Expanding Self-Direction in Services for the Aged and People with Disabilities

Ruth A. Burgess

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Expanding Self-Direction in Services for the Aged and People with Disabilities

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Thesis submitted to the Graduate College of Marshall University

In partial fulfillment of the requirements for the degree of

Master of Arts in Sociology

October 29, 2003

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Abstract

Medicaid-funded long-term care services are traditionally delivered in nursing homes. States may apply for waivers which allow them to provide home and community based services with Medicaid funds. Because these services are by definition an alternative to nursing home care, waiver services are generally based upon a medical model which emphasizes medical deficits and tends to restrict consumers’ movements to inside the home.

Recent developments such as the Olmstead Decision and federal New Freedom Initiatives have caused states to recognize that consumers desire and have a legal right to be part of a community rather than institutionalized or home-bound. These developments are forcing states to look for new ways to bring Medicaid services to consumers. One such model of service delivery is consumer directed services. The two key concepts of consumer directed services are 1) Individual budgeting: A pre-determined amount of Medicaid money set aside monthly through a fiscal intermediary that the consumer can use to purchase goods and services; 2) Consumer direction: The consumer is the employee of record for service providers and hires providers including friends, neighbors and family members or can contract for services through an agency. The consumer hires, trains, schedules, supervises and dismisses his or her providers.

West Virginia is one of only five states chosen to participate in a project funded by the Robert Wood Johnson Foundation and administered by the National Association of State Units on Aging (NASUA). The West Virginia Bureau of Senior Services (BoSS) is the agency representing the state in this
endeavor called “Expanding Consumer Direction in Aging Services”. BoSS is the agency that administers the Medicaid Aged and Disabled Waiver program in West Virginia and that population is targeted in the program. Recipients of the A/D waiver are adults (19-64) who have a disability and elders (65 or older) who meet the medical criteria.

This work documents the agency’s efforts over nineteen months to expand opportunities for participants in the A/D Waiver to exercise more control over the services they receive.
Introduction

This document represents nineteen months of work that I undertook more or less on a whim. With only one year’s tenure with the West Virginia Bureau of Senior Services and newly transferred to the Medicaid Aged and Disabled Waiver Program, I was completely uninitiated into the concept of self-direction. Although I had been employed in the aging network for many years and in varying capacities, I was somewhat naïve about the political nature of service provision and the power struggles that take place behind the scenes. Because my career had centered on aging, I had little knowledge of the needs and wishes of people with disabilities and even less about the independent living movement.

When I became aware of a technical assistance grant that was being offered by the National Association of State Units on Aging to promote expansion of self-direction in aging services, I viewed it as an opportunity to move our A/D waiver forward, and shake things up within a program that clings to the status quo. Being someone who believes strongly in patients’ rights, I had a sense that self-direction would enhance the lives of those who used A/D Waiver services, but I didn’t really know for sure what the term meant or how far my agency would allow me to take it. One thing that I knew for certain was that by pursuing the grant I would carve a unique niche for me and expand my career options.

I asked my agency’s commissioner to allow me to pursue the grant and submitted a proposal which was accepted. The grant provided only modest financial support, but provided me access to some extremely knowledgeable people and gave me an amazing education in self-direction.
While learning from people who had already initiated self-direction in their own states, they kept warning me about resistance from providers. I knew that our providers were fairly political (they were able to have a past governor’s appointment to the commissioner’s post replaced by one of their choosing), but had no idea the extent to which they would go to exert control over the program.

Our providers are made up of 31 case management agencies and 102 homemaker agencies. Of these agencies, 42 of them are senior centers that we rely on to carry out many of our responsibilities. These are the same centers that were responsible for having a past commissioner removed. This puts my agency in an uncomfortable situation within the A/D waiver program that is, by design, heavily provider driven.

Aside from the inter-dependence that we have with our senior centers, I have since learned that many of our providers have a good deal of direct political clout. Among our senior center directors, one has a state senator on his staff, one is closely related to an extremely powerful senator, one is a senator, two others are delegates. Among the provider network as a whole, there are at least thirteen direct connections to the West Virginia Legislature.

As the self-directed program progressed I began to experience a bit of the conflict that I’d been warned about. For example, one of the providers that I hand-picked to work with me on the project strongly encouraged me at the outset to initiate self-direction for younger program participants with disabilities but to leave the seniors alone. Even providers who I view as friends and who support person-centeredness in other aspects have begun to write critical letters to my
commissioner. As we come closer to launching a self-directed program, I fully expect pressure from the legislature and have begun to brief the commissioner on what to expect and give her facts to help her respond.

One would expect that a state agency would be in a position to exert strong control over businesses that provide services to the state. But as C. Wright Mills asserted in *The Power Elite*, some of the coordination between government and business comes from the interchange of personnel between the two. The closeness of business and government can be seen by the ease and frequency with which players pass from one to the other. A good deal of the coordination comes from a growing structural integration of dominant institutions. As each of the domains becomes larger, more centralized, and more consequential in its activities, its integration with the other sphere becomes more pronounced, increasingly coordinated and inter-linked. There becomes an unstated structured bias of government and business toward one another's interests.

Another component of conflict is the competition for resources. Contrary to popular thought, Medicaid is not a bottomless pit, particularly in a state like West Virginia where the economy is suffering. State and Federal dollars combined, about $42 million goes into the A/D waiver. Approximately $115 million is spent on the MR/DD Waiver to support people who would otherwise be placed in an Intermediate Care Facility for the Mentally Retarded (ICFMR). (Wiseman) $315 million is spent not only to support people in nursing homes, but to support the nursing homes themselves. (Samples) In most instances,
nursing homes get paid even for empty beds in order to ensure that those beds will be available should they be needed. The nursing home industry has deep pockets and a strong lobby, both federally and on a state level. Advocates of home and community based services express outrage at the use of public funds to support private industry, particularly while the A/D waiver maintains a six-month waiting list. The nursing home industry argues that in many counties, nursing homes are the largest employer and to undermine the industry would undermine the state’s economy. While I personally believe that if we demonstrated to nursing homes that there is money to be made in the community, they would begin to transition their services from facility-based to home and community based. This argument goes on and on and only serves to further illustrate the conflict that exists within the aging network.

