December 2009

# Striking a Balance:

## *Recommendations to Improve Indiana's Long-Term Care System*

**Prepared for AARP Indiana**

Roger Auerbach
**Auerbach Consulting, Inc.**
*Maximizing independence, quality and resources in long-term services.*

Copyright © 2010 AARP. May be copied only for noncommercial purposes and with attribution. Permission required for all other purposes.

# CONTENTS

# Striking a Balance:
## *Recommendations to Improve Indiana's Long-Term Care System*

AARP Indiana commissioned a study examining the status of Indiana's long-term care (LTC) system for older adults and adults with physical disabilities, analyzing "best practices" from other states' LTC systems and recommending actions to improve Indiana's system.

Over the past few years, AARP has conducted opinion research of its members and others in a variety of states and the findings are very similar regardless of the state: older adults want to be able to have a choice of what type of LTC services they receive and where those services are delivered. A huge majority wants to receive services in their own homes or in a residential setting such as an assisted living residence; very few want to receive services in a nursing facility. A recent AARP survey of Indiana AARP members and the general population confirmed that having choices of LTC services and settings should be Indiana's top or high priority. Eighty-four percent (84%) said that if they or a family member needed LTC services, they would prefer to receive those services at home or in a home-like setting such as an assisted living facility; only 2% said they would prefer care in a nursing facility.

## Indiana's Current System and Opportunities for Change

The State of Indiana offers a variety of long-term services and supports aimed at keeping older adults healthy and independent. In addition to vital supports supplied by family, friends and community organizations, Indiana government has a wide range of programs that can support older adults needing long-term care services. However, Indiana spends a disproportionate percentage of its public LTC funds on nursing facility care (95% of its Medicaid LTC spending in Federal Fiscal Year 2007) with Tennessee being the only state that spent a smaller percentage on its Medicaid home and community-based services (HCBS) for older adults and adults with physical disabilities. Although Indiana has made good progress since 2003 with the passage and implementation of Senate Enrolled Act (SEA) 493, it still has a long way to go to achieve a system that provides the timely, affordable and quality LTC services that its residents prefer.

## Access to Long-Term Services and Supports

### *Information and Assistance*

Individuals and families need to have understandable, comprehensive, unbiased information about the wide range of long-term care services generally available in most areas across the United States. They need to know where to get this information and very often need the information on an urgent basis. For a state to meet the long-term care needs of its residents, it needs not only to supply this information in a helpful and supportive manner, but also ensure that people know that it is available and how to access it.

The Indiana Division of Aging (IDOA) and each area agency on aging (AAA) provide such information through web sites and toll-free telephone numbers. Indiana has developed a statewide network of Aging and Disability Resource Centers (ADRCs) in its sixteen (16) AAAs that allows all people to get unbiased information about services choices and help with accessing those services. Since the AAAs assess the need for services for a variety of both state and federally-funded long-term care programs, the ADRCs, with adequate resources, should be able to assist people with both counseling about available options and streamlined access to services. However, determining program eligibility and starting needed services does not always begin quickly.

### *Counseling*

Giving people comprehensive and helpful information at crucial times should be a goal for all state long-term care (LTC) systems. Most often, the need for information and counseling happens immediately preceding a hospital discharge or after discharge when an individual's condition is more stable. This is the point when people need to know where to go for unbiased information and have someone knowledgeable and available to help them explore available options. LTC options counseling is crucial and should be available in people's homes, hospitals and nursing facilities. It should include an assessment of people's capacities, where they may need help and how they can access that help. Where needed, it can also assist in making sure that successful contact is made with appropriate service providers.

Indiana's ADRCs are designed to provide an options counseling function for all who need it. However, this crucial function is available only to those who know about it. There is no organized statewide attempt to reach people at the time of hospital discharge or soon after a nursing home admission, two crucial times when options counseling is needed. While the required nursing home pre-admission screening process provides a mechanism for options counseling, funding is inadequate to devote proper time and attention to such counseling. Targeted options counseling for individuals and families in nursing homes and hospitals should be implemented statewide to give people the vital information they need at a crucial time.

### *Program Eligibility*

Individuals and families requiring long-term services and supports need to know, on a timely basis, about programs and services available to them and whether they will be eligible. Unless people have that information, they cannot make an informed choice about what services and settings are the most appropriate to meet their needs. People often move to nursing facilities because they are unaware of the alternatives, cannot afford those alternatives without public financing or cannot piece together disjointed community services into a coherent plan that could help them remain at home.

Local AAAs can determine eligibility for and authorize both federally-funded Older Americans Act (OAA) and Social Services Block Grant services, as well as state-funded CHOICE services. They also perform assessments for *medical* eligibility for the Medicaid Aged and Disabled Waiver. However, *financial* eligibility for the Waiver is determined by the Division of Family Resources and people must wait a significant time before they are informed of their eligibility for Medicaid Waiver services. In a recent letter, the Division of Aging said it took just under 55 days on average for the AAAs to assess need and develop a care plan and for the state to approve that

plan. This is far better than the over 200 days average it took in June 2008, but still leaves people not knowing whether they will have access to these vital services. Of course, there are other factors that may also create delays in determining *financial* eligibility, also lengthening the total eligibility process. While these timeframes could still likely be shortened with additional efficiencies and resources, Indiana should consider allowing the AAAs to make "presumptive" eligibility decisions, as some other states have done, that would allow services to begin very quickly.

### *Opportunities to Improve Access*

There are many positive actions Indiana has taken to improve access to its long-term services and supports system and specifically to its home and community-based services (HCBS) over the last number of years. However, despite this progress, Indiana still lags behind most states in the resources it dedicates to HCBS. A number of key actions need to be taken to dramatically improve this part of Indiana's system.

**1. Provide more base funding for the ADRCs**

While it is very positive that the State has made a commitment to establish ADRCs statewide, ADRCs need adequate and dedicated funding to properly serve an ever-increasing work load of people needing assistance with long-term care services. The additional funding will especially be necessary with continuing outreach efforts to give people vital information and counseling at crucial times. The Division of Aging should also be clear about the outcomes it wants the ADRCs to achieve. The Division has done a good job reporting data on timeliness of Medicaid assessments and costs of care plans. It should also collect and publicly report data in other areas of focus that relate to consumer satisfaction and provider quality.

**2. Publicize and promote the ADRCs through a statewide media campaign and regional outreach**

Hoosiers need to know about this valuable resource and also need regular reminders about the need to plan for their long-term care needs and those of their families. The Division of Aging should develop and implement a statewide publicity campaign to publicize and promote the ADRCs, the statewide toll-free telephone number and the statewide web site, which needs to be operational as soon as possible. The Division should also require the ADRCs to submit annual regional outreach plans and the Division should fund specific budgets to implement those plans.

**3. Develop and implement a Targeted Options Counseling Program for people recently admitted to nursing facilities**

While it is very positive that the ADRCs have developed and implemented options counseling programs, targeted counseling needs to be accomplished for those recently admitted to nursing facilities. This is the time when individuals and families need to know and understand all the options that are available and start planning for future needs. Many people understand they are only in the facility for short-term rehabilitation and then they will return home. Others however may not know that their need for services could be met in their homes and these individuals must be made aware of those options. This is why there must be a specific effort to counsel people at this crucial time.

**4. Develop and Implement a Targeted Options Counseling Program for people being discharged from a hospital to a nursing facility**

The Indianapolis area AAA, with Administration on Aging funding and in partnership with the Division of Aging and Wishard Health Services, is developing and implementing a pilot program to work with hospital discharge planners and others to use interventions to avoid unnecessary long-term care placements and hospital readmissions. This project should be supported and carefully evaluated for replication. During this project, there should be a priority focus on appropriate timing for an initial counseling session about long-term care options.

**5. Implement presumptive eligibility determination procedures for the Medicaid Waiver**

The Division of Aging has placed great focus on making the Medicaid Waiver eligibility process more efficient. Both the Division and the AAAs have reduced the time needed to make such a determination. However, it still takes a long time for individuals and families to know whether they will be eligible for these services. The AAAs should be given the responsibility for making presumptive eligibility decisions, with appropriate safeguards, and immediately authorizing the start of Waiver services to people who are "at risk of institutionalization." The Division could choose to narrowly define the circumstances where this presumptive eligibility could be allowed or could pilot presumptive eligibility in a few AAAs before statewide implementation. The Division could also require, as some states have, a statement by the individual and family that attests to their income and assets and notifies them that they could be liable for those service costs if found ineligible for Medicaid. As in other states, Indiana would proceed with a formal eligibility determination for the individual and would not be able to receive federal matching funds for people ultimately not found eligible. As detailed below, states using presumptive eligibility have found their error rates to be extremely small while cost-savings are significant by avoiding unnecessary nursing facility care.

***– See page 25 for Successful State Models for Improving Access –***

## Financing Long-Term Services and Supports

### *State Budgeting*

Many individuals and families have no real choice about where they receive needed long-term services and supports unless timely decisions are made about the availability of public financing. If people decide that they want to receive services in their own home, arranging for those services should proceed efficiently without professionals wondering if there are enough dollars in the home-delivered services budget to support that choice. A number of states have adopted "unified" or "global" budgets where both institutional and home and community-based services (HCBS) are combined in one budget and managed by one entity so that the question is whether there is money in the entire long-term care budget rather than whether there is enough money in any one specific line item.

Indiana has different budget lines for nursing facility services, waiver services, Medicaid State Plan services, and non-Medicaid services. However, these budgets are all tracked and managed by the Indiana Division of Aging (IDOA) and the IDOA produces financial reviews on a regular basis, keeping all stakeholders aware of budget issues.

Separate program budgeting is a challenge, however, at the local level where AAAs are trying to provide needed services across a variety of federal, state, and federal-state programs. Although it is very positive that the AAAs perform nursing facility pre-admission screening and make the initial level-of-care determination for Medicaid long-term care eligibility, the Division of Aging has been very clear that it wants Medicaid dollars utilized before state-only funding. While not surprising that the state would want to maximize federal funding, people needing care quite often need services prior to finding out whether they qualify for Medicaid. The AAAs, working directly with individuals and families, are in the best position to know which programs offer the best and most efficient services. The state should allow the AAAs to have maximum flexibility in arranging HCBS across various programs and funding streams. Indiana must also establish a clear policy that allows use of the state CHOICE program to fund services while Medicaid eligibility is being determined, and allow for a presumptive Medicaid eligibility determination.

### *Managed Care*

Some states have chosen to adopt a managed care approach to long-term care service delivery. Most have chosen to contract with organizations to manage all or part of the Medicaid long-term care (LTC) benefit and some have worked to have the same entity manage both the primary and acute care Medicaid and Medicare benefit. The reasons for implementing these programs have been both for improved care delivery and cost savings. Although most of the managed LTC programs are still relatively small, there are a number of them that have grown enough to represent a large percentage of that state's population receiving Medicaid LTC benefits.

Indiana has not initiated any managed LTC programs. However, with the AAAs having such broad responsibility for developing care plans and contracting for and managing services, the state does have the basis to effectively expand both the authority and accountability of the AAAs for LTC management. For example, the Division of Aging could give each AAA a yearly budget for all long-term care enrollees in their region and set both financial and program outcomes in utilizing that funding. It could give incentives for exceeding financial and program goals such as keeping people healthy for as long as possible and avoiding unnecessary hospitalizations and nursing facility admissions. While this approach would not necessarily follow most of the other state managed LTC programs, Wisconsin did use its established local networks as a basis to implement its managed LTC program, FamilyCare.

### *Individualized Budgets*

Many states have adopted systems of individualized budgets where Medicaid LTC enrollees have control over a specified amount of money allocated for their needs. Adequate safeguards have been adopted to ensure financial integrity and the health and well-being of the individuals in the programs. For many years, the Centers for Medicare and Medicaid Services (CMS) has facilitated the adoption of individualized budgeting and consumer self-direction of services in Medicaid waivers. Although it clearly still requires a good deal of work by a state to design and implement an individualized program, it is not difficult to obtain CMS approval.

Indiana offers a self-directed attendant care option for both its Aging and Disabled Waiver and its CHOICE program. In each of these programs, individuals receiving services can choose an attendant and direct their own care. A fiscal intermediary is hired to pay the personal attendants, file tax and labor reports and provide program participants with reports on how authorized units of

service have been spent and the amount of taxes paid. However, program participants do not have actual budgets of their own and the flexibility to decide whether to spend resources on other items they may need. This type of arrangement, prevalent in many states, allows individuals more independence to control their services within a fixed budget. In addition, Indiana's program is relatively small given the number of people receiving Medicaid waiver and CHOICE services. There is almost no information about the details of this program available on the Department of Aging web site.

### *Opportunities to Improve Indiana's Financing of the LTC System*

Indiana has consolidated the management of its long-term care programs for older adults and adults with physical disabilities within its Division of Aging. The Division and its stakeholders are able to analyze trends and measure the impact of changes to the system. However, at the local level where the AAAs are working to meet individual care needs, there is a lack of flexibility to manage funding across programs that could delay getting the right services to people at the right time. In addition, there are a number of actions Indiana could pursue to make self-directed care more attractive to a larger group of individuals and families. Finally, public funds are not limitless and the state needs to develop an ongoing campaign to educate its residents, beginning in secondary school, that everyone will likely need long-term care in the future, and that people must plan for how they will pay for that care. Below are some actions that can improve the system.

**1. The Division of Aging should give more flexibility to the AAAs to manage the LTC programs at the local level, with appropriate program rules and performance standards.**

Currently, the ADRCs do a needs assessment for people seeking LTC services. The AAAs then begin an eligibility determination process for those who appear to qualify for public support. The result is that a person may qualify for a number of programs and services. Questions then arise about which program should be accessed to serve their needs. Once a person is assigned to a specific program, there is only one defined set of services and providers to meet their needs. Although it is important that services be allocated to specific budgets, systems should be developed to give more flexibility to meet people's needs across all programs for which they are eligible. For better customer service and improved outcomes, the Division should work with the AAAs to design a more flexible local system, which could include a single allocation for all LTC enrollees, that meets defined standards and outcomes.

**2. Indiana should make it clear that CHOICE funds are permitted to be utilized pending Medicaid eligibility.**

The Division of Aging has been very clear that it wants the AAAs to utilize federal funds before using the state-funded CHOICE program and has made it a requirement that people cannot receive CHOICE services unless they first apply for Medicaid. While it is understandable why a state may decide to maximize a federally-financed program, it needs to use its state funds to ensure that people can receive appropriate HCBS to avoid unnecessary institutionalization or a decline in their health condition. Since it can take months for Medicaid Waiver approval, people needing services and public support should be able to access needed CHOICE services in the interim. State policy must be clear that this is an appropriate use of state funds.

**3. The Self-Directed Attendant Care program should be enhanced to allow spouses and parents to serve as caregivers, with defined limits, provide people with individualized budgets, and deliver education and training programs for participants and caregivers.**

While it is very positive that Indiana has established a self-directed attendant care program, it should promote its usage by establishing individualized budgets for people to manage and allowing a broader definition of who can be a caregiver. Most states that have established self-directed programs in recent years have utilized a model of individualized budgets based on assessment of need. The enrollees manage that budget with the assistance of a fiscal intermediary. Indiana already has contracted for fiscal intermediary services and this would not be difficult or expensive to design and implement. States have also delegated authority and responsibility to enrollees to choose their own care providers, including spouses and parents. Indiana could allow for these additional categories of caregivers under limited circumstances and where there is a shortage of qualified in-home workers. In addition, participants and caregivers in these programs need education and training in the principles of self-direction and how this program could benefit them. The results for these programs have demonstrated at least cost neutrality, satisfactory quality and high consumer satisfaction.

**4. Indiana should develop and implement a LTC educational campaign targeted to all residents, beginning at the secondary school level and focused on younger working-age adults, that encourages planning for and financing their LTC needs**.

This important educational campaign would focus on making people aware of their potential need for long-term care and encourage them to make a plan for how to pay for that care. One state entity should be designated to coordinate this effort. It would certainly involve the education system and also the insurance department, as facilitating the purchase of LTC insurance should be part of this campaign. Building on the work done with the Indiana Long Term Care Partnership Program, this is a long-term effort where Indiana could demonstrate its leadership.

***– See page 33 for Successful State Models for Improved Financing –***

## Providing Needed LTC Services and Supports

Services are a vital component in any balanced long-term care (LTC) system. There must be a sufficient variety of available services offered and enough providers to deliver those services. In analyzing service adequacy, it is important to look at both publicly-funded services and privately-financed services.

