify a higher rating, compared to Georgia POMP caregivers; self-directed caregivers gave higher ratings to in-home respite care services (1.70 vs. 2.30). Compared to Georgia POMP caregivers, self-directed caregivers more often rated the following services as "excellent:" in-home respite services (53.57 vs. 24.37%); case management (53.85 vs. 28.60%); homemaker services (45.95 vs. 17.92%); transportation services (52.63 vs. 15.22%); and caregiver support groups (52.63 vs. 5.56%)

- **Table 16**: Compared to Georgia POMP caregivers, self-directed caregivers need more case management (66.67 vs. 34.97%); homemaker services (77.78 vs. 44.95%); home delivered meals (60.61 vs.19.46%); and information about services (84.21 vs. 32.81%).

- **Table 17**: Compared to Georgia POMP caregivers, self-directed caregivers need more help with medicines (39.84 vs. 21.35%); getting other family members involved in care, (46.88 vs. 24.15%); and respite care or adult daycare (68.75 vs. 31.04%).

- **Table 18**: Compared to Georgia POMP caregivers, self-directed caregivers need more help with medicines (39.84 vs. 21.35%); getting other family members involved in care, (46.88 vs. 24.15%); and respite care or adult daycare (68.75 vs. 31.04%). *Westat's findings provide some support for Hypothesis 1. Other than the need for someone to talk to and help understanding how to pay for a nursing home or adult daycare or other service, self-directed caregivers need less information regarding programs and services than Georgia POMP caregivers do*

- **Table 20**: Where lower mean scores signify higher rewards, self-directed caregivers defined companionship as a positive aspect of caregiving less often than did Georgia POMP caregivers (2.32 vs. 1.77).

- **Table 21**: Where lower mean scores signify greater burden, compared to Georgia POMP caregivers, self-directed caregivers reported that their caregiving duties more often left them with not enough time to care for themselves (2.33 vs. 3.26) or the rest of their family (2.65 vs. 3.62); affected their family relationships in a negative way (3.47 vs. 4.36); interfered with their personal needs for privacy (2.92 vs. 4.02); and created problems in their social lives (2.86 vs. 4.12). Compared to Georgia POMP caregivers, a higher percentage of self-directed caregivers felt that caregiving "quite frequently" interfered with their work (32.35 vs. 6.01%) and created stress (25.00 vs. 11.36%).

Appendix C

Comparison of Community-based Services Job Descriptions

	ICWP Case Manager	MRWP Support Coordinator	Volunteer Ombudsman	CCSP Care Coordinator	SOURCE Case Management Specialist
Skills		Knowledge of social, economic, health, service objectives, and methods of collecting and organizing data, problem solving skills, ability to plan programs, ability to prepare proposals, ability to monitor and evaluate service delivery, ability to provide technical assistance, ability to supervise, determine work priorities, communicate effectively, establish and maintain working relationships, and understand and apply rules, regulations, and policies	Ability to communicate with elderly and people with disabilities, problem solving skills,	Ability to effectively coordinate and communicate with clients, service providers, general public, and other staff members; Skill in establishing and sustaining interpersonal relationships; Knowledge of human behavior, gerontology; Skills in team building and group dynamics; Knowledge of community organization and service system development; Problem solving skills and techniques;	Ability to work independently within assigned deadlines; strong organizational skills; knowledge of local, state and regional health and social services; AND strong skills in verbal and written communication (including coordination with co-workers, SOURCE members and advocates, physicians, providers and community members. Professional and personal commitment to quality, advocacy, productivity, creativity and ethics

				Knowledge and skill in social and health service intervention techniques and methodology.	
Education	BA or BS			Bachelor's degree in social work, sociology, psychology, or a related field, OR (see "Experience" below.)	BS or BA degree in: social work, psychology, liberal arts, nursing/other clinical.
Training	4 classes per year through DCH		Training and certification process required: 24 hours of instruction, 10 days on-site; take home written exam; oral exam; 12 hours of continuing education to maintain certification		
Experience	3 years documented, including teamwork, written and verbal skills, knowledge of resources	Minimum 3 years as Mental Retardation Professional (MRP)	Some experience working with aging population or LTC facilities desired	Registered, professional nurse currently licensed to practice in the State of Georgia; two years experience in the human service or health related field.	Minimum five years demonstrated experience in healthcare or human services for the elderly or disabled and successful team participation in healthcare and/or human services.

Certification Requirement?			Yes		
Agency or individual?	Either			Agency	
Caseload	Max 20				
Duties	Intake interview, assist in coordination of services, review members' rights and MOU, provide list of providers, assist in making decisions, investigate community resources, provide ongoing case management, coordinate case conference, handle appropriate paperwork, communicate changes to care plan, review and evaluate care plan every 90 days, monitor delivery of services, resolve coordination problems, coordinate discharge, assist with requests for hearings, monthly face-to-face meetings with clients, make referrals to Adult Protective Services,	Coordinate all activities related to individual support plan (ISP), assist with implementation of ISP, review plan annually, assist with identification of most cost-effective services, observe client's participation in services, supports, and activities, complete DMA-80, comply with policies and procedures, monitor recertification process	Visit assigned LTC facilities, providing independent presence; investigate and resolve complaints; educate facility staff; report problems; maintain frequent contact with local LTCO office; adhere to confidentiality agreement; complete required paperwork	Under direction, performs work of moderate difficulty by providing skilled casework services to selected caseloads or clients with special problems such as health disability or those at risk of nursing home placement; provides specialized casework services aimed at securing the client's overall well being and maximum degree of independent functioning. Serves large geographic areas which may include one large county and/or many small counties which may involve extensive	Performs regular assessment of members' needs; develops individualized care paths based on level of need and resources available; develops a therapeutic working relationship with the SOURCE member/caregivers; acts as formal liaison and advocate for SRC members; complies with administrative duties inherent in case management; demonstrates the knowledge and skills necessary to provide care appropriate to needs of SOURCE members served.

	notify of death, report abuse and neglect			travel, and performs related work as required.*	
Other	Commitment to advocacy and ethics		Requests a minimum one-year commitment		

*CCSP duties were much more detailed but too lengthy to list here. Separate duties and training are specified for a care coordinator who is a registered nurse.

Appendix D

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