The self-directed project that I describe in this document continues to be developed and should be launched mid-year, 2004. I look forward to the opportunity to evaluate the project’s outcomes and it is my sincere hope that self-direction will not only enrich the lives of aged and disabled West Virginians, but spread to all other home and community based services in the state.
An Overview of Personal Assistance Services

Personal assistance services are services and supports designed to assist persons with disabilities and long-term care needs to live as independently as possible. Many people with disabilities and long-term care needs depend on personal assistance services to help them do everyday activities that they cannot do for themselves. Personal assistance services may also be known as attendant care, homemaker services, and personal care.

Personal assistance services include assistance with both activities of daily living (ADLs) and instrumental activities of daily living (IADLs). Activities of daily living are defined as: bathing or showering, dressing, getting in and out of bed or a chair, using the bathroom, and eating. Instrumental activities of daily living are defined as preparing meals, managing money, shopping for groceries and personal items, performing light or heavy housework, and using a telephone (National Center for Health Statistics, 2003).

The single largest source of funding for personal assistance services is Medicaid, the joint federal and state program of services for the elderly and people with disabilities with long-term care needs. Other sources of funding for personal assistance include the Division of Rehabilitation Services, third-party insurance, and private payment options. Medicaid-funded long-term care services are traditionally delivered in nursing homes. States are mandated to provide facility-based settings for long-term care and must insure that there are enough available nursing home beds to meet the need for such services.
Twenty years ago, the federal Medicaid Agency, the Center for Medicare and Medicaid Services (CMS), then called the Health Care Financing Administration, began to address that fact that people would rather remain at home than be forced to move to a long-term care facility. At this time, HCFA began granting Home and Community Based Waivers to states. States were allowed to waive certain Medicaid requirements, such as the requirement for statewideness in services, to pilot programs on a limited basis to offer long-term care in the home and community.

While the majority of personal assistance services are still provided by a human aide, such as an attendant or homemaker, the concept of personal assistance services has expanded to include non-traditional services and supports, such as home modifications and the purchase of assistive devices. Personal assistance services, typically provided in the home of the service recipient, are now frequently available outside the home in settings such as schools, workplaces, and the community. Expanded definitions and availability of personal assistance services in recent years has allowed persons with disabilities and long-term care needs to participate more fully in the life of their communities.
Personal Attendant Services in West Virginia

West Virginia currently has two Medicaid Waiver programs providing personal assistance services, the Aged and Disabled (A/D) Waiver and the MR/DD Waiver for people with mental retardation and related developmental disabilities. Personal care services are also available under the Medicaid State Plan and through the Ron Yost personal Assistance Services (RYPAS) program administered by the Division of Rehabilitation Services.

The Medicaid Aged & Disabled (A/D) Waiver is administered by the West Virginia Bureau of Senior Services under a contractual agreement with the state Medicaid Agency, the Bureau for Medical Services. The A/D Waiver serves people who are aged and require long-term care. It serves people who are eighteen years or older and who have a physical disability that creates a need for nursing-home level care. To determine medical eligibility, a nurse administers a pre-admission screening (PAS 2000). The PAS 2000 is used to determine eligibility for both nursing home and waiver services. It also serves to determine eligibility for the Medicaid Personal Care Program under the Medicaid State Plan. The PAS 2000 is also used to determine the level of service the participant is eligible to receive. There are four levels of care: A = 62 hours of service per month; B = 93 hours; C = 124 hours; and D = 155 hours.

In order for a participant to be nursing home or waiver eligible, they must have significant deficits in five activities of daily living as indicated on the PAS 2000. In West Virginia, activities of daily living (ADLs) include: eating, bathing,
dressing, grooming, continence (bladder and bowel), orientation, transferring, walking, wheeling, vision, hearing and communication. The five-deficit requirement for nursing home and waiver eligibility used by West Virginia is the most stringent in the nation. In contrast, to be eligible for the Personal Care Program, participants need only have deficits in three ADLs.

The MR/DD Waiver is administered by the Division of Behavior Health, also under a contractual agreement with the Bureau for Medical Services. The MR/DD Waiver serves people with mental retardation and/or a related condition. These participants must require the level of care provided by an Intermediate Care Facility for the Mentally Retarded (ICFMR). Applicants must have substantial limits in functioning in three or more major life activities which include: self care; learning (functional academics); mobility; capacity for independent living (home living, social skills, health, community use, and leisure); receptive and/or expressive language; and, economic self-sufficiency (employment).

Both waivers require a determination of financial eligibility or means test. This determination is made by the local office of the Department of Health and Human Resources (DHHR). Factors such as income and assets are taken into consideration when determining eligibility. An applicant's monthly income cannot exceed 300% of the current maximum Social Security Income (SSI) payment per month. Only the applicant's income is considered, not the income of the spouse, parents, or other family. The applicant's assets are also considered in the eligibility process.
For the purpose of this document, the Medicaid A/D Waiver will be most closely examined.

While these home and community based services are by definition an alternative to institutional care, traditional waiver services are based upon the medical model which emphasizes medical deficits and tend to restrict participants' movements to inside their homes. States have a good deal of autonomy in creating their Waiver regulations, however, in West Virginia's A/D Waiver, up until last year, the program would not pay for any services rendered outside the participant's home unless it was medically necessary, for example, a trip to the doctor's office or to pick up prescriptions. The DHHR has since amended the policy to allow up to 20 hours a month of community activity.

The A/D waiver has an annual budget of just under $42 million. The state share is $13 million, which is allocated by the state legislature and comes from lottery proceeds. The state share is matched by CMS on a three-to-one basis for services, and a one-to-one basis for administrative costs. These funds provide services for 5,400 people per year. The concept of determining the maximum number of people allowed to be served by a program is referred to as assigning slots. When a participant receives his or her first hour of services, a slot is filled for the year even if the participant uses only that one hour. (Bureau of Senior Services, 2002)

The services provided under the A/D waiver include case management services, homemaker services, and adult daycare. Case Managers facilitate
participants' entry into the long-term care system, helping them with financial eligibility and coordinating services. Participants may opt to coordinate their own services without a case manager. There are 31 approved Case Management Agencies with 65 offices. Homemaker services are provided through agencies that send a direct service provider (homemaker) to the participant's home to assist the participant with non-medical activities of daily living such as toileting, transferring, bathing, light housekeeping and food preparation. They cannot administer medication or provide wound care, catheterization or other tasks that must be performed by a Registered Nurse. There are 102 approved Homemaker Agencies with 144 offices.