Indiana has a broad array of services available under its Medicaid Aged and Disabled Waiver, the federally-funded Social Services Block Grant (SSBG), the federally-funded Older Americans Act and its state-funded CHOICE (Community and Home Options to Institutional Care for the Elderly and Disabled) program. However, it should be noted that there continues to be a significant waiting list for the CHOICE program and as of December 2009, there is now a waiting list for the Aged and Disabled Waiver.

### *Informal Caregivers*

When discussing service providers, one should really start with the "informal" caregiver. This term usually refers to unpaid individuals such as family members, friends and neighbors who pro-

vide care and can live with the person cared for or live separately. There have been many studies over the past number of years which estimate both the number and economic value of family caregivers. AARP research estimates that Indiana had an estimated 1.1 million family caregivers at some time during 2007 at a total economic value of $7.8 billion.

Most caregivers are employed and many provide care for many years. Not surprisingly, there are numerous studies that demonstrate the impact on caregivers' employment status and physical, mental and emotional health. Approximately two-thirds of working caregivers caring for someone over 65 reported having to rearrange work schedules, decrease their hours or take unpaid leave in order to meet caregiving responsibilities. Caregivers may also have an increased risk of cardiovascular disease among other adverse health outcomes and 40% of caregivers caring for people with dementia report depressive disorders.

It is vital for states to develop ways to support this valuable and much-needed caregiving resource. In Indiana, money is used for counseling support groups to assist caregivers in understanding issues that arise in the areas of health, nutrition, financial literacy, decision-making and problem-solving, and training and education that allows them to provide better care. There is also money for respite (relief) care, home modifications, assistive technologies, emergency response systems, and incontinence supplies.

Many state Medicaid programs are now also compensating family members for providing HCBS. They are utilizing both their Medicaid waivers and their "individualized budget" programs to accomplish this. This has proven a viable method for a number of states to increase the number of reliable in-home caregivers. In Indiana, individuals receiving services under the Medicaid Waiver or the CHOICE program may choose to participate in a Self-Directed Attendant Care program where they have the right to choose their own attendants including family members, but not spouses or parents and do not control an individual budget.

It is difficult to assess whether Indiana has an adequate supply of providers of all types of services. Provider supply was not an issue noted as problematic by Indiana state and local officials or consumer advocates. However, one can assume that there are provider supply issues for certain services in specific areas of the state due to a variety of pay rates and other issues. However, with the overall population aging and the demand for HCBS growing, provider supply is an issue worthy of additional focus in the near term.

### *Workforce Initiatives*

The strategies employed by states to ensure an adequate supply of trained workers are diverse, but can be grouped into broad areas: improving wages and benefits; improving the work environment; reforming the training and credentialing systems; and engaging the public workforce and education systems in recruitment and training. Indiana does not appear to have a comprehensive workforce strategy to support the LTC needs of older adults and adults with physical disabilities.

### *Housing*

Housing is a serious issue for states that seek a balanced LTC system for a variety of reasons. Many individuals who need care and want to remain at home often need their home modified after a fall, stroke or progressive illness, but either do not have the resources to make these modifications or cannot get permission from a landlord to do so. In Indiana, the Medicaid Aged and Disabled Waiver will pay for environmental modifications if necessary to ensure the health, welfare and safety

of the individual and without which the individual would require institutionalization. Maintenance is limited to $500 a year and there is a $15,000 lifetime cap on these modifications. The CHOICE program has a similar benefit without a lifetime cap, with similar requirements to avoid institutionalization, and will finance modifications in rental homes or apartments with permission of the landlord.

Many state Medicaid programs also pay for "housing with services" programs such as assisted living and adult foster care. While states vary in how they define these services and what they will pay for, they are all similar in that they have a community-based group housing arrangement where long-term services and supports are delivered to those who need them. Indiana's Aged and Disabled Waiver covers both adult foster care and assisted living services.

Additionally, state services programs have been working with their state housing counterparts to address these issues in a variety of ways including new construction, rehabilitation, and rent subsidies with preferences for older adults and individuals with disabilities. The Indiana Housing and Community Development Authority, in partnership with the Indiana Division of Aging, implemented a new program called Home Again targeted to people moving out of institutions which makes existing subsidized housing units accessible and even more affordable. This is a good example of a state partnership which should become the basis for other affordable, accessible housing development targeted to older adults and individuals with disabilities.

### *Opportunities to Improve Indiana's LTC Services and Supports System*

**1. Indiana should develop and implement a variety of methods to encourage and sustain family caregivers such as providing more opportunities for respite care, education, training and other forms of health and emotional support.**

Indiana has made progress in expanding the amount and type of HCBS. However, the state needs to put caregiver support higher on its priority list. No one denies how vital families are in supporting their loved ones who need long-term services and supports. One of the major reasons individuals are forced to leave their homes to get needed services is because there is not sufficient family support. Those family caregivers need to be encouraged to keep supporting their loved ones and know that their unpaid work is being acknowledged and supported. Education, training and time off from caregiving are all proven methods to accomplish this goal. A number of localities across the country are also focusing on the health and well-being of the caregiver. Indiana should assess caregiver needs and develop programs to address them.

**2. Indiana should designate a lead entity to take responsibility for recruiting and training needed LTC workers. AAAs should be charged with identifying gaps in services and be responsible for provider recruitment and retention, but the state must take responsibility to develop a sufficient, quality workforce to meet the state's LTC needs now and in the future.**

Although worker and provider shortages were not major issues identified in this study, there was no clear understanding what entity had responsibility for provider recruitment and retention. While some acknowledged that identifying gaps in services was an AAA responsibility, there was no clear authority or responsibility given for local provider recruitment and retention. The AAAs are in the best position to know about gaps and shortages and, with appropriate resources, should be clearly given responsibility for provider sufficiency. However, the state must have a coordinated LTC workforce strategy, espe-

cially in the recruitment and training of in-home workers, given projected demographic changes. Workforce and education entities must work with human services entities to develop and implement that strategy.

**3. Indiana must focus its workforce strategy on recruiting and retaining in-home care providers to meet the need for services where people want them. This must include a focus on increased pay and benefits as well as education and training.**

The Indiana Division of Disability and Rehabilitative Services (DDARS) has developed and implemented a solid program to develop the direct support professional workforce that serves its clients and others. While there was no evaluative work discovered on the outcomes of this program, this is exactly the type of program that needs to be considered for other parts of the workforce. Consumers want quality services and are willing to pay a reasonable amount for those services. A trained and well-compensated in-home workforce not only supports the individual needing care at home, but also supports family caregiving. Developing and implementing a thoughtful strategy is vital for the sustainability of a LTC system into the future.

**4. Affordable, accessible housing for individuals with disabilities and those needing long-term services and supports must be a priority for the state. A lead entity must be designated and given the responsibility of ensuring that a specific number of units are developed.**

The Indiana Housing and Community Development Authority, in partnership with the Division of Aging, appears to have developed a solid program of subsidized financing and accessibility modification through its Home Again program. This appears to be a good concept which is being implemented, but much more needs to be done. Whether new units are developed and/or existing ones are modified, there needs to be a coordinated focus on "housing with services" models. There are many ways to develop these models, but they all begin with affordable, accessible housing where people can receive the care services they need. Assisted living is just one model. Indiana needs to research and implement models that work for its state and give one entity responsibility for design and development.

***– See page 43 for Successful State Models for Improving Needed Services –***

## Ensuring Quality LTC Services

Everyone wants to have quality LTC services. However, there are no absolute standards by which all agree on what constitutes quality. The Centers for Medicare and Medicaid Services (CMS) has been focused on quality in nursing homes for decades and has more recently been focused on quality in HCBS. There are clearly-defined federal laws and regulations that states enforce for nursing home quality. However, states continue to have great latitude to design their quality assurance (QA) program for HCBS. CMS has adopted an HCBS "quality framework" for states to follow for the quality management of its quality assurance and improvement program. It also requires that a quality management strategy be defined in a Waiver application.

In reviewing Indiana's Aged and Disabled Waiver application, Indiana has developed a credible quality management strategy, on paper, for the operation of its Waiver program. It has identified areas that it will monitor, how it will monitor and methods it will utilize to remediate issues. It

has assigned specific roles and responsibilities for the Office of Medicaid Policy and Planning, the Division of Aging, the AAAs and its outside contractors. It is less clear how the system improvement process will work, but there are entities assigned to review and analyze data. One could assume that improvements would be made based on those evaluations.

The Division recently reported that it had begun field testing a plan of care review and a consumer outcomes and satisfaction survey for the Aged and Disabled Waiver. These activities should reveal data about whether individuals' plans of care are meeting their identified needs and whether program participants are satisfied with their services. This is part of the QA management strategy outlined in the waiver. In addition, the Division will begin surveying non-licensed providers on a random basis that have not been surveyed in the last three years. Again, this is part of the QA strategy outlined in the waiver.

### *Nursing Facility Quality*

While all states take responsibility, and are funded, to monitor and enforce federal law and regulation applicable to nursing facility quality, it should be noted that Indiana is one of a few, but growing number of states that have worked to structure their payment system to account for quality. The current reimbursement system, which is in the process of being changed, rewards all facilities based on quality from $1.50-$3.00 per resident day. The proposed system would eliminate a quality payment for those facilities scoring in the bottom quartile and would increase the payment in the top quartile from $3.00 to $5.75. This would clearly make a bigger distinction in paying for quality. The proposed new system would also eliminate the "profit add-on" for facilities in the bottom quartile, maintain the benefit for the top quartile and reward others on a graduated basis. Indiana is planning for further revision to take effect in 2011 based on a series of measures modeled on Minnesota and Iowa's current programs. This will continue its strategy to clarify its expectations for nursing facility quality.

### *Opportunities to Improve the Quality of Indiana's LTC System*

**1. Indiana must define specific measures of HCBS quality related to the health, wellness and satisfaction of the program participant.**

Indiana has done good work defining a quality assurance management strategy for participants in its Medicaid Waiver program. It clearly defines expectations and roles and responsibilities and is implementing a monitoring system that could ensure quality systems. However, it needs to adopt specific quality measures as they relate to the program participant. First, these need to include standards for consumer satisfaction, especially as it relates to supporting the independence of the individual and the dignity and respect each deserves in how services are delivered. Additionally, certain measures such as avoidable hospitalizations and nursing facility admissions, and emergency room visits ought to be considered.

**2. The Division of Aging should ensure that appropriate consumer stakeholders are involved in designing the quality measures and quality incentive program utilized to reward nursing facility quality.**

State and local consumer advocacy organizations, AAAs, LTC ombudsman program staff and other consumer advocates have direct experience in assessing quality and advocating for improvements in nursing home care. As such, they should be included in a formal and

ongoing process to monitor nursing facility quality and make recommendations for continued improvements.

## CONCLUSION

Indiana has made good progress developing a long-term care system that gives more people choices of services and setting with the passage and implementation of SEA 493 of 2003. However, it still ranks near the bottom of all states in the percentage of public resources it spends on home and community-based services, those services people want the most and are most cost-effective, compared to money spent on nursing facilities. Indiana has developed a good base from which it needs to continue to build in order to meet the current and projected demand for HCBS. As outlined in this paper, there are many steps it could take to improve its ability to deliver the quality, cost-effective home and community-based services that Hoosiers want and deserve.

Indiana needs to make sure that its residents understand their individual and family requirements for future long-term care services and how to plan and pay for them. It needs to ensure that people needing long-term care have comprehensive, understandable and unbiased information at crucial times and places, and counseling when needed, to make proper choices for themselves and their families. Indiana must make rapid decisions on eligibility for public resources so that families have meaningful choices to address their long-term care needs. It should give its AAAs the resources and funding flexibility at the local level to address a growing population of individuals needing counseling and services. Indiana must support family caregiving in new and expanding ways and ensure there are an adequate number of qualified paid caregivers, especially those who deliver services at home. It needs to give clear authority and direction to its AAAs in developing sufficient provider resources and delivering quality, cost-effective services options. It also needs to ensure that services are delivered according to individual needs and desires and that they reach desired consumer and system outcomes. Reaching these goals will take a focused effort, but with the commitment of consumer advocates, individuals and families, providers, government and non-profit organizations, Indiana can meet the needs and preferences of its residents for quality, affordable long-term care services and supports.

# Striking a Balance:
## *Recommendations to Improve Indiana's Long-Term Care System*

## INTRODUCTION

AARP Indiana commissioned a study examining the status of Indiana's long-term care (LTC) system for older adults and adults with physical disabilities, analyzing "best practices" from other states' LTC systems and recommending actions to improve Indiana's system. This study was conducted over a period between June and November 2009 using data from local and national sources, and from interviews and meetings conducted in-person and by telephone with Indiana state and local leaders.

Over the past few years, AARP has conducted opinion research of its members and others in a variety of states and the findings are very similar regardless of the state: older adults want to be able to have a choice of what type of LTC services they receive and where those services are delivered. A huge majority wants to receive services in their own homes or in a residential setting such as an assisted living residence; very few want to receive services in a nursing facility. A recent AARP survey of Indiana AARP members age 50-64 and the general population age 30-49 revealed that 82% said Indiana should make having LTC choices a top (38%) or high (44%) priority. In that same survey, Hoosiers said that if they or a family member needed LTC services, they would prefer to receive those services at home with care provided by family, friends and/or a personal care aide (66%) or in a home-like setting like an assisted living facility (18%). Only 2% said they would prefer care in a nursing home (AARP Knowledge Management, 2008).

Author's Note: The terms "long-term care" and "long-term services and supports" are used interchangeably in this report. Many individuals with disabilities understandably prefer to use the term "services and supports" to articulate their independence and clarify that they do not need to receive "care", only "support" to assist with their needs. However, the common parlance is to refer to these services and supports as long-term care.

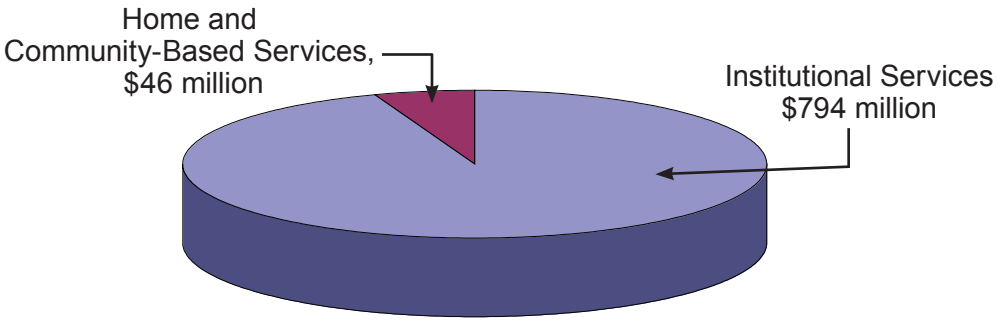
### The Current Long-Term Care System in Indiana

The State of Indiana offers a variety of long-term services and supports aimed at keeping older adults healthy and independent. In addition to vital supports supplied by family, friends and community organizations, Indiana government has a wide range of programs that can support older adults needing long-term care services. Those programs include services provided under the Older Americans Act (OAA), Medicaid and Medicaid Home and Community-Based Services (HCBS) Waivers, a robust state-funded Community and Home Options to Institutional Care for the Elderly and Disabled (CHOICE) program and the Social Services Block Grant (SSBG), as well as state-funded room and board subsidies under the Residential Care Assistance Program.

There are many ways to evaluate whether a state is meeting the needs of its citizens requiring long-term services and supports. One way is to look at reported data on services pro-

**FIGURE 1**

## Indiana Medicaid LTC Expenditures, 2007



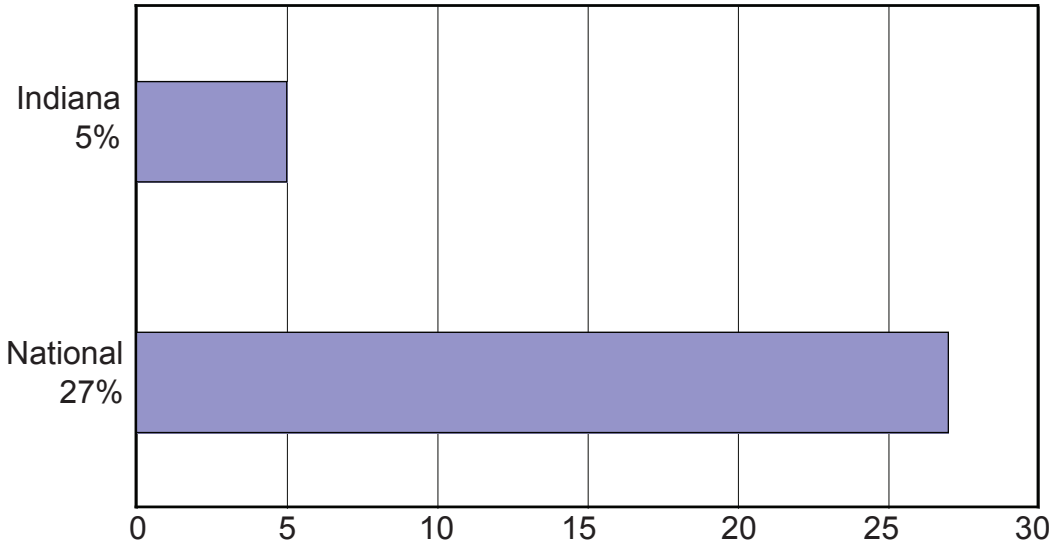

*Source: AARP, Across the States, 2009*

vided and settings where those services are delivered. In Federal Fiscal Year 2007, Indiana spent $794 million in Medicaid funds for nursing facility services, while spending $46 million on Medicaid HCBS waivers for older adults and adults with physical disabilities (AARP, 2009). That year only Tennessee spent a smaller percentage of Medicaid long-term care dollars for HCBS. Indiana spent 5% of its Medicaid LTC funds on HCBS for older adults and adults with physical disabilities, while the national average was 27% (AARP, 2009). However, a recent Indiana Division of Aging report shows over $84 million in Medicaid HCBS waiver spending for older adults and adults with physical disabilities in State Fiscal Year 2009, while spending $1.06 billion on nursing facility

**FIGURE 2**

## Medicaid HCBS Percentage Expenditures, 2007

*– Older Adults and Adults with Physical Disbilities –*



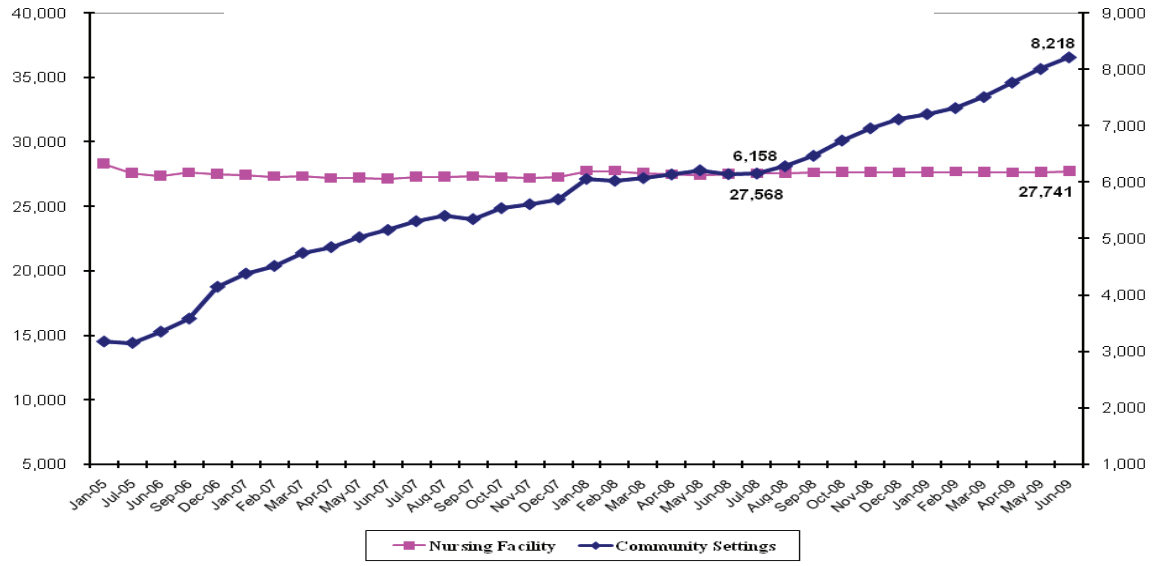

*Source: AARP, Across the States, 2009*

services (IDOA, 2009). These data represent a clear trend for increasing Medicaid HCBS spending. However, even considering 2009 spending of almost $32 million for CHOICE, $9.5 million from SSBG and over $24 million in OAA Title III funds, the overwhelming percentage of funds are still being spent for nursing facility services.

The Indiana Division of Aging (IDOA) also closely tracks the number of Medicaid enrollees needing long-term care services and where they receive those services. IDOA data show an increase of 158% in people served with HCBS from January 2005-June 2009 and a decrease of 2% of those served in nursing facilities. While the total numbers still reflect a large disproportion of people receiving nursing facility services, 27,741 versus 8,218 receiving HCBS (IDOA, 2009), the trend to more people receiving HCBS is clear.

**FIGURE 3**

**Division of Aging**
**Medicaid Services**
**Nursing Facility vs. Community Clients**

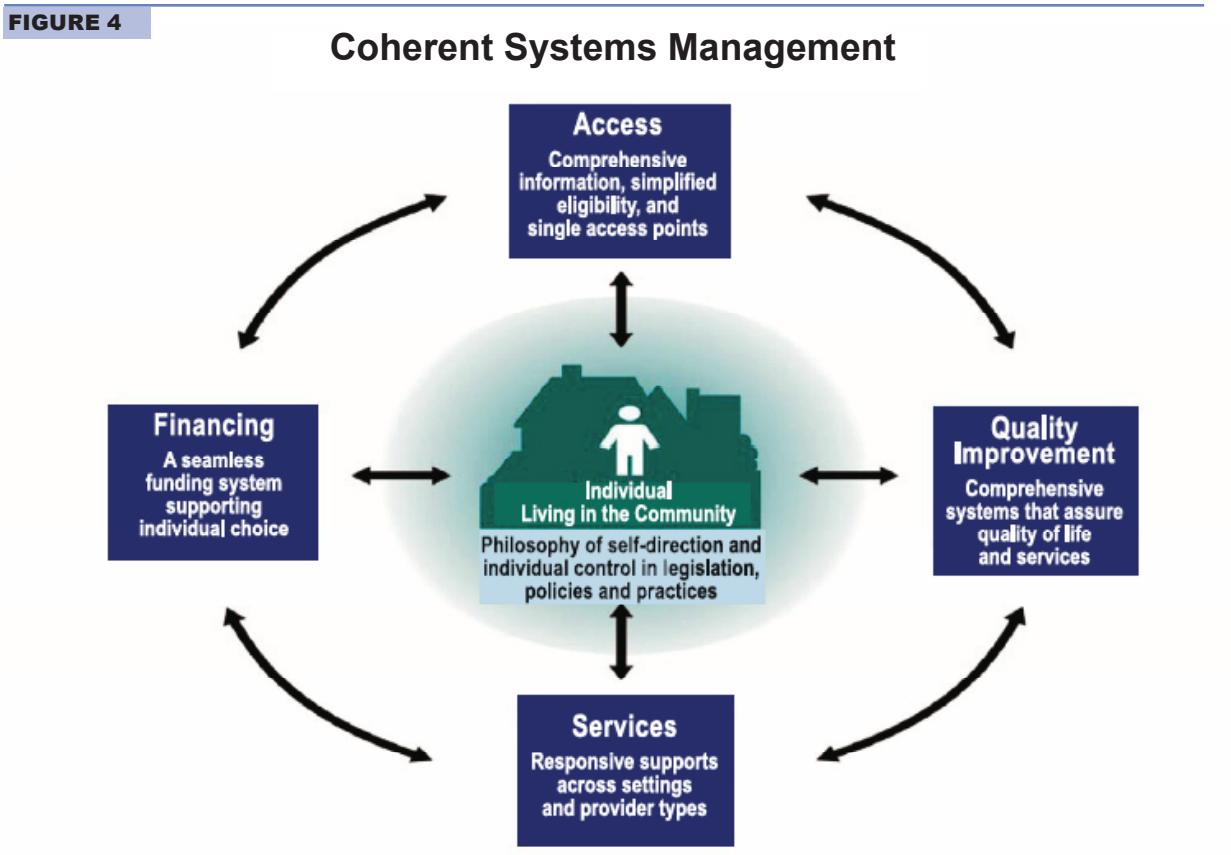



*Source: Indiana Division of Aging. Financial Review. June 30, 2009*

Another way to analyze whether a state is meeting the needs of its citizens for long-term services and supports is to analyze what it has achieved using the Centers for Medicare and Medicaid Services (CMS) description of the "key building blocks of coherent systems management" of long-term services: access; financing; services; and quality. CMS has used this analysis repeatedly in describing state efforts to balance their long-term support systems (CMS, 2003)*(See Figure 4)*.

More recently, CMS contracted for a Technical Assistance Guide to Assessing a State Long-Term Care System (Thomson Reuters, 2006) which a number of states have used to assess their systems. The key system components identified in that guide include: consolidated state agencies; single access points; institution supply controls; transition from institutions; a continuum of residential options; HCBS infrastructure development; participant direction; and quality management. All of these components in Indiana are addressed in this report and are included within the access, financing, services and quality framework.

**FIGURE 4**




*Source: Adapted from Lutzsky,S.: Key Building Blocks in Designing a System in Which Money Can Follow the Person, September 2003*

# ACCESS

## Information and Assistance

Individuals and families need to have understandable, comprehensive information about the wide range of long-term care services generally available in most areas across the United States. They need to know where to get this information and very often need the information on an urgent basis. For a state to meet the long-term care needs of its residents, it needs not only to supply this information in a helpful and supportive manner, but also ensure that people know that it is available and how to access it.

There are many ways Hoosiers can obtain information about long-term services and supports. The Indiana Division of Aging (IDOA) provides information through its web site and a toll-free telephone number. The web site (www.in.gov/fssa/da, accessed October 24, 2009) contains useful information about available services, a county listing where more specific services information can be found, a listing of area agencies on aging (AAAs) and aging and disability resource centers (ADRCs) and forms to apply for services. Each AAA also maintains a web site with helpful information about available services and each also has a toll-free telephone number. However, the publicized statewide web site for the ADRCs, in written information on the IDOA web site and in brochures, www.Link-Age.org (last accessed on October 25, 2009), states that the site is "temporarily unavailable while undergoing reconstruction". Unfortunately, that message has been there for almost a year.

### *Aging and Disability Resource Centers*

In 2004, Indiana was awarded a three year grant from the U.S. Administration on Aging (AoA) and the Centers for Medicare and Medicaid Services (CMS) to develop six Aging and Disability Resource Centers (ADRCs). The grant proposal called for the new ADRCs to provide information and referral services as well as coordinating programmatic and financial eligibility determinations for both older adults and adults with physical disabilities. In addition, the information and referral system and the eligibility system were to be integrated and internet-based to provide a foundation for statewide expansion (www.aoa.gov, accessed 10/25/09).

Indiana now has ADRCs in all sixteen (16) AAAs. It is one of only 12 states in the country to have achieved statewide coverage (ADRC-TAE, 2009). Its chief goal is to create a single, coordinated system and information and access for all people seeking long-term services and support. The "single point of entry" allows all people to get unbiased information about services choices and help with accessing those services. Since the AAAs assess the need for services for a variety of both state and federally-funded long-term care programs, the ADRCs, with adequate resources, should be able to assist people with both counseling about available options and streamlined access to services. As explained below, however, determining program eligibility and starting needed services does not always begin quickly.

## Counseling

Giving people comprehensive and helpful information at crucial times should be a goal for all state long-term care (LTC) systems. While many state policy makers are understandably focused on disseminating information before a person actually needs LTC services and attempting to get people to plan for the future, most people seek information only when they need it. Sometimes, the need for LTC results from a progressive illness or the "natural" aging process. This group of people, their families and friends, can seek out information and make plans over a period of time. However, very often the need for LTC results from a specific occurrence, like a fall, stroke or heart attack. A typical scenario is that individuals are hospitalized, their conditions are stabilized, and they and their families are told that hospital discharge will occur within 48 hours, often sooner. This is the point when people need to know where to go for unbiased information and have someone knowledgeable and available help them explore available options. Often a person may be able to immediately return home with visits from a home health nurse and/or aide, but unless people have that information, in a timely manner, returning home may not even be considered.

LTC counseling about options for services and settings is crucial. It should be readily available to the public and information should be understandable so that people can have real choices about long-term services and supports. Counseling should be available in people's homes, hospitals and nursing facilities. It should include an assessment of people's capacities, where they may need help and how they can access that help. Where needed, it can also assist in making sure that successful contact is made with appropriate service providers.

Indiana's ADRCs are designed to provide an options counseling function for all who need it. This process includes a needs assessment, identification of options and development of a plan. This is an excellent recognition of a vital need. However, this crucial function is available only to those who know about it. There is no organized statewide attempt to reach people at the time of hospital discharge or soon after a nursing home admission, two crucial times when options counseling is

needed. While the required nursing home pre-admission screening process provides a mechanism for options counseling, funding is inadequate to devote proper time and attention to such counseling. The ADRCs have done some excellent work making outreach to a variety of community organizations throughout the state (IDOA SART, 9/08) and it should be noted that there is at least one AAA that has targeted options counseling to nursing homes. In addition, the IDOA recently received a grant from the Administration on Aging to implement options counseling in a major hospital. However, targeted options counseling for individuals and families in nursing homes and hospitals should be implemented statewide to give people the vital information they need at a crucial time.

### Program Eligibility

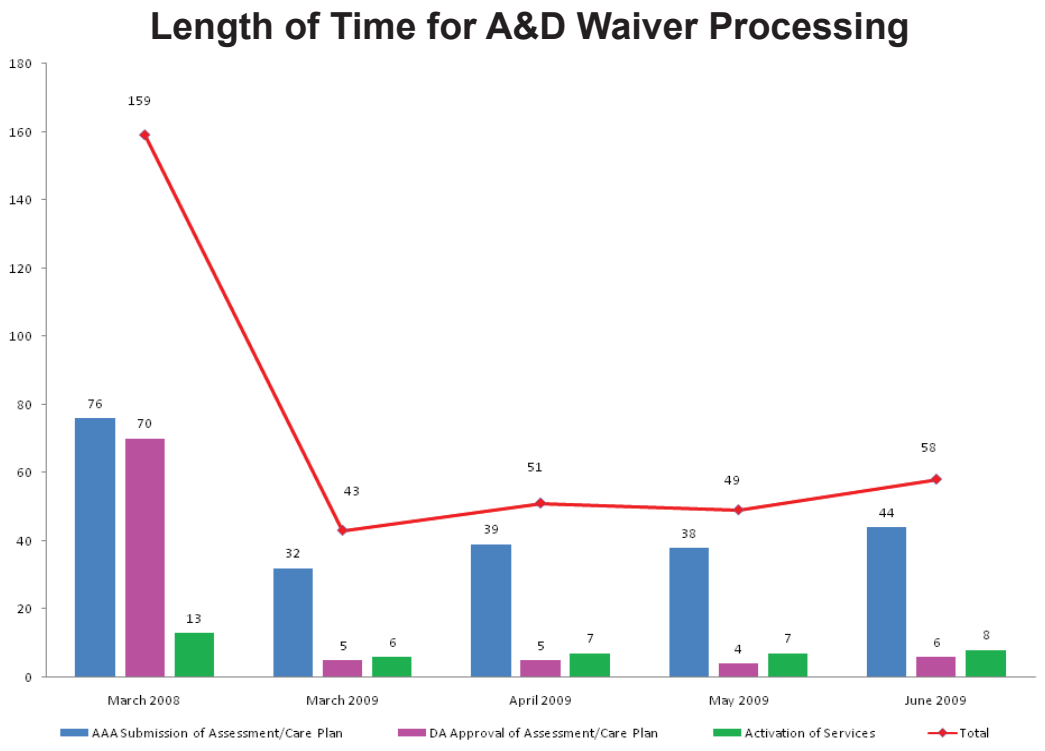
Individuals and families requiring long-term services and supports need to know about programs and services available to them and whether they will be eligible for any of these public programs in a timely manner. Unless people have that information, they cannot make an informed choice about what services and settings are the most appropriate to meet their needs. People often move to nursing facilities because they are unaware of the alternatives, cannot afford those alternatives without public financing or cannot piece together disjointed community services into a coherent plan that could help them remain at home.