Homemakers are required to have 32 hours of training before rendering services. This training includes three mandatory trainings:

1. Orientation to the agency, community & services
2. Accident prevention and safety
3. Occupational Safety and Health Administration (OSHA) standards related to blood-borne pathogens cardiopulmonary resuscitation (CPR) and first aid training.

The other hours of training may be chosen from the following areas:

1. Working with specific populations, including the elderly, persons with behavioral disorders, distinct categories of physical or cognitive disabilities
2. Body Mechanics
3. Personal care skills including, but not limited to bathing, grooming, feeding, toileting, transferring, positioning, ambulation and vital signs.

4. Care of the home and personal belongings

5. Food, nutrition and meal preparation

Adult daycare settings provide services similar to homemaker services, but they are delivered in a congregate setting. There are only two adult day care centers in the State.

While generally considered preferable to nursing home services, home and community based services are still based on the medical model. Under the medical model, even non-medical services are planned and provided or delegated by a nurse with a physician's authorization. These practices remain in legislation known as The Nurse Practices Act. The medical model focuses on a person's deficits rather than strengths, based upon long held societal attitudes that people who are aged or who have a disability are sick or incompetent and in need of "fixing" or someone to look out for them. Service recipients have little choice regarding when, where, how, and by whom services are provided. Services are provider-driven, with professionals making most, if not all, decisions regarding service provision. The medical model encourages dependency and institutionally-biased services. This model has frequently left people with disabilities and long-term care needs feeling like passive participants in a system controlled by medical professionals and service providers.
The medical model is provider driven. Under the traditional waiver, an RN does a pre-admission screening, another RN reviews the PAS and a MD signs it, a case manager completes a service coordination plan to decide what services the participant needs, a homemaker RN does another assessment and develops a plan of care which determines what tasks will be performed on which days, by whom and at what time. Throughout this process, the participant is a spectator.

Under self-direction, the PAS process is the same, but is only used to determine program eligibility and to establish the level of services the participant is eligible for. At that point, the participant will develop a resource management plan to decide how his or her service and supports needs will be met. Participants may use as much or as little support as they need or want from their Resource consultants. Because they are the employer of their workers, scheduling and assigning duties is the responsibility of participants.

Under the medical model, participants choose a case management agency which “steers them toward” a homemaker agency, which then sends whoever is available to the participants’ homes to provide services which are often very personal in nature. In many cases, the participant doesn’t have an assigned caregiver that they see on a regular basis or their caregiver changes so often that there is little time to develop a relationship, or even a level of comfort, with that person. If participants don’t like the caregiver that the agency sends, they have to rely upon the agency to send someone else or choose another agency altogether. Because workers are agency employees their responsibility
is to satisfy the agency rather than the client. The agency is the employee and the participant is someone who needs to be helped by them.

Under self-direction, participants may hire friends or family, a neighbor or fellow church member to be their worker. They may advertise for and interview their workers. If the employee doesn't work out, participants may fire them and find another. Because workers are employees of the participant, their sense of duty is to the participant and the worker generally has a greater sense of respect for the participant than under the traditional, or medical model.

Traditional providers have thrived under the medical model and are, naturally, threatened by self-direction. Aside from the loss of control over the system, traditional providers fear a loss of revenue as participants are allowed to hire independent workers rather than being dependent upon agency workers.

During the development of the partnership group that was formed with the NASUA project, BoSS staff identified providers who they thought would be the most receptive to self-direction and easiest to work with. Even those hand-picked providers told the group that if plans for self-direction began to threaten their agencies they would do everything within their power to stop the movement.

The management team has attempted to demonstrate that self-direction will not be as big a financial threat as traditional providers fear. In states which allow for self-direction within existing waiver programs, only 8-13% choose the self-direction option. The team estimates that initial interest in self-direction within the A/D waiver will lean toward the low end of the spectrum, given the fact
that services have been provider driven for so long, and that people in West Virginia are generally more cautious about trying out new ideas.

Traditional providers are experiencing a good deal of difficulty in recruiting and retaining staff. This is due to low wages and the difficulty of the work being performed. Particularly in the northern panhandle of the state, workers can cross state lines and earn much higher wages for the same work. They can also earn similar wages working in the fast food industry as they do as caregivers. The management team has pointed out to providers that often agencies cannot staff their existing caseloads. By introducing new, independent workers into the workforce, self-direction will free their workers up to give participants receiving traditional services the all hours of service they’re entitled to.

These measures have prevented any preemptive action upon the part of providers so far, but in the three Independence Plus states, traditional providers proved to be a huge impediment during the enrollment process. Provider resistance in New Jersey was so bad that the state couldn’t get enough participants to enrolled until program administrators appealed to providers to refer their “problem” clients—the people the traditional providers couldn’t, or didn’t want to serve because they were difficult to deal with or were so medically needy that they weren’t profitable to serve. (Ditto interview). As the management team proceeds in the implementation of a self-directed demonstration, they must be prepared to face similar resistance.
Self-Directed Services: The Cash and Counseling Model

Traditional ways of supporting people with long term care needs have begun to change. For the past two decades, people with disabilities and their advocates have aggressively challenged the medical model. They believe that they should have more control over their lives and can make the best decisions about the services they need, where they receive those services, and who provides them. They want to manage their own long term care funds and make decisions about how those funds are spent. Rather than having services provided by a person selected by a homemaker agency, they want to be free to recruit, hire, train, manage, and if necessary, fire their providers. Rather than being limited to a menu of services, they want to be able to use their funds in new ways such as saving part of it to purchase home modification or assistive technology that will lessen their need for labor. For example, rather than sending their homemaker to the Laundromat for two hours, they may wish to use their funds to purchase a washer and dryer that would allow them to down their own laundry or at least keep the homemaker in the home to perform other tasks while doing the laundry.

A new model of personal assistance services has emerged. Rising out of the independent living movement, self-directed personal assistance services are based on the principles of freedom, dignity, and respect. Through a process of person-centered planning, services and supports are designed around a participant’s strengths and needs rather than fitting the participant into narrowly
defined programs and services. Another key feature of self-direction is that people with disabilities and long-term care needs define quality and actively participate in the planning, delivery, and evaluation of services.