As noted above, Indiana has built and is continuing to build a robust system of information and assistance for everyone, regardless of income. In addition, the AAAs, through the ADRCs, can help individuals and families assess their needs, understand their options and develop a plan for current or future long-term support. Perhaps most importantly, the AAAs can determine eligibility for and authorize both federally-funded Older Americans Act (OAA) and Social Services Block Grant (SSBG) services, as well as state-funded CHOICE services (detailed below).

The AAAs also perform assessments for *medical* eligibility for the Medicaid Aged and Disabled Waiver. However, *financial* eligibility for the Waiver is determined by the Division of Family Resources and people must wait a significant time before they are informed of their eligibility for Medicaid Waiver services. Federal rules require that determinations of financial eligibility for Medicaid must be made within 45 days from the date of application and up to 90 days when a disability (medical) determination must be made. Even though the CHOICE, SSBG and OAA programs finance needed services and could be initiated more quickly, all of these programs combined are much smaller than the Aged and Disabled Waiver. Because these programs have more limited resources, it is vital that Medicaid eligibility determination be done more quickly.

The Indiana Division of Aging does an excellent job tracking and publicizing the amount of time it takes to make a decision on whether a person qualifies for Waiver services *(See Figure 5)*. It should be noted that federal law requires that a person must need a nursing home "level of care" in order to qualify for Medicaid Waiver services. In October 2009, it took an average of just under 55 days for the AAAs to assess need and develop a care plan and for the state to approve that plan (Laird, 12/09). This timeframe is far better than the over 200 days average it took in June 2008 (Laird, 12/09), but it still leaves people not knowing whether they will have access to these vital services and could result in unnecessary institutionalization. While these timeframes could still likely be shortened with additional efficiencies and resources, Indiana should consider allowing the AAAs to make "presumptive" eligibility decisions, as some other states have done, that would allow services to begin very quickly. This option will be discussed later in this report.

**FIGURE 5**




*Source: Indiana Division of Aging. Financial Review. June 30, 2009*

## Recent Progress in Expanding Access to HCBS

It is appropriate to acknowledge Indiana's recent significant progress in expanding access to home and community-based services, while remembering that it spent only 7% of its 2009 Medicaid LTC dollars on HCBS and had 23% of its Medicaid LTC enrollees receiving HCBS (IDOA, 2009). While the spending and the settings where people are served are still extremely weighted in favor of nursing facility services, Indiana has made steady progress over the past few years in balancing its LTC system. Below are some of the actions it has taken (IDOA, 9/09), many of which were required under SEA 493 of 2003:

- Created uniform financial eligibility of 300% of SSI (Supplemental Security Income) for both Medicaid nursing facility and waiver services; waiver services formerly had a 100% of SSI eligibility standard making it far easier to qualify for nursing facility care than HCBS;
- Eliminated the Medicaid Waiver waiting list for older adults (IDOA, 9/09), but in December 2009 reinstated a waiting list due to budget constraints (Laird, 12/09); in August 2008, the waiting list was 2,270 (IDOA, 2009);
- Amended the Medicaid Waiver to include a broader range of available HCBS, similar to the CHOICE program;
- Created a self-directed attendant care program for individuals enrolled in both the Medicaid Waiver and CHOICE;

- Established a Division of Aging, allowing a more focused approach to serving older adults, with the responsibility for managing both nursing facility and HCBS budgets;
- Promoted assisted living, adult foster care and adult day services as alternatives to institutional care;
- Developed and financed the creation of a statewide network of Aging and Disability Resource Centers (ADRCs);
- Partnered with the University of Indianapolis Center for Aging and Community on establishing 5 naturally occurring retirement communities (NORCs) across the state, where consolidated LTC services can be combined with existing housing to allow people to receive needed services in their own home (state funding for these programs has recently been eliminated due to budget shortfalls);
- Partnered with the Department of Transportation to help community organizations receive 174 accessible vehicles; and
- Partnered with the Housing and Community Development Department to develop a Home Again program focused on providing affordable and accessible housing for people moving out of nursing facilities.

### *Phase 2*

Except as lessened by more recent budget constraints, these are all very positive developments, many of which occurred due to the passage of SEA 493 in the 2003 session of the Indiana General Assembly. In addition, the Division of Aging has initiated what it is calling Phase 2 (SEA 493 requirements are considered Phase 1), which continues its work to give people more choices and options for LTC services.

Phase 2 addresses the Medicaid nursing facility reimbursement rate structure to give a financial disincentive for caring for low-need individuals who could be served outside of a facility, an incentive for higher occupancy, revised enhanced incentives to improve quality care, and additional rate incentives to address the added costs to provide ventilator care and for facilities which have an Alzheimer's unit. With these actions, the IDOA estimates it will have an additional $20 million available for HCBS.

The IDOA has also announced a Phase 3, which will focus on value-based purchasing of nursing facility services utilizing staffing, clinical quality of care and administration/management measures, with a weighted value for clinical quality of care. While this new approach will not redirect additional funding for HCBS, it continues to focus payment for quality services as it redistributes funding equivalent to 10-12% of a facility's rate based on measurable performance (IDOA, 9/09).

### *Money Follows the Person Grant*

Indiana is also working to transition about 1000 people from nursing homes to community settings over a five year period under a $21 million commitment of funds from the Centers for Medicare and Medicaid Services under its Money Follows the Person Program. The program targets people who are Medicaid enrollees who have lived in a nursing facility for at least six months and want to receive services in the community. Part of this work includes developing a targeting strategy to identify those who may want to participate in the program and a housing strategy for those who

do not have adequate community housing (see housing section below for a description of the Home Again program). As of September 30, 2009, 20 people have transitioned out of a nursing home to a community residence under this program (IDOA, 9/09).

## Successful State Models

Access to information about long-term care programs, qualification for those programs and rapid eligibility determination for needed services are vital components for a successful long-term care system. Unless people understand their options, especially at critical times, they cannot have a real choice of services and the settings in which they receive them. The two states highlighted below have created excellent models of giving individuals and families timely and crucial information and counseling and letting them know very quickly what type and amount of public support they can receive.

### ■ *Washington*

Washington has developed and implemented a single entry point system at the local level for all publicly-funded long-term care and other needed services. State employees at local offices throughout the state offer thorough information on all publicly-financed programs and offer similar information through the State web site. A person can apply for cash assistance, food assistance, medical assistance, nursing facility, assisted living or in-home care and alcohol and drug treatment.

If a person is applying for long-term care, a case manager will conduct an assessment of the applicant in their home or other location within five (5) days. However, if an individual is being discharged from a hospital or rehabilitation center or if an applicant resides in the community and is in immediate risk of admission to a nursing facility, the assessment must be performed within one working day of the referral.

The assessment instrument is highly technologically-based. The person performing the assessment uses a laptop loaded with a software program which guides the person through the assessment and then automatically determines whether the applicant meets the required level of care for services and what services can be authorized. They are also able at that time to develop a plan of care for the individual. This automated level-of-care assessment is a huge benefit for an applicant and family as they immediately know that if they meet the *financial* qualifications for the program, they will receive a defined amount of services.

Simultaneous with performing the described level-of-care assessment, the financial eligibility worker, located in the same office as the employee performing the assessment, begins the process of determining financial eligibility. Financial eligibility determinations must be completed within 45 days from the time the financial eligibility worker is notified that the applicant is applying, although there is an internal standard to complete the determination within 15 days. Once the applicant's financial information is gathered and entered into the system, the automated technology determines the public programs for which the applicant is eligible (CMS Promising Practices, 2003).

*Presumptive Eligibility*

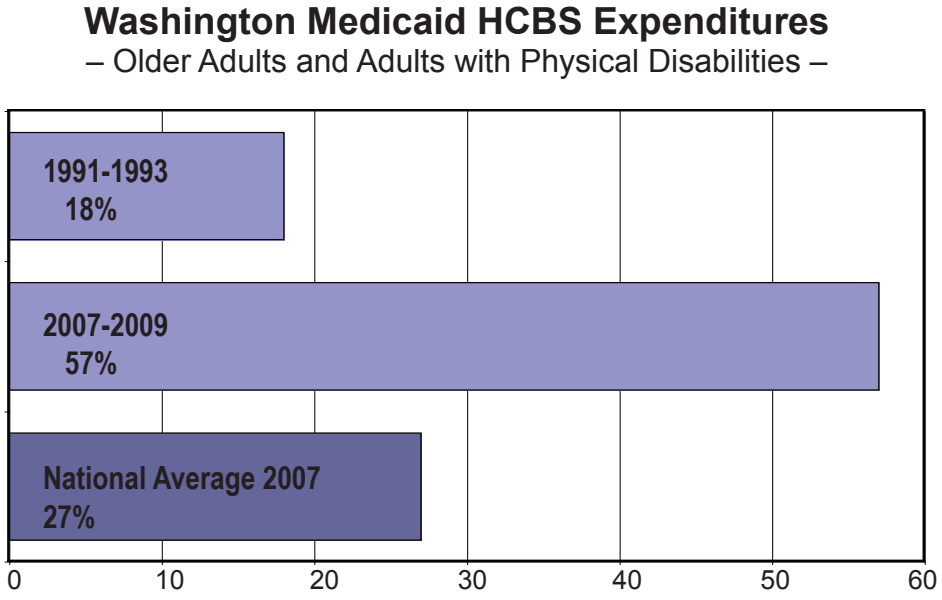
Washington also has a "Fast Track" process where vital home and community-based services can be authorized in one day, prior to the completion of a formal eligibility determination, if state staff, after gathering sufficient financial information, "presume" that the person will be eligible.

Services can be immediately authorized up to ninety (90) days if the person applies for HCBS waiver services within the first ten (10) days. Individuals must sign an agreement acknowledging that the services are temporary pending eligibility and will be terminated if they fail to apply for Medicaid within ten (10) days or are eventually found to be ineligible for Medicaid (Mollica, 2004). If the individual is found ineligible for Medicaid, state funds are used to pay for services. Some states also use Older Americans Act and Social Services Block Grant funds if an applicant is found ineligible (Mollica, 2005). Washington reports that its error rate using presumptive eligibility has been less than 1% and believes it has saved substantial funds using this process (Kane, 2006).

**Ohio** has also used presumptive eligibility for its Medicaid Waiver program since 1985. In a 2004 report on "Expediting Medicaid Financial Eligibility", Ohio officials estimated that over half of the waiver applications were processed through the presumptive eligibility process and that over that time period, the error rate was about 1% (Mollica, 2004). In a significantly-sized pilot project in **Pennsylvania** in 2003-04, the error rate was between 1 and 2% (Mollica, 2004, 2005).

Another key part of Washington's access system is its ***Nursing Facility Case Management*** program. State-employed case managers are assigned to specific nursing facilities where, within 7 days of admission, they visit new Medicaid residents and those likely to become Medicaid-eligible within 180 days. They conduct an assessment and discuss available HCBS options. If a person wants to receive services at home or in a community residence, the case manager conducts a more comprehensive assessment and works with the facility staff, the individual and family to develop and implement a transition plan (CMS Promising Practices, 2004). One reason why individual choice of settings and services is a real option is that there is an ample supply of community providers and there is no waiting list for Medicaid HCBS.

**FIGURE 6**

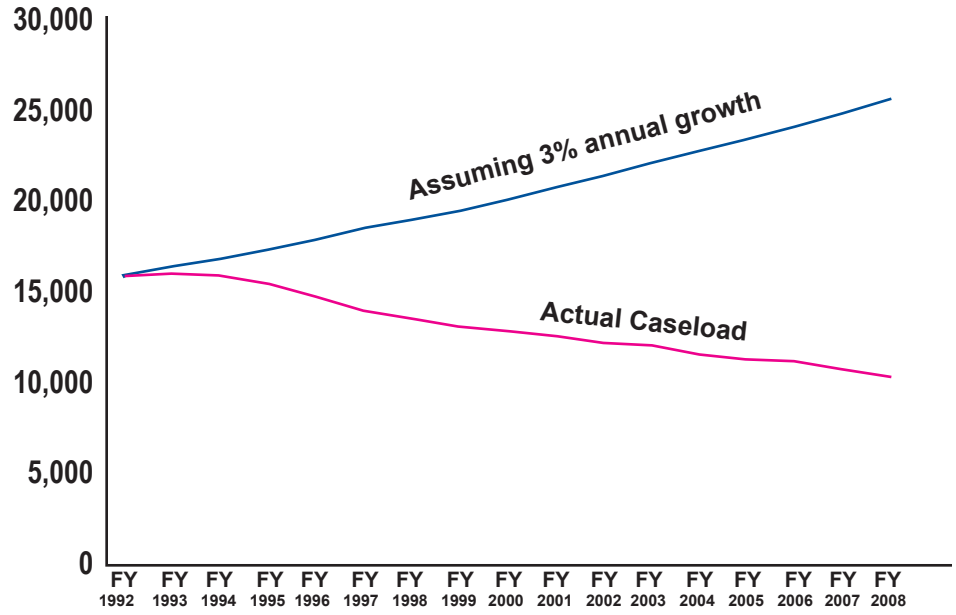



*Source: Washington ADSA Fact Sheet, 2009; AARP Accross the States, 2009*

Washington's system really gives people timely information on services for which they qualify and the amount and scope of those services. Armed with this information, consumers can truly make an "informed choice" about the services they need and the options on where those services can be received. Washington Medicaid was supporting a monthly average of 10,645 people in nursing facilities in January 2009, down from 17,353 per month reported in 1992 (ADSA, 2009). In addition, it is spending about 57% of its 2007-09 long-term care resources on home and community-based services for older adults and people with physical disabilities compared to 18% in 1991-93 (ADSA, 2009)*(See Figure 6)*. AARP reported Medicaid HCBS expenditures for older adults and adults with disabilities as 55% of the total in 2007 compared to an average of 27% for the U.S. (AARP, 2009). This represents a large shift in funding to support people's desires to live at home and in community dwellings. Finally, it estimates that if nursing home growth would have continued at a 3% a year increase from 1992, it would have spent an additional $782 million more on Medicaid nursing facility payments than it did in 2008 (ADSA Intro., 2009).

**FIGURE 7**

## Estimate of Medicaid Nursing Home Clients if Washington Had Not Expanded Home and Community Services




*Source: Washington ADSA from MMIS data*

+ We can serve three times the number of people in home and community that we would have spent on nursing homes had we not re-balanced.

+ Without our re-balancing efforts, acute care costs would be higher because people who need long-term care services would not be eligible to get them.

+If nursing home growth had continued at 3% per year, in FY08 we would have approximately 28,000 nursing home clients at a cost of $1.3 billion per year.

+ In FY08, we are serving about 11,000 clients at a cost of $508 million per year.

### ■ *New Jersey*

New Jersey developed and implemented a program called Community Choice, which offers nursing facility residents and hospital patients information about in-home services, housing alternatives, and community programs. Its stated goal is to encourage participants to make well-informed decisions about what is best for their long-term care (www.state.nj.us/health/senior/choice, accessed September 9, 2009). The program started in 1998 when the state hired registered nurses

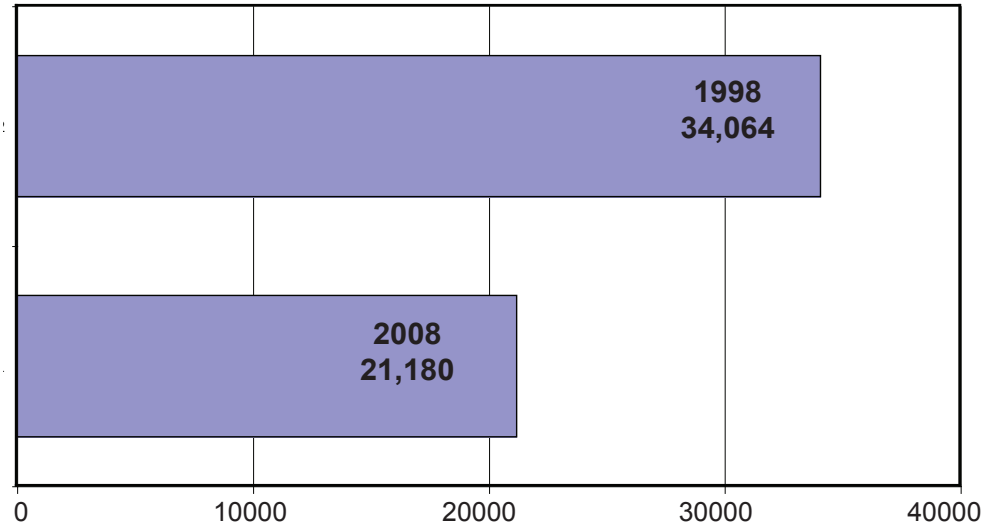
and social workers to work with Medicaid participants and people who would likely be Medicaid-eligible within 180 days of entering a nursing facility. State regulations require that nursing facilities notify the state when people meeting this profile enter their facility.