Self-direction is a philosophy and orientation to the delivery of home and community based services whereby consumers make informed choices about the services they receive. They can assess their own needs, determine how and by whom these needs should be met and monitor the quality of services received. Self-direction ranges from the individual independently making all decisions and managing services directly; to the individual designating a representative to manage services as needed. The unifying force in the range of self-directed and consumer choice models is that individuals have the primary authority to make choices that work best for them, regardless of the nature or extent of their disability or the source of payment for services (Stone 2002).

The Supreme Court’s 1999 Olmstead Decision set a legal precedent for self-direction in a more official way. The decision interpreted the Americans with Disabilities Act in such a way as to require states to provide services in the least restrictive setting and manner. It challenged Federal, State and Local governments to develop more opportunities for people with disabilities through systems of cost-effective, community-based services and supports. States are now required to administer services, programs and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities. (Center for Medicare and Medicaid Services, 2003)
Olmstead opened up a floodgate of new ideas about service delivery and different ways of looking at people who are aged or have disabilities. Some of these have been generally labeled Systems Change Initiatives.

One such systems change was the New Freedom Initiative, announced by President Bush in 2001 as a nationwide effort to remove barriers to community living. This includes grants as incentives for states to develop systems of increased access to community life. Though primarily geared toward those with disabilities, the aged population has done extremely well with these expanded opportunities within the A/D Waiver in other states who have embraced these changes.

The most notable example of self-directed personal assistance services is the Cash and Counseling demonstration currently supported by The Centers for Medicare and Medicaid Services and the Robert Wood Johnson Foundation. The Cash and Counseling demonstration is administered with oversight from the Boston College Graduate School of Social Work and the National Association of States Units on Aging (NASUA). Mathematica Policy Research, Inc. was contracted to collect and compile evaluation data. Preliminary results of Cash and Counseling demonstrations in three states (Arkansas, Florida, and New Jersey) indicate a high degree of participant satisfaction and quality of life, with no adverse effects on health and safety.

Arkansas, Florida, and New Jersey are the only states in which self-directed services and supports are being stringently evaluated using scientific
methodology. In the Cash and Counseling model, service recipients participate in a randomized-controlled trial of what happens when consumers are given supplemental income to spend as they need instead of a set of services prescribed by a case manager. Participants receive a monthly allotment to provide for their service needs. With the assistance of a counselor, participants develop a plan to meet their needs, including the ability to hire family and friends to provide personal assistance if they choose. A fiscal intermediary provides services such as accounting and payroll functions, in order to ensure that participants fulfill their obligations as employers. Participants in the Cash and Counseling model can set aside a portion of unspent funds to purchase non-traditional services and supports, such as home modifications or appliances, to meet their needs.

Data for the analysis were drawn from computer-assisted, pre-coded telephone interviews with demonstration participants nine months after random assignment. To obtain a complete picture of participants’ experiences, Mathematica Policy research (MPR) also conducted nine-month interviews with disenrolled participants and with the proxies of deceased clients. MPR asked questions about the participants’ present quality of life and unmet needs because that is what clients can report most accurately. They used a two-week reference period for questions about daily activities because the interview day might have been atypical, and the use of a two-week reference period should not lead to serious recall error. They also asked participants about their use of community services or equipment purchases during the entire nine months because these
events were likely to be relatively infrequent and easy to recall. Finally, questions about changes in participants' activities as employers and purchasers of goods and services refer to the period between the six-and nine-month point of their random assignment.

Because their goal was to simply describe participants' experiences, MPR did not present standard errors, confidence intervals or tests of hypotheses. Given the relatively small sample available for analysis in each state, they note only subgroup differences which are 15 percentage points or larger and that involve at least fifteen respondents. Smaller differences, those involving very few respondents, may well be due to chance (Mathematica, 5).

In Florida, the caseload evaluated was 2,820 with 814 elderly; 1,002 adults with disabilities; and, 1,004 children with developmental disabilities. They began their project in June, 2000. Florida's project requires participants to work with a consultant/counselor who trains and coaches the participants in overseeing their services and a bookkeeper to "hold" the participants' funds, pay invoices and timesheets approved by the participant, and be responsible for employment-related fiscal matters such as workers' compensation and payroll taxes. Participants are provided education about using their consultant and bookkeeper services, being an employer, and developing a purchasing plan. Participants decide what services, equipment and supplies they need. They can choose providers from traditional homemaker agencies or choose independent workers, friends or family. They may select someone to act as their
representative in the project. They may bank funds to make large purchases such as home modification and assistive technology. After six month, funds that are not spent or earmarked for purchases are returned to the program.

In Florida, 81% of participants used their monthly budget to hire caregivers. Of these, 99% were satisfied with their relationship to the caregiver and 96% of those satisfied described themselves as "very satisfied". Ninety-six percent of participants who used the monthly budget to hire caregivers would recommend the self-directed program to others wanting more control over their services. Fifty percent of participants used funds to purchase supplies, and 16% used funds to purchase care-related equipment. Eighty-eight percent of all participants said that the project has improved their quality of life, with the most commonly cited improvements being the ability to hire their own caregivers and obtain the right types of services. Despite this overwhelming satisfaction, one half of participants said that they needed more help with meal preparation or housework (Mathematica - Florida).
The table below represents areas in which participants expressed improvements in their lives as a result of participation in the self-directed program.

<table>
<thead>
<tr>
<th>Improvement</th>
<th>Number Citing Improvement</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Improvements Pertaining to Care and Caregivers</strong></td>
<td></td>
</tr>
<tr>
<td>Monthly Budget Enables Client to:</td>
<td></td>
</tr>
<tr>
<td>Choose Caregivers</td>
<td>45</td>
</tr>
<tr>
<td>Obtain the right types of personal assistance or services</td>
<td>32</td>
</tr>
<tr>
<td>Obtain enough care or care at the right time</td>
<td>17</td>
</tr>
<tr>
<td>Obtain higher quality care than had before</td>
<td>15</td>
</tr>
<tr>
<td>Compensate caregivers or enable them to leave other jobs</td>
<td>9</td>
</tr>
<tr>
<td><strong>Improvements Pertaining to Supplies and Modifications</strong></td>
<td></td>
</tr>
<tr>
<td>Budget Enables Client to Buy:</td>
<td></td>
</tr>
<tr>
<td>Unspecified items related to personal assistance needs</td>
<td>11</td>
</tr>
<tr>
<td>Food or nutritional supplements</td>
<td>3</td>
</tr>
<tr>
<td>Diapers</td>
<td>1</td>
</tr>
<tr>
<td>Budget Enables Client to Modify Home</td>
<td>1</td>
</tr>
<tr>
<td><strong>Attitudinal and Health-Related Improvements</strong></td>
<td></td>
</tr>
<tr>
<td>Client feels more independent or in control of care</td>
<td>17</td>
</tr>
<tr>
<td>Client worries less, is happier, or has more self-esteem</td>
<td>7</td>
</tr>
<tr>
<td>Client is happier since receiving the monthly budget</td>
<td>3</td>
</tr>
<tr>
<td><strong>Other Improvements</strong></td>
<td></td>
</tr>
<tr>
<td>Program’s flexibility enables clients to choose the best combination of goods and services</td>
<td>17</td>
</tr>
<tr>
<td>For clients younger than age 18, budget provides respite for</td>
<td>7</td>
</tr>
<tr>
<td>parents or increases the amount of &quot;quality time&quot; that parent and child spend together</td>
<td></td>
</tr>
<tr>
<td>Client is more financially secure</td>
<td>1</td>
</tr>
<tr>
<td><strong>Number of Clients</strong> *</td>
<td>148</td>
</tr>
</tbody>
</table>

Source: Mathematica Policy Research, Inc's Nine-Month Cash & Counseling Evaluation Interview, question J37

Note: This table is based upon open-ended responses that were coded postinterview. Although they were asked to provide the most important reason, some respondents gave more than one; all are represented here.

* The number of respondents who said the cash benefit had improved their quality of life.
Arkansas evaluated a caseload of 2,008 participants that included 1,454 elderly and 556 adults with disabilities. Their program began in December, 1998. Participants in Arkansas work with a single consulting/fiscal agency to receive support and bookkeeping services. They may also choose to not to use the fiscal agency and receive instead a budget check directly to their homes. Participants receive telephone counseling and complete a self-assessment to ensure that they are able to direct their own care. They may also choose a representative to assist them. Arkansas participants may also accumulate funds for up to six months to make specific, pre-approved large purchases.

In Arkansas, 78% of participants hired a family member; 15% hired a friend, neighbor, or fellow church member. Two percent hired someone recommended by a family member or friend; two percent hired their former agency worker; and, two percent hired someone other than those cited above. Ninety-three percent of participants said that they would recommend self-direction to others. Four out of five participants said that the program has improved their lives. No participants said that they were worse off than before enrollment in the project (Mathematica - Arkansas).
The table below represents areas in which participants expressed improvements in their lives as a result of participation in the self-directed program.

<table>
<thead>
<tr>
<th>Improvement</th>
<th>Number Citing Improvement</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Improvements Pertaining to Care and Caregivers</strong></td>
<td></td>
</tr>
<tr>
<td>Monthly Budget Enables Client to:</td>
<td></td>
</tr>
<tr>
<td>Choose Caregivers</td>
<td>21</td>
</tr>
<tr>
<td>Obtain the right types of personal assistance or services</td>
<td>12</td>
</tr>
<tr>
<td>Obtain enough care or care at the right time</td>
<td>9</td>
</tr>
<tr>
<td>Compensate caregivers or enable them to leave other jobs</td>
<td>6</td>
</tr>
<tr>
<td>Have tasks performed to their specifications</td>
<td>5</td>
</tr>
<tr>
<td>Relieve family members</td>
<td>3</td>
</tr>
<tr>
<td>Non-specific reasons pertaining to caregivers</td>
<td>4</td>
</tr>
<tr>
<td><strong>Improvements Pertaining to Supplies and Modifications</strong></td>
<td></td>
</tr>
<tr>
<td>Budget Enables Client to Buy:</td>
<td></td>
</tr>
<tr>
<td>Medicine</td>
<td>13</td>
</tr>
<tr>
<td>Personal items related to personal care and health</td>
<td>11</td>
</tr>
<tr>
<td>Food or nutritional supplements</td>
<td>9</td>
</tr>
<tr>
<td>Medical equipment or supplies</td>
<td>9</td>
</tr>
<tr>
<td>Microwave oven</td>
<td>2</td>
</tr>
<tr>
<td>Other items related to personal assistance needs</td>
<td>13</td>
</tr>
<tr>
<td><strong>Attitudinal and Health-Related Improvements</strong></td>
<td></td>
</tr>
<tr>
<td>Client feels more independent, dignified or in control of care</td>
<td>14</td>
</tr>
<tr>
<td>Client worries less</td>
<td>3</td>
</tr>
<tr>
<td><strong>Financial Reasons</strong></td>
<td></td>
</tr>
<tr>
<td>Benefit enables client to pay bills/provides extra money</td>
<td>6</td>
</tr>
</tbody>
</table>

**Number of Clients** * 122


Note: This table is based upon open-ended responses that were coded postinterview. Although they were asked to provide the most important reason, some respondents gave more than all are represented here.

* The number of respondents who said the cash benefit had improved their quality of life.
New Jersey evaluated 1762 participants with 941 being elderly and 821 persons with a disability. Their project began in July, 2000. The design of their project is similar to Florida and Arkansas.

90% of New Jersey's participants used their budget to hire caregivers, 45% obtained or repaired equipment, 17% modified their homes. 85% said that they were largely satisfied with their lives; 64% of those satisfied stated that they were very satisfied. 90% said that they were very satisfied with their services. 86% said they would recommend the program to others. As with the other states, while participants were happy with the services they got, many said they were not receiving as much help as they needed. Unmet needs were identified as transportation, medication, routine health care personal care, or household activities. (Mathematica-New Jersey)

Overall, the early data suggests that participants in the Cash and Counseling project experienced greater satisfaction with their services and to date, there have been no major instances of fraud or abuse in any of the project states. Participants appear to be much better at spending Medicaid funds to meet their long term care needs than States are. All three states had to develop mechanisms to recover unspent funds. It is interesting to note that while two states allow participants to forgo a fiscal agent. However, once participants realize how complicated payroll taxes are, no participant has opted to receive their funds directly.
Under the self-directed model, consumers are often the employer of record for their service providers. As such, they recruit, hire, train, schedule, supervise and fire their employees. They negotiate salaries and may use their budget to provide benefits for their workers. They are allowed to use the services of a homemaker agency, but may also hire a friend, family member or neighbor to work for them. Participants may also have a representative of their choosing help them with these responsibilities.