When it began, the Community Choice program built upon the work that New Jersey had been doing in its pre-admission screening program, which targeted the same Medicaid and potentially Medicaid-eligible participants for screening for the appropriateness of nursing facility placement. In addition, the state-employed registered nurses performing the screening indicated whether short-stay or longer-term stay was appropriate. State-employed social workers then visited people recommended for short-term stay and discussed options after discharge from the facility. The Community Choice program improved what had been done with pre-admission screening by adding more resources to hire and thoroughly train staff to perform the counseling and standardize operations on a statewide basis (CMS Promising Practices, 2003).

**FIGURE 8**

**New Jersey Medicaid Nursing Facility Population**

*(Average Monthly Census )*




*Source: New Jersey Department of Health and Senior Services, 2008*

Today Community Choice counselors, registered nurses and social workers, meet with nursing home residents and hospital patients and their families and assess care needs and the level of care required, suggest appropriate alternatives, offer information about services and housing, explain any financial and medical eligibility requirements and recommend services that support dignity, choice and independence. The program encourages people capable of living in the community to do so. Counselors can begin the process before or after admission to a facility and work with discharge planners to make the transitions as easy as possible (www.state.nj.us/health/senior/choice, accessed September 9, 2009).

***Presumptive Eligibility***

The state is also using a Medicaid Eligibility Fast Track Determination process that can authorize up to 90 days of home and community-based services for individuals who are clinically eligible for nursing home care and appear to have a high probability of being eligible for Medicaid, while they complete the full application and eligibility determination process. As of October 2007, individuals could be approved for services within five to seven business days (NJDHSS, 2007). However, it is anticipated that the state may be able to improve the time efficiency as it continues to refine its processes.

***Results***

Between March 1998 and September 2005, the Community Choice counseling program helped 5,583 people transition from a nursing facility (Reinhard & Polansky, 2005). Medicaid nursing facility utilization decreased from a 1998 average monthly census of 34,064 to a 2004 average monthly census of 30,395, a reduction of 11% (CMS Promising Practices, 2005). More recent data show that Medicaid nursing facility utilization continued to decrease and was 21,180 as of July 2008 (NJDHSS, 2009), a huge reduction in a decade of focused work *(See Figure 8)*. New Jersey has increased its percentage of Medicaid LTC spending on HCBS from 14% in 2001 to 20% in 2007 (AARP, 2008, 2009).

## Opportunities to Improve Access in Indiana's LTC System

There are many positive actions Indiana has taken to improve access to its long-term services and supports system and specifically to its home and community-based services (HCBS) over the last number of years. Indiana's "single point-of-entry" system has historically been a strength and more recently has improved its access system through creating ADRCs in all areas of the state. Given sufficient funding, the ADRCs, located within the AAAs, will allow everyone to receive unbiased information about LTC options, receive an assessment of need, counseling about options and assistance developing a plan of action. In addition, the AAAs serve as the place where people can receive public support such as Title III services, SSBG and CHOICE services. They can also receive a medical assessment for eligibility for Medicaid Waiver services. This is all very positive for consumer responsiveness and administrative efficiency. However, despite this progress, Indiana still lags behind most states in the resources it dedicates to HCBS. A number of key actions need to be taken to dramatically improve this part of Indiana's system.

**1. Provide more base funding for the ADRCs**

While it is very positive that the State has made a commitment to establish ADRCs statewide, ADRCs need adequate and dedicated funding to properly serve an ever-increasing work load of people needing assistance with long-term care services. The additional funding will especially be necessary with continuing outreach efforts to give people vital information and counseling at crucial times, including in-home counseling for at-risk individuals who are unable to travel to the ADRC. The Division of Aging should also be clear about the outcomes it wants the ADRCs to achieve. The Division has done a good job reporting data on timeliness of Medicaid assessments and costs of care plans. It should also collect and publicly report data in other areas of focus that relate to consumer satisfaction and provider quality.

**2. Publicize and promote the ADRCs through a statewide media campaign and regional outreach**

Hoosiers need to know about this valuable resource and also need regular reminders about the need to plan for their long-term care needs and those of their families. The Division of Aging should develop and implement a statewide publicity campaign to publicize and promote the ADRCs, the statewide toll-free telephone number and the statewide web site, which needs to be operational as soon as possible. The Division should also require the ADRCs to submit annual regional outreach plans and the Division should fund specific budgets to implement those plans.

**3. Develop and implement a Targeted Options Counseling Program for people recently admitted to nursing facilities**

While it is very positive that the ADRCs have developed and implemented options counseling programs, targeted counseling needs to be accomplished for those recently admitted to nursing facilities. This is the time when individuals and families need to know and understand all the options that are available and start planning for future needs. Many people understand they are only in the facility for short-term rehabilitation and then they will return home. Others, however, may not know that their need for services could be met in their homes and these individuals must be made aware of those options. This is why there must be a specific effort to counsel people at this crucial time. The South Bend area AAA has operated such a program since 2006. Case managers are assigned to specific nursing facilities, where they provide options counseling to newly admitted individuals on a weekly basis to determine whether they may be better served at home with appropriate supports. The Division of Aging should evaluate this program with the goal of expanding it statewide.

**4. Develop and Implement a Targeted Options Counseling Program for people being discharged from a hospital to a nursing facility**

The Indianapolis area AAA, with Administration on Aging funding and in partnership with the Division of Aging and Wishard Health Services, is developing and implementing a pilot program to work with hospital discharge planners and others to use interventions to avoid unnecessary long-term care placements and hospital readmissions. This project should be supported and carefully evaluated for replication. During this project, there should be a priority focus on appropriate timing for an initial counseling session about long-term care options.

**5. Implement presumptive eligibility determination procedures for the Medicaid Waiver**

The Division of Aging has placed great focus on making the Medicaid Waiver eligibility process more efficient. Both the Division and the AAAs have reduced the time needed to make such a determination. However, it still takes a long time for individuals and families to know whether they will be eligible for these services. The AAAs should be given the responsibility for making presumptive eligibility decisions, with appropriate safeguards, and immediately authorizing the start of Waiver services to people who are "at risk of institutionalization." The Division could choose to narrowly define the circumstances where this presumptive eligibility could be allowed or could pilot presumptive eligibility procedures in a few AAAs before statewide implementation. The Division could also require,

as some states have, a statement by the individual and family that attests to their income and assets and notifies them that they could be liable for those service costs if found ineligible for Medicaid. As in other states, Indiana would proceed with a formal eligibility determination for the individual and would not be able to receive federal matching funds for people ultimately not found eligible. As noted above, states using presumptive eligibility have found their error rates to be extremely small while cost-savings are significant by avoiding unnecessary nursing facility care.

## FINANCING

### State Budgeting

Many individuals and families have no real choice about where they will receive needed long-term services and supports unless timely decisions are made about the availability of public financing. If people decide that they want to receive services in their own home, arranging for those services should proceed efficiently without professionals wondering if there are enough dollars in the home-delivered services budget to support that choice. Many states have separate budgets for institutional services and home and community-based services. Many times those separate budgets are authorized by the legislature and are managed by different state entities. Most states also have a defined number of Medicaid Waiver "slots" that can only be increased by executive and/or legislative action and approval by CMS. This time delay in obtaining new "slots" results in people not having access to HCBS at a crucial time and the risk of unnecessary institutionalization.

As discussed below, a number of states have adopted "unified" or "global" budgets where both institutional and home and community-based services (HCBS) are combined in one budget and managed by one entity. Under a "unified" or "global" budget, financing individual choice of services and settings is less complicated. The question becomes whether there is money in the entire long-term care budget rather than whether there is enough money in any one specific line item. Obviously, that type of budget is easier to manage and, with appropriate authority and flexibility given to those responsible for arranging LTC services, the corresponding efficiency results in people receiving timely decisions on whether they can receive services where they choose to receive them.

Indiana has different budget lines for nursing facility services, waiver services, Medicaid State Plan services, and non-Medicaid services. However, these budgets are all tracked and managed by the Indiana Division of Aging (IDOA) and the IDOA produces financial reviews on a regular basis, keeping all stakeholders aware of budget issues.

Separate program budgeting is a challenge, however, at the local level where AAAs are trying to provide needed services across a variety of federal, state, and federal-state programs. Although it is very positive that the AAAs perform nursing facility pre-admission screening and make the initial level-of-care determination for Medicaid long-term care eligibility, the Division of Aging has been very clear that it wants Medicaid dollars utilized before state-only funding. While not surprising that the state would want to maximize federal funding, people needing care quite often need services prior to finding out whether they qualify for Medicaid. The AAAs, working directly with individuals and families, are in the best position to know which programs offer the best and most efficient services. The state should allow the AAAs to have maximum flexibility in arranging HCBS across various programs and funding streams. As discussed elsewhere in this report, establishing a

clear policy that allows use of the state CHOICE program to fund services while Medicaid eligibility is being determined and allowing for a presumptive Medicaid eligibility determination may allow needed home-delivered services to begin and avoid forcing people to choose an institution in order to receive services.

### Institutional Supply Controls

Many economists believe that one effective method for decreasing expenditure growth is to limit the supply of a commodity or service. Most states have enacted either a certificate of need program for nursing facility construction or major renovation, a moratorium on the construction of new beds or on the Medicaid certification of additional beds, or a combination of these. Indiana has focused on this issue for many years and currently has a moratorium on new Medicaid beds. In addition, it has created a Closure and Conversion Fund through a quality assessment fee on the nursing facilities that is focused on delicensing existing Medicaid beds and either closing nursing facilities with low patient populations or converting them to more independent living settings. Indiana needs to keep a strong focus on reducing the number of institutional beds as it continues to have a nursing facility census per 1000 persons age 65 and over that is well above the national average (Alecxih, 2007).

### Managed Care

Some states have chosen to adopt a managed care approach to long-term care service delivery. Most have chosen to contract with organizations to manage all or part of the Medicaid long-term care (LTC) benefit and some have worked to have the same entity manage both the primary and acute care Medicaid and Medicare benefit. The reasons for implementing these programs have been both for improved care delivery and cost savings. Although most of the managed LTC programs are still relatively small, there are a number of them that have grown enough to represent a large percentage of that state's population receiving Medicaid LTC benefits. A few state programs are discussed below.

Indiana has not initiated any managed LTC programs. However, with the AAAs having such broad responsibility for developing care plans and contracting for and managing services, the state does have the basis to effectively expand both the authority and accountability of the AAAs for LTC management. For example, the Division of Aging could give each AAA a yearly budget for all long-term care enrollees in their region and set both financial and program outcomes in utilizing that funding. It could give incentives for exceeding financial and program goals such as keeping people healthy for as long as possible and avoiding unnecessary hospitalizations and nursing facility admissions. While this approach would not necessarily follow most of the other state managed LTC programs, Wisconsin did use its established local networks as a basis to implement its managed LTC program, FamilyCare, and is described below.

### Individualized Budgets (Consumer Direction)

Many states have adopted systems of individualized budgets where Medicaid LTC enrollees have control over a specified amount of money allocated for their needs. Adequate safeguards have been adopted to ensure financial integrity and the health and well-being of the individuals in the programs. For many years, CMS has facilitated the adoption of individualized budgeting and con-

sumer self-direction of services in Medicaid waivers. Although it clearly still requires a good deal of work by a state to design and implement an individualized program, it is not difficult to obtain CMS approval.

Indiana offers a self-directed attendant care option for both its Aging and Disabled Waiver and its CHOICE program. In each of these programs, individuals receiving services can choose an attendant and direct their own care. A fiscal intermediary is hired to pay the personal attendants, file tax and labor reports and provide program participants with reports on how authorized units have been spent and the amount of taxes paid. However, program participants do not have actual budgets of their own and the flexibility to decide whether to spend resources on other items they may need. This type of arrangement, prevalent in many states, allows individuals more independence to control their services within a fixed budget. In addition, Indiana's program is relatively small given the number of people receiving Medicaid waiver and CHOICE services. There is almost no information about the details of this program available on the Department of Aging web site.

## Successful State Models

States have focused on the key building block of financing from a variety of perspectives. A number of states have worked to ensure that state budgetary practices, management and regulatory structures work efficiently to support an individual's choice of setting and services at the local level. Some have consolidated long-term care financial and program management in one state entity while others have created strong linkages between state entities. Others have delegated a large portion of financial and program management to local public or nonprofit entities and/or care management entities. Many other states have worked hard to implement programs which give more financial independence and control to the individual receiving services allowing them to manage their own care through an established individualized budget. Following are examples of states that have both consolidated their financial and program management and delegated responsibility to other entities and individuals to manage needed services and supports.

### ■ *Vermont*

#### *Early Work*

In 1996, the Vermont legislature passed legislation requiring reductions in the Medicaid nursing facility budget and an investment in the HCBS budget. Act 160 had four primary goals: 1) improve the state's independent living options for older people and people with physical disabilities; 2) create a climate where Vermonters could live in the most independent, least restrictive environments they choose; 3) decrease the growth of the Medicaid nursing facility budget through the development of consumer options; and 4) redirect nursing facility dollars into HCBS with consumer participation and oversight in the planning and delivery of long-term care services (CMS Promising Practices, 2003).

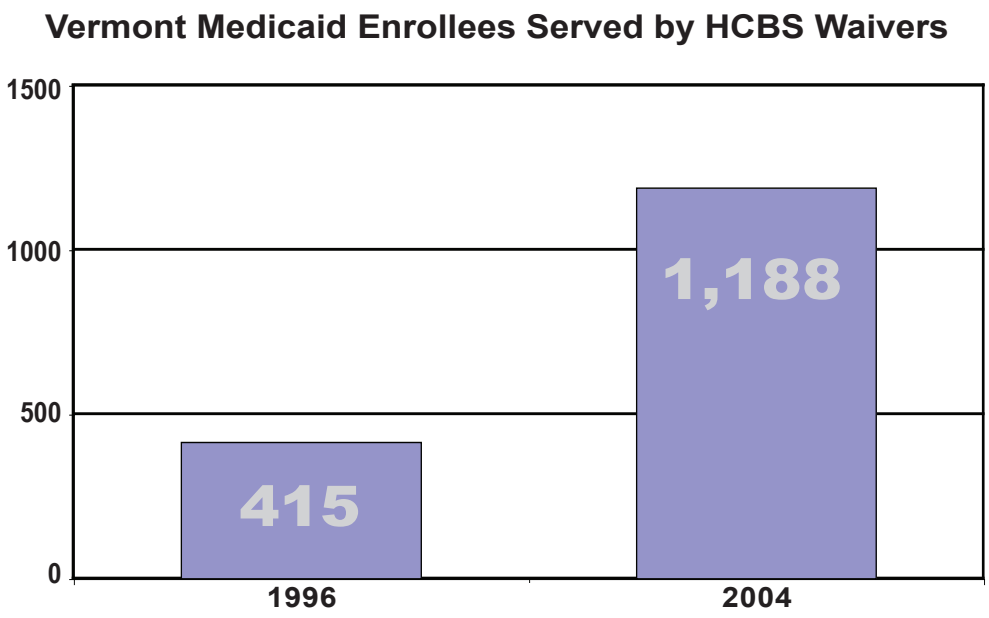
Vermont began a number of initiatives to achieve these goals. It created ten (10) Long-Term Care Community Coalitions, comprised of consumers and their advocates, providers and local Area Agencies on Aging, and charged them with the responsibility of planning and coordinating their local long-term care systems. The state asked the coalitions to concentrate on implementing strategies to reduce unnecessary nursing facility and emergency room utilization and find ways to expand and develop new HCBS services, using the savings generated from Act 160.

Vermont also changed the way people gained access to the Medicaid HCBS Waiver. The state began to admit people based on the urgency of their need rather than based on the date of their application. The written policy gave priority to four distinct groups: 1) applicants in a nursing facility who wanted to transition out; 2) applicants in a hospital who would otherwise be transferred to a nursing facility; 3) applicants in the community at risk of harm without waiver services; and 4) applicants at risk of moving to a more restrictive setting. Vermont also established a new Medicaid Waiver to offer enhanced residential care that provided a wide range of services in a 24-hour licensed care setting (CMS Promising Practices, 2003).