While most self-directed programs provide the participant with training to support the client in the employer role, critics of self-direction cite the danger of exploitation, abuse or fraud. Well-designed programs have systems in place to avoid these pitfalls and help the participant succeed in self-direction. Careful monitoring helps assure that participants are using their funds responsibility to meet all their long term care needs. In New Jersey, for example, consultants are required to contact participants by telephone on a monthly basis and schedule a face-to-face meeting every three months. In addition to giving participants the support they need, the consultant performs a monitoring function as well (Bill Ditto interview).

Other states have developed electronic monitoring instruments that require employees to call in when they arrive at the participant’s home, select from a menu of services the participant has built into their spending plan, and call again to check out. These types of monitoring tools also serve a dual purpose in
that they are capable of generating electronic time sheets that go directly to the fiscal agent for payment (Bill Vass interview).

There is no evidence that self-directed models of service delivery are inherently riskier than professionally managed services. In fact, when experiences and outcomes were compared in self-directed and agency-based services, no significant differences were found in client outcomes in the areas of client safety and unmet needs. Clients in self-directed models who hired family members as their homemakers had better outcome measures related to safety and sense of security (Squillace 2002).

With freedom of choice comes responsibility. When participants receiving services and supports are involved as full partners in the operation and direction of services, they take on responsibility for the decisions they make. People can be held accountable to the extent they have the capacity to respond, act and understand the implications of their actions. States may assign the responsibility for assuring health and safety to participants in a self-directed program as long as participants have the support necessary to become informed about the implications of their decisions and answerable for the outcomes of those decisions. Many states do this by developing negotiated risk agreements. Under these agreements participants make informed decisions to accept the liability that is involved with being in charge of their own services and funds (Moseley 2001).

Such assignment of authority does not totally displace the state's responsibility to carry out its statutorily defined duties and responsibilities. The
state remains obliged to ensure the presence of a comprehensive, effectively working system that is able to respond to the needs of individuals requiring support. The development of an infrastructure of supports, including intermediary service organizations such as fiscal agents and counselors, can minimize concerns about misuse of funds or financial exploitation of vulnerable individuals while diminishing administrative responsibilities placed on self-directed participants (Squillace 2002).

Intermediary service organizations (ISOs) provide an array of fiscal and supportive services to the state, participants and to a limited extent, workers. They vary in their structure, the types of services provided, administrative costs and the nature of the employer/employee relationship. CMS has classified ISO services into two primary categories: Fiscal Management Services (Cash) and Supports Brokerage Services (Counseling). There also exist "spectrum" ISOs that provide a variety of fiscal management and supports brokerage services under one umbrella organization. These ISOs can be state entities, agencies, or individuals. In well-designed programs, participants can move within a continuum-they can use as much or as little support from ISOs as they need or want.

Fiscal intermediaries serve as fiscal conduits that disburse public funds to participants/representatives and perform other related duties. Fiscal intermediaries provide an array of fiscal and payroll-related services. While participants are the employers of record for their workers, the fiscal intermediary
agrees to accept legal responsibility for employment-related fiscal matters such as workers' compensation and payroll taxes.

Supports brokerages assist participants with training and teach them how to be successful at self-direction. Supports brokerage is a broadly defined service designed to enable participants to develop an effective person-centered plan, manage an individual budget, and locate, access and coordinate needed services. A supports broker acts on behalf of participants at their direction. They must understand and adhere to the philosophy of self-direction and have specific skills, not necessarily specific degrees or certification. Supports brokers do not provide support services directly, but teaches and supports the participant in self-direction. Typical functions of a supports brokerage include developing person-centered care plans, assisting with the development and updating of individual spending plans, assisting participants in securing needed services and monitoring service quality and participant satisfaction (Flanagan 2003).
Self-Direction in West Virginia

In recent years, West Virginia has taken action to promote self-directed personal assistance services. In 1999, the state legislature created the Ron Yost Personal Assistance Services (RYPAS) program. This program, administered by the Division of Rehabilitation Services, is designed to make personal assistance services available to people with disabilities who are not eligible for Medicaid or other funding. Participants in the RYPAS program are able to hire friends, family members, and others of their own choosing and are reimbursed for the hours of service received/provided. The RYPAS program provides technical assistance to help participants meet their obligations as employers of personal assistants. Participants in the program have expressed satisfaction with the ability to control their own services as well as frustration with the burdensome paperwork requirements of meeting their obligations as employers.

In 2001, the West Virginia Bureau of Senior Services (BoSS) offered persons receiving personal care services under the Medicaid State Plan the option of becoming their own case manager. Participants in this option have grown steadily from one to 55, with very few participants opting to return to traditional services. Participants have expressed that they are receiving the services they need and that they enjoy being able to coordinate directly with their personal care provider rather than communicate through a case manager.

In January, 2002, the National Association for State Units on Aging (NASUA) invited states to apply for participation in a three-year project called
Expanding Consumer Direction in Aging Services. NASUA wanted five states to participate the first year and then provide assistance to five more states to be added the second and third years, making a total of 15 states. The project provided modest financial support ($1500) to states to assess their current system's level of opportunity for self-direction and to explore ways to expand self-direction. While the financial support was minimal, the project gave states access to technical support from national leaders in self-direction.

The West Virginia Bureau of Senior Services (BoSS) applied and was accepted to the project in its first year. BoSS convened a stakeholder group of representatives from state agencies, disability and senior advocacy groups, providers and consumers. The stakeholder group consisted of representatives from AARP, BMS, The Statewide Independent Living Council, AARP, The Alzheimer's Association, providers, consumers and the WV Division of Behavioral Health, The Center for Excellence in Disabilities at West Virginia University (CED) and the WV Developmental Disabilities (DD) Council. These stakeholders met monthly to learn about self-direction and to provide input about the impact of such an option on the groups they represent. The group assisted BoSS staff in holding public forums around the state to receive public input.

Of this group, BMS, CED, Behavioral Health and DD Council representatives joined BoSS as part of an internal management team or core group. The team made the decision to take the project further and design an infrastructure of self-direction that could be used by all Medicaid home and
community based services as each of them reaches a point of readiness for self-direction. The team’s plan was that the A/D Waiver would be the target group for expansion and that the MR/DD Waiver would follow the A/D Waiver into self-direction within three years. The group has not been able to gain support from the administrators of the Personal Care program.