This example demonstrates what a state can do when it adopts a clear policy and budget strategy and takes action to both develop new community options and prevent unnecessary nursing facility utilization. It was clear that money for new community options was only going to come from reductions in existing nursing facility expenditures. It is also an example of how vital it is to develop sufficient amounts and types of community options and using local stakeholder entities to plan for and implement needed services.

***Early Results***

**FIGURE 9**



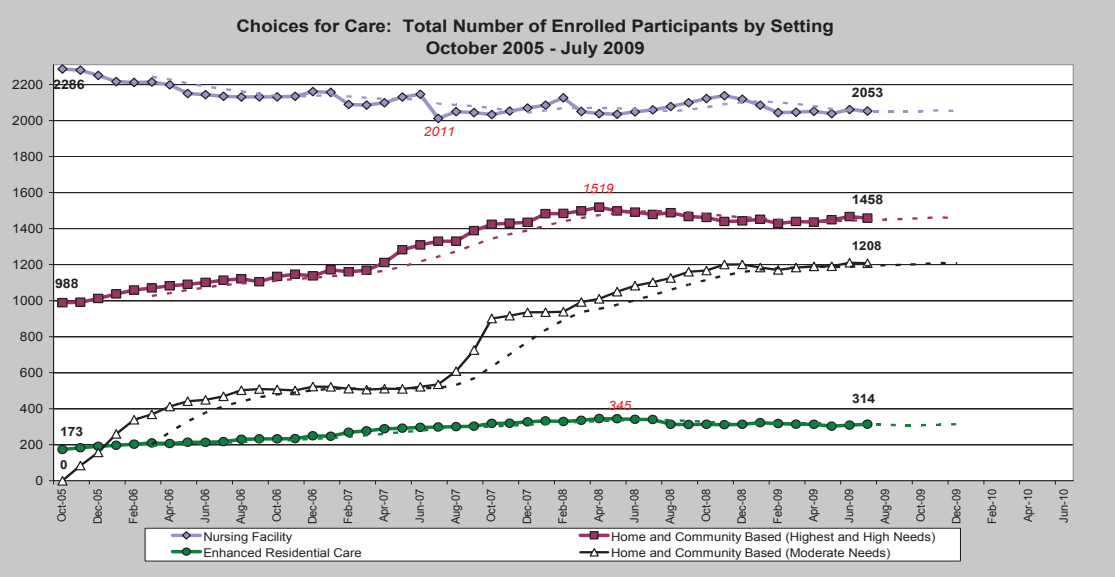

*Source: Flood, 2005*

Between 1996 and 2004, Vermont's percentage of long-term care dollars spent on nursing facilities for older adults and people with physical disabilities fell from 88% to 70%, a substantial achievement over a sustained period of time (CMS Promising Practices, 2004). During that same time period, Medicaid enrollees served by HCBS Waivers grew from 415 to 1188, a growth of over 186% while people served in nursing facilities dropped from 3630 to 3216, almost 13% (Flood, 2005).

### *Choices for Care*

In October 2005 Vermont implemented a Section 1115 Medicaid Waiver to further expand access to HCBS while reducing nursing facility utilization all within a global cap on federal financing. With its consolidated Medicaid long-term care budget, it assessed people's needs into three categories: "highest need" individuals can receive either nursing facility or HCBS; "high need" can also receive either set of services, subject to availability of resources; and "moderate need" do not meet a nursing facility level-of-care and can receive a limited set of services, subject to available resources (Crowley, 2008). One of the most noteworthy aspects of this demonstration is that everyone who meets a nursing facility level-of-care is entitled to both nursing facility and HCBS, making it absolutely clear that individuals have a choice of services for the care they need.

**FIGURE 10**




*Data source: DAIL/DDAS SAMS database.*

### *Results of Choices for Care*

Prior to the implementation of Choices for Care in October 2005, the number of people served by HCBS increased fairly steadily, but in State Fiscal Year 2007, the number of people enrolled increased by nearly 300, followed by an increase of nearly 240 in 2008. These increases were significantly higher than in previous years, with annual increases approaching 20%. Other data show a decrease of over 10% in the number of people being served in nursing homes, an increase of 48% in the number of high and highest needs people being served with HCBS, and 1028 people receiving a new limited set of HCBS for a total HCBS increase of 157% since the program began. Counting the "moderate needs" group, Vermont now serves 59% of its Medicaid long-term care enrollees with HCBS, up from 34% when the program began (Vermont, 2009).

## ■ *Wisconsin*

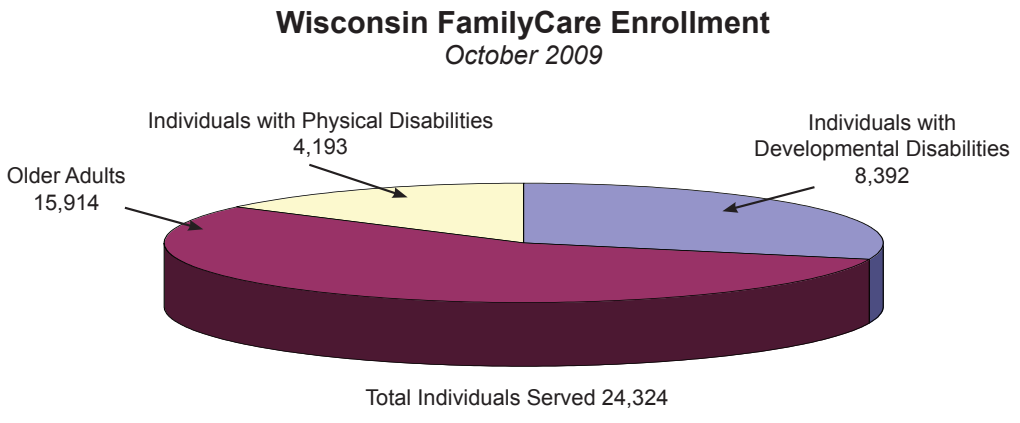
Wisconsin is implementing perhaps the most extensive new Aging and Disability Resource Center (ADRC) model in the country. Beginning in 1999, the ADRCs were developed as a component of Family Care, a redesign of the LTC system in Wisconsin which includes a managed LTC benefit. The Centers are units of county government and as of August 1, 2009, there were 34 ADRCs covering 56 counties. They describe themselves as service centers that provide a place for the public to get accurate, unbiased information on all aspects of life related to aging or living with a disability and assistance with all programs and services available in the area tailored specifically to each person's situation (www.dhs.wisconsin.gov/ltcare, accessed November 18, 2009).

The ADRCs provide benefits counseling on private and government programs and assist individuals if they have problems with Medicare, Social Security or other benefits. They also offer consultation and advice about available options to meet an individual's long-term care needs including a pre-admission consultation for all individuals entering nursing facilities, community-based residential facilities and apartment complexes. Services are provided at the Centers, via telephone or through a home visit, whichever is most convenient for the individual seeking help. The ADRCs can also assess an individual's need for services, determine functional eligibility for Medicaid long-term care services, and actually enroll an individual in the state's Family Care Program, a managed long-term care program, if the individual chooses that option (www.dhs.wisconsin.gov/ltcare, accessed November 18, 2009). An extensive recent evaluation of 18 ADRCs (Analytic Insight, 2009) revealed that over 90% of the customers would recommend the ADRC to someone else in almost every ADRC studied.

*Family Care (Managed Long-Term Care)*

As stated above, the ADRCs can assess an individual's level of need for services. Once the individual's level of need is determined, the resource center will provide advice about the options available: enroll in Family Care, the managed long-term care program; choose a different case management system, if available, to stay in the Medicaid fee-for-service system; or to privately pay for services. If the individual chooses Family Care, the resource center will enroll that person in a managed care organization (www.dhs.wisconsin.gov/ltcare, accessed November 18, 2009).

**FIGURE 11**




*Source: FamilyCare and PACE/Partnership Enrollment Data, October 2009. Accessed from www.dhs.wisconsin.gov/ltcare*

Family Care is a Medicaid long-term care program, operating in 48 of Wisconsin's counties, that coordinates a large number of health and long-term care services through a managed care organization (MCO). The MCO receives a monthly per person payment to manage and purchase care for their members who may be living in their own homes, group living arrangements or nursing facilities. The per person payment is based on the level of assessed need performed by the ADRC.

The benefit package contains an extensive list of HCBS, home health, nursing, physical, occupational and speech therapy, adult family homes, other residential options and nursing facility services. MCOs have many options to provide needed services to enrollees to help them achieve their personal outcomes, identified through a person-centered process conducted as part of the assessment and plan of care development process.

Wisconsin differs from other states' managed long-term care systems in a few significant ways. First, it built upon a well-developed system of home and community-based services. Second, it built upon its experience with small, but successful, managed care programs. Finally, it gave its counties and tribes first opportunity to develop and implement the MCO. This has resulted in the Milwaukee County Department of Aging running the largest MCO in Wisconsin with 6,801 members and has resulted in a total of nine (9) MCOs that are all locally-based organizations serving 24,324 members as of October 2009 (www.dhs.wisconsin.gov/ltcare, accessed November 18, 2009). MCOs serve individuals with developmental disabilities (8,392), older adults (15,914) and individuals with physical disabilities (4,193) (October 2009 figures) *(See Figure 11)*.

*Results*

An early independent assessment (APS Healthcare, 2005) found that Family Care produced substantial savings for Wisconsin's Medicaid program. The study compared Medicaid-funded long-term care costs in 2003 and 2004 for people in Family Care to costs for similar people who received long-term care in other programs. Average monthly costs for the Family Care members were $452 lower per person. Spending was $55 lower per person for Milwaukee County. This savings was achieved while managed care enrollees continued to be very satisfied with their services (CMO Member Outcomes, 2003-04).

Analyses of the reasons for the cost savings found that, among other reasons, Family Care favorably affects its members' health and abilities to function, so that over time they have less need for services than their counterparts in the comparison group. While Family Care members had more frequent physician office visits for primary care, expenditures for non-primary care office visits decreased among Family Care members. It appears that more-frequent primary care physician visits provide opportunities to increase prevention and early intervention health care services, which in turn reduce the need for more acute and costly services among members of Family Care (www.dhs.wisconsin.gov/ltcare, accessed November 18, 2009).

Wisconsin continues to be a leader in developing person-centered services for individuals needing long-term care. Another measure of progress is the percentage spending on Medicaid HCBS. Wisconsin has moved from 23% of Medicaid LTC spending on HCBS in 2001 to 28% in 2007 (AARP, 2008, 2009).

## ■ *Arkansas*

Arkansas was one of three (3) states, along with New Jersey and Florida, that were part of the original Cash and Counseling Demonstration. This demonstration program was sponsored

by the Assistant Secretary for Planning and Evaluation in the U.S. Department of Health and Human Services and the Robert Wood Johnson Foundation. The program was evaluated, in part, by using a control group being served with traditional Medicaid personal care services from a licensed provider agency contrasted with a "treatment" group that received a cash allowance based on needs, along with assistance in managing the funds. The "treatment" group participants had great flexibility to hire whomever they wanted to provide personal assistance and could purchase assistive technology, appliances and home modifications. The counseling/fiscal agencies offered a wide variety of services to help people manage their cash including assistance in establishing the required budget plan, developing a plan for back-up support, and training people to hire and manage their own caregivers. They also made contact with participants each month and did reassessments every six (6) months to ensure care needs were being met (CMS Promising Practices, 2003).

Initial results from the demonstration showed high satisfaction rates for overall care arrangements and quality of life, significantly higher than people in the control group. Because monthly cash allowances were approximately equal to the cost of Medicaid personal care services that people would otherwise have received, Arkansas reported no increased cost for providing the cash benefit in lieu of traditional personal care services (CMS Promising Practices, 2003). CMS acknowledged the positive results of the evaluation and began to promote consumer-direction as a viable option for HCBS.

*Independence Plus Waivers*

In 2002, CMS launched the Independence Plus Initiative to afford Medicaid participants and their families increased choice and control over their own services and supports. Independence Plus was based on the experiences and lessons learned from states that pioneered the philosophy of consumer-directed care, including the very successful "cash and counseling" demonstrations. Evaluation results demonstrated a higher level of member satisfaction than with traditional programs with no increase in expenditures.

Independence Plus expedited the process for states to request waiver or demonstration projects. The Independence Plus Waiver programs allow participants to design a package of individualized supports, identify and attain personal goals, and supervise and pay their caregivers. CMS approved eleven Independence Plus waivers (www.cms.hhs.gov, accessed November 19, 2009).

*Current Trends*

Participant-directed services in the Medicaid program continue to grow. The federal government has facilitated this growth. In addition to the Independence Plus program described above, the Deficit Reduction Act of 2005 allows states to develop these programs as part of their Medicaid State Plan, without seeking a waiver. This development makes it easier to implement and manage a participant-directed program. CMS also incorporated language on participant-directed services in its 1915 (c) HCBS waiver template, also facilitating the development and implementation of these programs within a waiver. In addition, beginning in 2008, the U.S. Administration on Aging has funded 28 states, including Indiana, to develop a Community Living Program which emphasizes participant-directed services to avoid institutionalization and in 2008 began partnering with the U.S. Veterans Administration to deliver a Veteran's Directed HCBS program coordinated by a state agency on aging. There is no doubt that participant-direction and the use of individualized budgeting is becoming a Medicaid delivery option throughout the U.S.

## Opportunities to Improve the Financing of Indiana's LTC System

Indiana has consolidated the management of its long-term care programs for older adults and adults with physical disabilities within its Division on Aging. The Division tracks its program expenditures and makes them public. The Division and its stakeholders are able to analyze trends and measure the impact of changes to the system. However, at the local level where the AAAs are working to meet individual care needs, there is a lack of flexibility to manage funding across programs that could delay getting the right services to people at the right time. In addition, there are a number of actions Indiana could pursue to make self-directed care more attractive to a larger group of individuals and families. Finally, public funds are not limitless and the state needs to develop an ongoing campaign to educate its residents, beginning in secondary school, that everyone will likely need long-term care in the future, and that people must plan for how they will pay for that care. Below are some actions that can improve the system.

**1. The Division of Aging should give more flexibility to the AAAs to manage the LTC programs at the local level, with appropriate program rules and performance standards.**

Currently, the ADRCs do a needs assessment for people seeking LTC services. The AAAs then begin an eligibility determination process for those who appear to qualify for public support. The result is that a person may qualify for a number of programs and services. Questions then arise about which program should be accessed to serve their needs. Once a person is assigned to a specific program, there is only one defined set of services and providers to meet their needs. Although it is important that services be allocated to specific budgets, systems should be developed to give more flexibility to meet people's needs across all programs for which they are eligible. For better customer service and improved outcomes, the Division should work with the AAAs to design a more flexible local system, which could include a single allocation for all LTC enrollees, that meets defined standards and outcomes.

**2. Indiana should make it clear that CHOICE funds are permitted to be used pending Medicaid eligibility.**

The Division of Aging has been very clear that it wants the AAAs to utilize federal funds before using the state-funded CHOICE program and has made it a requirement that people cannot receive CHOICE services unless they first apply for Medicaid. At various times the Division has placed additional restrictions on the use of CHOICE funds. While it is understandable why a state may decide to maximize a federally-financed program, it needs to use its state funds to ensure that people can receive appropriate HCBS to avoid unnecessary institutionalization or a decline in their health condition. Since it can take months for Medicaid Waiver approval, people needing services and public support should be able to access needed CHOICE services in the interim. State policy must be clear that this is an appropriate use of state funds.

**3. The Self-Directed Attendant Care program should be enhanced to allow spouses and parents to serve as caregivers, with defined limits, provide people with individualized budgets, and deliver education and training programs for participants and caregivers.**

While it is very positive that Indiana has established a self-directed attendant care program, it should promote its usage by establishing individualized budgets for people to

manage and allowing a broader definition of who can be a caregiver. Most states that have established self-directed programs in recent years have utilized a model of individualized budgets based on assessment of need. The enrollees manage that budget with the assistance of a fiscal intermediary. These state programs are modeled after the successful "cash and counseling" demonstrations, funded and evaluated by CMS, and regularly receive CMS approval. Indiana already has contracted for fiscal intermediary services and this would not be difficult or expensive to design and implement. States have also delegated authority and responsibility to enrollees to choose their own care providers, including spouses and parents. Indiana could allow for these additional categories of caregivers under limited circumstances and where there is a shortage of qualified in-home workers. In addition, participants and caregivers in these programs need education and training in the principles of self-direction and how this program could benefit them. The results for these programs have demonstrated at least cost neutrality, satisfactory quality and high consumer satisfaction.

**4. Indiana should develop and implement a LTC educational campaign targeted to all residents, beginning at the secondary school level and focused on younger working-age adults, that encourages planning for and financing their LTC needs.**

This important educational campaign would focus on making people aware of their potential need for long-term care and encourage them to make a plan for how to pay for that care. One state entity should be designated to coordinate this effort. It would certainly involve the education system and also the insurance department, as facilitating the purchase of LTC insurance should be part of this campaign. Building on the work done with the Indiana Long Term Care Partnership Program, this is a long-term effort where Indiana could demonstrate its leadership.

## SERVICES

Services are a vital component in any balanced long-term care (LTC) system. There must be a sufficient variety of available services offered and enough providers to deliver those services. In analyzing service adequacy, it is important to look at both publicly-funded services and privately-financed services.

### Service Programs

Indiana has a broad array of services available under its Medicaid Aged and Disabled Waiver, the federally-funded Social Services Block Grant (SSBG), the federally-funded Older Americans Act and its state-funded CHOICE (Community and Home Options to Institutional Care for the Elderly and Disabled) program. The Indiana Division of Aging (IDOA) is clear about outlining the services available under each of these programs on its web site (www.in.gov/fssa/da accessed 10/26/09).

**Title III-B of the Older Americans Act** services, available to people without regard to their income or assets, include adult day services, attendant care, handy chore, homemaker, home health aide, licensed practical nurse, counseling, legal assistance, nutrition counseling, pest control, personal emergency response systems, specialized medical equipment and supplies and transportation.

**Social Services Block Grant** services include almost all the same services as Title III-B with the addition of auditory therapy, physical fitness education and programs, and respite care.

**The Medicaid Aged and Disabled Waiver**, targeted to low-income people as an alternative to those individuals requiring a nursing home level of care, includes adult day services, adult foster care, assisted living, attendant care, case management, community transition services (for those leaving nursing facilities), environmental modifications, health care coordination, homemaker, home delivered meals, nutritional supplements, personal emergency response systems, pest control, respite, specialized medical equipment and supplies, transportation, and vehicle modifications. Note: The Indiana Division of Aging has instituted a waiting list for Aged and Disabled Waiver services effective December, 2009.

**The CHOICE program** includes most of the services provided under the Waiver except for adult foster care, assisted living, nutritional supplements and vehicle modifications and covers most of the services covered under Title III-B while also covering day and residential habilitation, behavior management, occupational, speech and physical therapies, registered nurse and other services. It can serve individuals with a lower level of care need than required by the Aged and Disabled Waiver and its financial eligibility requirements are also less strict. However, there has been and continues to be a large waiting list for CHOICE services.

Indiana also maintains a state-funded **Residential Care Assistance Program** which provides financial assistance to people who reside in licensed residential care facilities and county homes operated by local government units. This funding is available only to people who need less care than a Medicaid nursing facility level of care. The state recently placed a moratorium on any new clients due to ongoing budget shortfalls.

In conducting research for this report, there appeared to be no major issues with the variety of services provided, although some services were not readily available in all areas of the state. However, waiting lists for CHOICE and Waiver services affect access to HCBS providers and make it more likely that individuals will end up in a nursing facility whether or not they require care in an institutional setting.

***For Indiana, there were an estimated 1.1 million family caregivers at some time during 2007 at a total economic value of $7.8 billion.***

## Service Providers

When discussing service providers, one should really start with the "informal" caregiver. This term usually refers to unpaid individuals such as family members, friends and neighbors who provide care and can live with the person cared for or live separately. There have been many studies over the past number of years which estimate both the number and economic value of family caregivers. AARP research estimates that in 2007 about 34 million family caregivers provided care at any given point in time and about 52 million provided care at some time during the year. The estimated economic value of their unpaid contribution was approximately $375 billion. AARP research further quantifies these data by state. For Indiana, there were an estimated 1.1 million family caregivers at some time during 2007 at a total economic value of $7.8 billion (AARP PPI, 2008).

Other studies reveal additional interesting facts about these informal caregivers. While the majority of caregivers are between 35-64 years old (NAC and AARP, 2004), for adults over 65

needing care, the average age of caregivers is 63 (AoA, NFCSP, 2004). However, the largest number (41%) of those caring for someone over 65 are children, followed by other relatives (27%), spouses (23%) and non-relatives (8%) (Spector, 2000). Most caregivers are employed (NAC and AARP, 2004) and many provide care for many years. One national study revealed over 40% of caregivers had been providing care for over 5 years and nearly 20% for over 10 years (Donelan, 2002). Not surprisingly, there are numerous studies that demonstrate the impact on caregivers' employment status and physical, mental and emotional health. Approximately two-thirds of working caregivers caring for someone over 65 reported having to rearrange work schedules, decrease their hours or take unpaid leave in order to meet caregiving responsibilities (HHS, Informal Caregiving, 1998). Caregivers may also have an increased risk of cardiovascular disease (Lee, others, 2003) among other adverse health outcomes and 40% of caregivers caring for people with dementia report depressive disorders (Alzheimer's Association and NAC, 2004).

***Forty percent of caregivers caring for people with dementia report issues with depression.***

It is vital for states to develop ways to support this valuable and much-needed caregiving resource. All states take advantage of the federally-funded National Family Caregiver Support Program (Title III-E of the Older Americans Act) which provides services to caregivers of adults over age 60. In Indiana, that money is used for counseling support groups to assist caregivers in understanding issues that arise in the areas of health, nutrition, financial literacy, decision making and problem solving, and training and education that allows them to provide better care. It also provides respite care which can include in-home respite (personal care, homemaker, and others), respite provided by attendance of the client at a senior center or other non-residential program, and institutional respite, which is provided by placing the individual in a setting such as a nursing facility for a short period of time. Supplemental Services are also available and can include home modifications, assistive technologies, emergency response systems, and incontinence supplies. Finally, Family Care Assistance and Information helps caregivers in obtaining information and access to the services and resources that are available within their communities.

Many state Medicaid programs are now also compensating family members for the same home and community-based services (HCBS) described in this report. They are utilizing both their HCBS waivers and their "individualized budget" programs to accomplish this. This has proven a viable method for a number of states to increase the number of reliable in-home caregivers. In Indiana, individuals receiving services under the Medicaid Waiver or the CHOICE program may choose to participate in a Self-Directed Attendant Care program where they have the right to choose their own attendants and essentially serve as the direct employer of the caregiver. This option does not give an individual a specific budget to manage, but it certainly does afford more consumer control and allows the care receiver to choose certain family members and friends to support their care. However, program utilization could be increased by expanding who can be a caregiver.

It is difficult to assess whether Indiana has an adequate supply of providers of all types of services. As previously noted, provider supply was not an issue noted as problematic by Indiana state and local officials or consumer advocates. However, one can assume that there are provider supply issues for certain services in specific areas of the state due to a variety of pay rates and other issues. However, with the overall population aging and the demand for HCBS growing, provider supply is an issue worthy of additional focus in the near term.

It is interesting to note that the Indiana Division of Disability and Rehabilitative Services (DDARS) has developed a training initiative designed to support direct support professionals to help them gain new information, learn new skills and make career connections. Nine providers are participating and there are three different pathway choices: the Ivy Tech Direct Support Professional (DSP) Development Certificate in Human Services; the Indiana College of Direct Support; and the Department of Labor's Apprenticeship Program. Each pathway includes 200 hours of instruction, 300 hours of on-the-job training or work experience and results in a DSP certificate (www.fssa.gov accessed 10/25/09). The Division of Aging should certainly evaluate this model for replication with its own provider work force.

## Housing

Housing is a serious issue for states that seek a balanced LTC system for a variety of reasons. Many individuals who need care and want to remain at home often need their home modified after a fall, stroke or progressive illness, but either do not have the resources to make these modifications or cannot get permission from a landlord to do so. In Indiana, the Medicaid Aged and Disabled Waiver will pay for environmental modifications if necessary to ensure the health, welfare and safety of the individual and without which the individual would require institutionalization. Maintenance is limited to $500 a year and there is a $15,000 lifetime cap on these modifications. The CHOICE program has a similar benefit without a lifetime cap, with similar requirements to avoid institutionalization, and will finance modifications in rental homes or apartments with permission of the landlord.

Many state Medicaid programs also pay for "housing with services" programs such as assisted living and adult foster care. While states vary in how they define these services and what they will pay for, they are all similar in that they have a community-based group housing arrangement where long-term services and supports are delivered to those who need them. Indiana's Aged and Disabled Waiver covers both adult foster care and assisted living services. It should be noted that Medicaid does not cover room and board, but only covers care services.

Additionally, state services programs have been working with their state housing counterparts to address these issues in a variety of ways including new construction, rehabilitation, and rent subsidies with preferences for older adults and individuals with disabilities. The Indiana Housing and Community Development Authority, in partnership with the Indiana Division of Aging, implemented a new program called Home Again targeted to people moving out of institutions which makes existing subsidized housing units accessible and even more affordable (www.in.gov/ihcda accessed 10/25/09). This is a good example of a state partnership which should become the basis for other affordable, accessible housing development targeted to individuals with disabilities.

## Successful State Models

Indiana is operating some programs that show it understands the need for a broad range of services now and in the future. As noted above, the Medicaid Waiver pays for both adult foster care and assisted living, models that pay for services delivered within specific housing. Family caregivers are supported with a broad range of services, although the need far exceeds what is available. A subsidized housing program has begun to support individuals moving from a nursing facility back to a community residence.

Following are examples of what other states are doing to support caregivers, develop affordable, accessible housing coupled with needed services and ensure an adequate supply of trained workers, especially those working with people in their homes.

### *Workforce Initiatives*

**State Actions to Address the Need for Trained Direct Service Workers**

- *Improving wages and benefits*
- *Improving the work environment*
- *Reforming training and credentialing systems*
- *Engaging the public workforce and education systems in recruitment and training*

The National Direct Service Workforce (DSW) Resource Center was created by the Centers for Medicare and Medicaid Services (CMS) in 2006 to respond to the large and growing shortage of workers who provide direct care and personal assistance to individuals who need long term services and supports in the United States. The Center strives to support the successful implementation of efforts to improve recruitment and retention of direct support professionals who assist people with disabilities and older adults to live independently and with dignity in the community. This includes direct support professionals, personal care attendants, personal assistance providers, home care aides, home health aides and others. The DSW Resource Center brings together experts in the field of direct service workforce policy from organizations including The Lewin Group, the Paraprofessional Healthcare Institute (PHI), the Institute for the Future of Aging Services and the University of Minnesota's Research and Training Center on Community Living (www.dswresourcecenter.org). Rather than focus on any particular state, below are several examples of what states are doing to address this issue.

Two recent publications by the DSW Resource Center synthesize states' strategies and actions to address the need for an adequate supply of trained workers. The strategies are grouped into broad areas below:

#### *Improving wages and benefits*

Studies have concluded that wage rates for these workers impact vacancy rates (Larson and Hewitt, 2005) and turnover (IOM, 2008). Higher wages and better benefits significantly reduced turnover and increased job satisfaction and intent to stay in some demonstration sites (BJBC, 2008). State and local wage strategies have included: targeted wage increases; minimum wage requirements; public authorities to allow collective bargaining for independent providers; guaranteed hours; and wage increases tied to training (Hewitt, 2008; IOM, 2008; Wright, 2009). State and local strategies for accessing health benefits have included: allowing employers and workers to purchase coverage through larger purchasers, like state plans; providing increased compensation directed to health coverage; and assisting workers with health expenses through prescription discount cards, health savings accounts and health reimbursement accounts (Hewitt, 2008).

#### *Improving the work environment*

Studies have shown that the relationship between supervisors and workers plays a significant role in job satisfaction and intent to stay (IOM, 2008; Hewitt, 2008, Larson & Hewitt, 2005; BJBC, 2008). Positive supervision (as opposed to punitive) can greatly increase a worker's sense of value, job satisfaction and intent to stay (IOM, 2008). A variety of workplace approaches, such

as mentoring, use of self-directed work teams and career ladders, have been linked to employee satisfaction (IOM, 2008). State and local strategies have included: employer recognition programs; payment incentives; enhanced availability of training opportunities; and opportunities for career advancement (Hewitt, 2008).

***Reforming the training and credentialing systems***

States and providers are working on both their training and credentialing programs to increase workforce skills and improve retention (Hewitt, 2008). Some states such as Washington have increased the amount of training needed to provide Medicaid in-home care and have specified the requirements of that training. Others have developed and implemented standardized training curricula and streamlined credentialing for these workers (Hewitt, 2008). Still others have adopted the U.S. Department of Labor apprenticeship programs for different types of direct service workers. Four apprenticeship programs have been developed: Direct Support Specialist; Certified Nurse Assistant; Home Health Aide; and Health Support Specialist. These programs combine workplace learning, training and on the job skill implementation (Hewitt, 2008).

***Engaging the public workforce and education systems in recruitment and training***

Some states have created strong partnerships between the workforce development system, employers and educational institutions such as community colleges (Seavey, 2006) to enhance recruitment and job quality through improved training, job redesign and creating career pathways for advancement (Hewitt, 2008). The state department of labor is a good source for potential workers, workforce investment boards can work with employers on job creation initiatives and post-secondary and adult education programs can help design and deliver needed training. Direct service worker development requires the resources that are found in a variety of public and private entities and demands a coordinated approach.

## *Housing*

An increasing number of states have realized that supporting individuals' choices to receive long-term services and supports in community settings requires both the necessary services and affordable, accessible housing. While human services entities generally do not have any direct control over housing development, many have engaged public and private entities at the state and local level to help them realize the need for affordable, accessible housing for older adults and adults with disabilities.

There are now numerous examples of state and local cooperation to provide housing opportunities for people leaving nursing facilities, as has been developed in Indiana. There has also been renewed emphasis on developing new subsidized housing through federal housing programs, such as the Supportive Housing for the Elderly (Section 202) and Supportive Housing for People with Disabilities (Section 811). However, some advocates for these populations argue that this housing is segregated and have pressed for more integrated housing with people of various incomes and abilities. Federal Housing Choice Vouchers are being used to allow older adults and adults with disabilities to live in a variety of settings, but there is usually a long waiting list for these vouchers. There is also work on supportive housing to create units within existing building where services can be delivered. Additionally, states such as Indiana have realized that one of the best methods to ensure accessible, affordable housing is to help individuals needing services to modify their existing housing to suit their changing needs.

Below are two examples of "purpose-built" affordable assisted living. One was new construction and one was a conversion of an existing building. Housing is so vital to supporting community service delivery that it needs to be addressed in many ways to meet individual needs and preferences. Again, these are just two successful examples.

### ■ *Arkansas (new construction)*

Arkansas constructed an affordable assisted living residence consisting of 45 units, all of which are available to individuals who qualify for Arkansas' Medicaid HCBS Waiver. The project was developed under the Robert Wood Johnson Foundation's Coming Home Program, an affordable assisted living demonstration program.

This project demonstrates excellent collaboration between housing finance and development agencies and LTC service agencies and providers at the state and local level. From the state housing side, the Arkansas Development Finance Authority agreed to set aside Low Income Housing Tax Credits and HOME funds, both federal development programs, to support the project and publicized the availability of predevelopment funds and state and federal tax credits for the project. On the state services side, the Division of Aging and Adult Services helped enact legislation governing the assisted living industry and created regulations to implement the legislation. It also applied for and received approval for a new Medicaid HCBS Waiver to cover services in assisted living.

On the local level, the Community Development Corporation of Bentonville/Bella Vista, Inc. recognized the need for assisted living and while it had experience developing housing, it had no experience providing personal care and health services. It found a service provider, Mercy Health Systems of Northwest Arkansas, that was willing to provide services to assisted living residents and was already delivering similar services to Medicaid enrollees in that area.

Below are some interesting data about the residents who had moved into the residence, six months after its opening:

91% of the residents were from that county

73% were Medicaid enrollees

56% moved from a private home, alone or with spouse

24% moved from a private home, with family

15% moved from a residential care facility

5% moved from a nursing facility

49% had mild cognitive impairment or dementia

93% were incapable of administering their medications

67% would have gone to a nursing facility if affordable assisted living not available

*(NCB Capital Impact, 2007)*

### ■ *Vermont (conversion of existing building)*

Cathedral Square Senior Living (CSSL) is a U.S. Department of Housing and Urban Development (HUD) Assisted Living Conversion Project with 80 independent and 28 assisted living units in a 10-story building located in Burlington, Vermont. This existing building was rehabilitated in order to meet the physical standards for assisted living licensing. The facility is a combination of independent and assisted living. The building provides apartments ranging in size from 300 to 560 square

feet. All of the assisted living units are divided between the second and third floors of the building, are fully accessible and include a kitchenette with refrigerator, microwave, sink and storage cabinets. These single occupancy units also provide a private accessible bathroom and telephone hookup.