In October of 2002, the Center for Excellence in Disabilities at West Virginia University, in partnership with BMS and BoSS, received a Community-Integrated Personal Assistance Services and Supports (C-PASS) grant. The purpose of the C-PASS grant is to promote self-directed personal assistance services in West Virginia through demonstration, training, and technical assistance. Grant activities include plans for an 18-month pilot project similar to the Cash and Counseling model. However, the scope of the pilot project has been limited by political and fiscal constraints. The flexibility needed to implement self-directed personal assistance services may not be possible without an additional waiver, which state officials are not inclined to pursue. Many questions remain regarding implementation of the pilot project within the existing political and financial climate.

Current plans are to conduct a limited demonstration within the A/D Waiver (homemaker services). Initial plans for the pilot project are to include 250 participants in a control group and 250 participants in an experimental group. While still in the developmental stages, the following design elements are being considered:
Fiscal:

- Participants will have an individual budget based upon their assessment.
- The plan of care will become a resource management plan to be developed by the consumer with the support of a resource consultant who makes sure that the plan meets the needs of the participant within the parameters of the program. (Emphasis is on the participant doing plan for him or herself with support from the consultant.)
- Resource management plan will be approved by the participant and A/D Waiver staff.
- Participants may use their budget to purchase home modifications, assistive technology, or save funds toward these purchases as long as these items fall within the parameters of the program.
- Any modification in the resource management plan must be approved by both the participant and A/D Waiver staff.
- The fiscal intermediary will be responsible for all employment related fiscal matters such as payroll taxes and workers' compensation.
- The function of the fiscal intermediary is to pay invoices that the participant approves and forwards to them. They will have no voice in how funds are spent.
- Funds that are not spent or earmarked after six months go back to the program.
- Participants will be monitored by regular telephone calls and visits from their resource consultant.
Employment:

- Participants will be the employer of record for non-agency workers.
- Participants may choose agency services in which homemaker agencies who agree to cooperate will be the employer of record and the participant will be the manager of his/her workers.
- Participants may have, and are encouraged to have, multiple employees.
- Participants may combine non-agency workers and workers provided through an agency.
- Participants must have a viable backup plan that can involve agency services.

Liability/Quality Assurance:

- Participants will receive, and must sign a statement of rights and responsibilities which serves as an agreement between the state and the participant in which the participant assumes the responsibilities that come with his/her role as an employer.
- Any employee that performs tasks requiring training under the traditional model must receive that training.
- Employees who perform tasks such as shopping or housekeeping will be trained by the participant.
- Before receiving services, participants will receive training on recruitment, hiring, training and management of employees.
- A monitoring instrument such as Care Call is under consideration.
The management team needs to establish a statewide network of resource management consultants to support participants in self-direction. Because philosophy is as important as policy in self-directed services, the team believes that it is necessary to create a new provider group rather than allow existing providers of traditional services to step into this role. They are entrenched in the medical model in which providers control services. They also stand to gain more financially under the traditional model. Therefore, resource management consulting will not be performed by existing providers or by those having any affiliation with present providers of traditional services. Extensive provider training will need to be done to ensure that resource management consultants understand the philosophy of person-centered planning and self-direction.

It is not as important that the fiscal intermediary be initiated to the philosophy because the intent of the FI is to assume the fiscal-related responsibilities that participants have when they become employers. States that have experience with fiscal intermediaries have found that it is better to have one FI rather than multiples because it is much easier to oversee.

The management team is considering the pros and cons of having one FI rather than several. Certainly from a management standpoint it is preferable to have only one entity to deal with but this would require that BoSS go through the State’s purchasing process to put out a Request for Proposals (RFP). This process is cumbersome and can take months to complete. Should the team decide to establish the FI in this manner it would be considered an administrative function rather than a service. This is problematic because the federal Medicaid
agency will match service dollars on a three for one basis whereas the match on administrative dollars is only one on one.

The management team anticipates a good deal of resistance from traditional providers and expects that they will try to appeal to the Legislature to stop the move to self-direction. The team must be ready to demonstrate that self-direction is good for participants and that it is a national trend which cannot be ignored.

Once the pilot is over, the self-directed program will become an option under the A/D Waiver. A/D Waiver participants will be allowed to choose between traditional services and self-direction. They will also be able to move between the two models with relative ease as their needs and situations change.

The management team intends to build an infrastructure for self-direction that will serve the needs of the MR/DD Waiver as well as the Personal Care program when these programs become ready to move toward self-direction for their participants. This is important not only from a philosophical standpoint, but for a practical one as well. Volume is important to the FI and Resource Consultant and will serve to keep costs low. Low administrative costs mean that participants have bigger monthly budgets to use toward meeting their long-term care needs.

It is part of the long term goal of the team to assist these other programs in transitioning to self-direction. As previously discussed, the MR/DD Waiver staff has been involved with the original NASUA self-direction project and is very interested in following the A/D Waiver’s lead toward that goal.
In the summer of 2003, CMS and the Robert Wood Johnson Foundation both announced the availability of separate, second rounds of funding to states to expand the Cash and Counseling demonstration. BoSS and BMS staff considered these opportunities and decided to pursue Robert Wood Johnson funding rather than CMS funding because good relationships had already been established between their agencies and the evaluators of that program. The Robert Wood Johnson grant also provides technical assistance from experts who most knowledgeable about designing and implementing successful self-directed programs. Preliminary work is underway to prepare to develop and submit a grant proposal that, if funded, will assist in designing a program, developing infrastructure and doing training geared toward policymakers, providers and participants. Because of the groundwork already established by the NASUA project and other initiatives, West Virginia is in an ideal position to receive the funding. This will greatly expand opportunities for self-directed personal assistance services.
Self-Direction and the Big Picture

When developing public policy, sometimes it seems that one finds more questions than answers. The management team must not only develop policy, they must be watchful for unintended consequences and larger political, economic and social implications.

One such political implication is the fine balance between individual rights and the state’s responsibility. Elected officials fight for maximum choice and freedoms for their constituents, but when public dollars are involved they are quick to bring up 1) issues of accountability of public dollars, 2) balance between safety and freedom for low income individuals, and 3) fraud and abuse.

The concepts of autonomy and the freedom to control one’s own destiny are intricately interwoven into the fabric of the American ideal. But people who are aged or who have physical disabilities, particularly those who are also poor, oftentimes find their lives being dictated by the providers of the services they need to make it through the day. When addressing this issue, policymakers would be foolish not to agree that people who have disabilities should enjoy the same right to autonomy as the non-disabled. But these same policymakers must face the political repercussions should the public decide that self-direction is not a responsible use of public funds. There is this pervasive notion that if you give poor people control over the public funds that pay for their services, they will either use the funds fraudulently, or at the very least, make poor decisions about the use of the funds.
What’s missing in this misconception is that fact that people who rely on those services and supports realize just how valuable the services are to them. Who could possibly value the services more than a person who wouldn’t be able to get out of bed in the morning without them? Participants in the three Independence Plus states have proven that they can make good use of their funds. Furthermore, the use of well-developed negotiated risk agreements can alleviate the fears of policymakers in terms of liability issues.

An important economic and social implication of self-direction is the impact that the principles of self-direction have upon the family. If a participant is allowed to pay family members to provide services, how does this change the family relationship? Should we even allow people to be paid for caring for someone in their family? Are participants likely to continue to pay for the services of a family member even if the services are inadequately delivered or not delivered at all in order to maintain the income of the paid family caregiver? While the Independence Plus demonstration projects have reported no major problems in regard to these issues, the management team in West Virginia will be closely watching the family relationships of the participants in their demonstration.

There are class issues that must be addressed as well. For example, as with the mythological “welfare queen” of the Ronald Reagan era, many people believe that being poor means that the individual is a poor decision-maker or just wants to “rip off the system”. Poor people, aged people and people with
disabilities are viewed by the larger society as not as capable or otherwise “less than” the rest of society.

Another thing that must be considered is the right of an individual to take reasonable risks and make mistakes. People learn from their mistakes. Nobody worries about much about the risks that are taken or the mistakes that are made by those in our society who are not disabled or who don’t use public funds for personal assistances services and supports. How far must we go to “protect” people with disabilities? Should a person who uses a wheelchair be banned from checking into a hotel room that is located above the ground floor? Or should we trust that person to weigh the risk of not being able to use the elevator in the event of a fire against the pleasure of the view from the twenty-fifth floor?
Lessons Learned

Through participation in the NASUA project, BoSS learned that traditional service providers are resistant to the concept of self-direction because they stand to lose control and revenue when service recipients directly hire their own personal assistants. Providers also expressed concern regarding the safety of participants in self-directed service models. West Virginia has a strong and politically active provider network. Two providers are state legislators and one Senator is employed by a major provider. The agency must be prepared to demonstrate that self-direction is good for participants, that it is not inherently riskier than services received through traditional means, and self-direction is a national trend that must be addressed.

Perhaps the most valuable lesson learned is that when undertaking such innovative projects, technical assistance is just as important as financial support. The NASUA project provided only $1200 in funding, but gave the management team access to invaluable expertise in the people who have already pioneered self-direction on both state and federal levels. By building upon the work that has already been done and borrowing from prior experience, the team can design a program that will work for West Virginia without having to repeat the mistakes of our predecessors.
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Education:

Marshall University Graduate School  
Department of Sociology. August 1999 – Present.  
Masters Degree in Sociology, 2003  

West Virginia State College  
Bachelor of Arts in Political Science and Sociology.  
1999  

Garnet Career Center  
Master Certification in Accounting/Data Processing and Clerical/Word Processing, 1992

Professional Experience:  
West Virginia Bureau of Senior Services:  
Senior Services Specialist with Medicaid Aged/Disabled Waiver, January, 2000 to present.  

• Program Director, Community Living Exchange Program: Manage federally funded grant program to establish resource centers to serve as single points of entry into long term care services in West Virginia for the aged and people with disabilities.  

• Project Director, Medicaid Aged/Disabled Waiver Self-Directed Case Management Program: Coordinate self-directed case management programs under Medicaid Aged/Disabled Waiver program, research and pursue systems change initiatives specifically targeted to moving the A/D Waiver toward the principles of the Olmstead Decision and person-centeredness, develop policy and procedures for training and implementation of self-direction within A/D Waiver.  

• Research: Compile and analyze data specific to West Virginia’s senior and disabled population.  

• Legislative: Prepare data for use during the legislative session. Track national and state legislation pertaining to issues of importance to seniors and people with disabilities.  

• Other: Bureau representative for Statewide Independent Living Council (SILC), WV Real Choice Partnership, M-WIN (Medicaid Buy-In) Advisory Board, State Health Strategic Planning
Group Advisory Council, C-PASS Grant Advisory Board and WV State Health Planning Advisory Council.

**Legislative Internship:** College and University Systems
- Tracked legislation during 1998 legislative session
- Attended committee meetings
- Submitted daily reports to central office
- Provided political analysis of proposed legislation

**West Virginia State College:** College Work Study. 1995-1997
- Kanawha County Public Library Systems: Assisted patrons, maintained series books, performed general library duties
- Shawnee Community Education Center: Daycare worker

- Accounting: Used MAS 90 software to perform all accounting functions, prepared financial statements and annual reports, managed investment account.
- Membership services: Administered group life insurance policy, served as staff support for various committees, compiled newsletter and legislative updates.
- Meeting planning: Assisted in the planning and execution of seminars and conventions.

**Related Experience:**

**International Studies Initiative:** Participated in the founding of a South African Studies Program, 1998-1999
- Travel: Organized and participated in a study abroad trip to South Africa
- Fundraising:Led campaign that raised $21,000 in three months.
- Promotion: Designed brochures and promotional materials to publicize the trip and aid in fundraising.
- Program development: Established foundation for exchange program between WVSC and University of Cape Town.

**Graphic and Web Design:** Designed websites and brochures to promote academic departments at West Virginia State College, personal travel.
Honors and Activities:


Dean’s List, West Virginia State College: 1996-1999

Sociology Newsletter: Editor, 1999

Sociology Department Student of the Year: 1999

Alpha Kappa Delta International Honor Society for Sociology: Secretary, 1997; Treasurer, 1998; President, 1999

Phi Sigma Alpha National Honor Society for Political Science: Inducted in 1998

Alpha Delta Mu National Honor Society: Inducted in 1998

Alpha Lambda Delta Honor Society for Business: Inducted in 1992

Daniel L. Ferguson Sociological Society: Secretary, 1997; Treasurer, 1998; President, 1999

Kanawha Valley Alumni Chapter, West Virginia State College: Secretary, 2000 to Present