Seven units are designated for individuals with incomes not exceeding 100% area median income while the remaining units are available to individuals with incomes at 30% to 80% area median income. The facility gives preference to individuals with incomes below 30% median income.

The non-profit developer's goal was to provide an alternative for its low income seniors when their service needs exceeded the support available in independent housing. Among the challenges were that this was a new HUD program, state assisted living regulations had not been issued and its experience was in housing not in health care. Even with these challenges, the building serves a population that is 100% low or moderate income and a large number of residents assessed at a nursing home level-of-care.

The Cathedral Square facility provides assisted living to 28 residents who are in need of a greater level of service than offered in the independent living floors of the building. When a recent case study was completed (NCB, 2007), data revealed:

| | |
|---|---|
| 75% | of the assisted living residents used a housing subsidy in order to cover the room and board cost |
| 54% | were Medicaid clients with the remaining residents paying privately for their services |
| 46% | of the residents were at the basic level of personal care services needing assistance with activities of daily living (ADL), medication management, general supervision, and nursing when the facility opened |
| 54% | needed additional services |
| 25% | of the residents had a mild cognitive impairment |
| 86% | of the residents were from the local area and moved to the facility from a personal residence when they could no longer live by themselves at home |
| 13% | of the residents were living in a residential care facility before moving in |
| 8% | were living in a nursing home before locating in the assisted living facility. |

## Family Caregiver Support

### ■ *Pennsylvania*

The Commonwealth of Pennsylvania began its Family Caregiver Support Program with a four county pilot program in 1987 and expanded it to a statewide program in 1990, well before the passage of the National Family Caregivers Support Act in 2000. The program's services were targeted to supporting primary family caregivers of relatives with disabilities age 60 and older who were unable to perform some activities of daily living (ADLs) or under age 60 with chronic dementia. Caregivers had to be related by blood or marriage and live together.

Services began with an assessment of a family's needs by a specially trained social worker who developed a care plan. The social worker also provided information about federal and state programs, Medicare supplemental and long-term care insurance, caregiver support groups and techniques for better caregiving (CMS Promising Practices, 2004). The assessment is the same one used to determine eligibility for several other HCBS programs and social workers could assist in the application process.

Today the Department of Aging describes the program as a package of benefits that begins with an assessment of both caregiver needs and the older person receiving care. Benefits can also include counseling, education and information. Families that qualify based on income can receive up to $200 a month for help with out-of-pocket expenses ranging from respite care to adult briefs and grants up to $2000 to modify a home or purchase assistive devices to accommodate the frail relative. Such adaptations could include a stair climb or bathroom modification (www.aging.pa.us accessed 11/21/09).

## Opportunities to Improve Indiana's LTC Services and Supports

**1. Indiana should develop and implement a variety of methods to encourage and sustain family caregivers such as providing more opportunities for respite care, education, training and other forms of health and emotional support.**

As stated above, Indiana has made progress in expanding the amount and type of HCBS. The state needs to put caregiver support higher on its priority list. No one denies how vital families are in supporting their loved ones who need long-term services and supports. One of the major reasons individuals are forced to leave their homes to get needed services is because there is not sufficient family support. Those family caregivers need to be encouraged to keep supporting their loved ones and know that their unpaid work is being acknowledged and supported. Education, training and time off from caregiving, including paid family medical leave, are all proven methods to accomplish this goal. A number of localities across the country are also focusing on the health and well-being of the caregiver. Indiana should assess caregiver needs and develop programs to address them.

**2. Indiana should designate a lead entity to take responsibility for recruiting and training needed LTC workers. AAAs should be charged with identifying gaps in services and be responsible for provider recruitment and retention, but the state must take responsibility to develop a sufficient, quality workforce to meet the state's LTC needs now and in the future.**

Although worker and provider shortages were not major issues identified in this study, there was no clear understanding what entity had responsibility for provider recruitment and retention. While some acknowledged that identifying gaps in services was an AAA responsibility, there was no clear authority or responsibility given for local provider recruitment and retention. The AAAs are in the best position to know about gaps and shortages and, with appropriate resources, should be clearly given responsibility for provider sufficiency. However, the state must have a coordinated LTC workforce strategy, especially in the recruitment and training of in-home workers, given projected demographic changes. Workforce and education entities must work with human services entities to develop and implement that strategy.

**3. Indiana must focus its workforce strategy on recruiting and retaining in-home care providers to meet the need for services where people want them. This must include a focus on increased pay and benefits as well as education and training.**

As noted above, DDARS has developed and implemented a solid program to develop the direct support professional workforce that serves its clients and others. While there was no evaluative work discovered on the outcomes of this program, this is exactly the type of program that needs to be considered for other parts of the workforce. Consumers want quality services and are willing to pay a reasonable amount for those services. A trained and well-compensated in-home workforce not only supports the individual needing care at home, but

also supports family caregiving. Developing and implementing a thoughtful strategy is vital for the sustainability of a LTC system into the future.

**4. Affordable, accessible housing for individuals with disabilities and those needing long-term services and supports must be a priority for the state. A lead entity must be designated and given the responsibility of ensuring that a specific number of units are developed.**

The Indiana Housing and Community Development Authority, in partnership with the Division of Aging, appears to have developed a solid program of subsidized financing and accessibility modification through its Home Again program. This appears to be a good concept which is being implemented, but much more needs to be done. Whether new units are developed and/or existing ones are modified, there needs to be a coordinated focus on "housing with services" models. There are many ways to develop these models, but they all begin with affordable, accessible housing where people can receive the care services they need. Assisted living is just one model. Indiana needs to research and implement models that work for its state and give one entity responsibility for design and development.

## QUALITY

Everyone wants to have quality LTC services: consumers who receive services; government, insurers and individuals who pay for services; policy makers who design services programs; and regulators who license and monitor those services. However, there are no absolute standards by which all agree on what constitutes quality. Some individuals and entities are focused on ensuring that services are delivered by correctly licensed personnel; others are focused on whether the right services are being provided. Some are focused on whether services are being delivered on a timely basis; others are focused on whether they are being billed for services that are not being provided. Some are focused on whether the services are being delivered in a respectful manner; other are focused on the outcomes achieved through the delivery of the services. There are many ways to evaluate quality, but certainly consumer opinions of quality must be solicited and government must ensure that the right services are being delivered at the right time and in the right manner and it is not paying for services that are not authorized and/or delivered.

**What is Quality LTC Service?**

- *services being delivered by correctly licensed personnel*
- *the right services being provided*
- *services being delivered on a timely basis*
- *being billed only for services provided*
- *services being delivered in a respectful manner*
- *specific outcomes achieved through services delivery*

The Centers for Medicare and Medicaid Services (CMS) has been focused on quality in nursing homes for decades and has more recently been focused on quality in HCBS. There are clearly-defined federal laws and regulations that states enforce for nursing home quality. However, states continue to have great latitude to design their quality assurance (QA) program for HCBS. CMS has adopted an HCBS "quality framework" for states to follow for the quality management of its quality assurance and improvement program. It also requires that a quality management (QM) strategy be defined in a Waiver application. The QM strategy must include:

- discovery activities conducted to ensure the health and welfare of the waiver participant;

- remediation processes followed when problems are identified;
- system improvement processes followed in response to aggregated, analyzed information collected;
- the roles and responsibilities of those conducting discovery activities, assessing, remediating and improving system functions; and
- the process the state will use to continually assess the effectiveness of the QM strategy and revise it as necessary and appropriate.

CMS also requires the state to describe how it assesses and addresses risk to a participant, how it addresses emergencies and how it makes provision for back-up plans when there is a service failure.

In reviewing Indiana's Aged and Disabled Waiver application, Indiana has developed a credible quality management strategy, on paper, for the operation of its Waiver program. It has identified areas that it will monitor, how it will monitor and methods it will utilize to remediate issues. It has assigned specific roles and responsibilities for the Office of Medicaid Policy and Planning, the Division of Aging, the AAAs and its outside contractors. It is less clear how the system improvement process will work, but there are entities assigned to review and analyze data. One could assume that improvements would be made based on those evaluations.

The Division recently reported (IDOA, 9/09) that it had begun field testing a plan of care review and a consumer outcomes and satisfaction survey for the Aged and Disabled Waiver. These activities should reveal data about whether individuals' plans of care are meeting their identified needs and whether program participants are satisfied with their services. This is part of the QA management strategy outlined in the waiver. In addition, the IDOA will begin surveying non-licensed providers on a random basis that have not been surveyed in the last three years. Again, this is part of the QA strategy outlined in the waiver.

## Nursing Facility Quality

While all states take responsibility, and are funded, to monitor and enforce federal law and regulation applicable to nursing facility quality, it should be noted that Indiana is one of a few, but growing number of states that have worked to structure their payment system to account for quality. The current reimbursement system, which is in the process of being changed, rewards all facilities based on quality from $1.50-$3.00 per resident day. The proposed system (IDOA, 9/09) would eliminate a quality payment for those facilities scoring in the bottom quartile and would increase the payment in the top quartile from $3.00 to $5.75. This would clearly make a bigger distinction in paying for quality. The proposed new system would also eliminate the "profit add-on" for facilities in the bottom quartile, maintain the benefit for the top quartile and reward others on a graduated basis. Indiana is planning for further revision to take effect in 2011 based on a series of measures modeled on Minnesota and Iowa's current programs. This will continue its strategy to clarify its expectations for nursing facility quality.

## Opportunities to Improve the Quality of Indiana's LTC System

**1. Indiana must define specific measures of HCBS quality related to the health, wellness and satisfaction of the program participant.**

Indiana has done good work defining a quality assurance management strategy for participants in its Medicaid waiver program. It clearly defines expectations and roles and

responsibilities and is implementing a monitoring system that could ensure quality systems. However, it needs to adopt specific quality measures as they relate to the program participant. First, these need to include standards for consumer satisfaction, especially as it relates to supporting the independence of the individual and the dignity and respect each deserves in how services are delivered. Additionally, certain measures such as avoidable hospitalizations and nursing facility admissions, and emergency room visits ought to be considered. Similar quality assurance standards should be developed and implemented for non-Medicaid HCBS.

**2. The Division of Aging should ensure that appropriate consumer stakeholders are involved in designing the quality measures and quality incentive program utilized to reward nursing facility quality.**

State and local consumer advocacy organizations, AAAs, LTC ombudsman program staff and other consumer advocates have direct experience in assessing quality and advocating for improvements in nursing home care. As such, they should be included in a formal and ongoing process to monitor nursing facility quality and make recommendations for continued improvements.

## CONCLUSION

Indiana has made good progress developing a long-term care system that gives more people choices of services and setting with the passage and implementation of SEA 493 of 2003. However, it still ranks near the bottom of all states in the percentage of public resources it spends on home and community-based services, those services people want the most and are most cost-effective, compared to money spent on nursing facilities. Indiana has developed a good base from which it needs to continue to build in order to meet the current and projected demand for HCBS. As outlined in this paper, there are many steps it could take to improve its ability to deliver the quality, cost-effective home and community-based services that Hoosiers want and deserve.

Indiana needs to make sure that its residents understand their individual and family requirements for future long-term care services and how to plan and pay for them. It needs to ensure that people needing long-term care have comprehensive, understandable and unbiased information at crucial times and places, and counseling when needed, to make proper choices for themselves and their families. Indiana must make rapid decisions on eligibility for public resources so that families have meaningful choices to address their long-term care needs. It should give its AAAs the resources and funding flexibility at the local level to address a growing population of individuals needing counseling and services. Indiana must support family caregiving in new and expanding ways and ensure there are an adequate number of qualified paid caregivers, especially those who deliver services at home. It needs to give clear authority and direction to its AAAs in developing sufficient provider resources and delivering quality, cost-effective services options. It also needs to ensure that services are delivered according to individual needs and desires and that they reach desired consumer and system outcomes. Reaching these goals will take a focused effort, but with the commitment of consumer advocates, individuals and families, providers, government and non-profit organizations, Indiana can meet the needs and preferences of its residents for quality, affordable long-term care services and supports.

# INTERVIEWS

*- People Interviewed for this Paper -*

## State Legislators

**The Honorable Senator Vaneta Becker**

**The Honorable Representative Charlie Brown**

**The Honorable Representative Tim N. Brown**

**The Honorable Senator Patricia L. Miller**

**The Honorable Representative Peggy Welch**

## State Executive Branch Officials

**Pat Cassanova**, Director, Office of Medicaid Policy and Planning, Indiana Family and Social Services Administration

**Faith Laird**, Director, Division of Aging, Indiana Family and Social Services Administration

**Megan Ornellas**, Chief Financial Officer, Indiana Family and Social Services Administration, former Director, Indiana Division of Aging

## Area Agencies on Aging

**Kenneth Adkins**, President/CEO, LifeStream Services, Inc. (Area 6 AAA)

**Sally Beckley**, Executive Director, LifeTime Resources, Inc. (Area 12 AAA)

**Orion Bell**, Executive Director, Central Indiana Council on Aging (Area 8 AAA)

**Joan Cuson**, Executive Director, REAL Services, Inc. (Area 2 AAA)

**Amy DiStaulo**, Interim Executive Director, Indiana Association of Area Agencies on Aging

**Anne Jacoby**, former Executive Director, Generations, Inc. (Area 13 AAA); AARP Volunteer Consultant on Health Care

**Loralee Moore**, Program Director, Link-Age, Aging and Community Services of South Central Indiana (Area 11 AAA)

## Service Providers

**Robert Decker**, President, Hoosier Owners and Providers for the Elderly

**Jim Leich**, President/CEO, Indiana Association of Homes and Services for the Aging

**Jean Macdonald**, Director of Regulatory Affairs, Indiana Association for Home and Hospice Care

**Vince McGowen**, Chairman and Legislative/Reimbursement Advisor, Hoosier Owners and Providers for the Elderly

**Amy Mendoza**, former Director of Public Affairs and Communication, Indiana Health Care Association

**Steve Smith**, Executive Director, Indiana Health Care Association

**Todd Stallings**, Executive Director, Indiana Association for Home and Hospice Care

## Long Term Care Insurance Industry

**Susan Coronel**, Senior Long-Term Care Director, America's Health Insurance Plans

## Consumer Advocates

**Elmer Blankenship**, President, Indiana Alliance of Retired Americans

**John Cardwell**, Executive Director, Generations Project; Chair, Indiana Home Care Task Force

**Rich Couture**, Member, AARP Volunteer Executive Council/Consumer

**John Dickerson**, Executive Director, The Arc of Indiana

**Joe Everett**, Member, AARP Volunteer Executive Council/Consumer

**Dennis Frick**, Director, Senior Law Project, Indiana Legal Services, Inc.

**Clyde Hall**, President, AARP Volunteer Executive Council/Consumer

**Anita Hardin**, AARP Volunteer/Consumer

**Arnell Hill**, AARP Volunteer/Consumer

**Bob Jackson**, Member, AARP Volunteer Executive Council/Consumer

**Ben Leslie**, AARP Volunteer/Consumer

**Norma Leslie**, AARP Volunteer/Consumer

**Claire E. Lewis**, Attorney at Law

**Pat McQuade**, AARP Volunteer/Consumer

**Michelle Niemier**, Executive Director, United Senior Action, Inc.

**Anita Price**, AARP Volunteer/Consumer

**Bill Schaefer**, AARP Volunteer/Consumer

**Gene Wease**, AARP Volunteer/Consumer

**Jeanne Wease**, AARP Volunteer/Consumer

**Bob White**, Member, AARP Volunteer Executive Council/Consumer

**Marilyn White**, AARP Volunteer/Consumer

# REFERENCES


Alecxih, L.: *1995-2005 Medicaid LTC Trends for Elderly and Individuals Under Age 65 with Physical Disabilities*. Presentation to the 2007 CMS New Freedom Initiative Conference. Baltimore, MD. 2007.

Alzheimer's Association and the National Alliance for Caregiving: *Families Care: Alzheimer's Caregiving in the United States*. Chicago, IL and Bethesda, MD. 2004.

Analytic Insight: *Wisconsin Department of Health Services, Aging and Disability Resource Center Evaluation*. Auburn, ME. April 2009.

APS Healthcare, Inc: *Family Care Independent Assessment*, 2003-04. Madison, Wisconsin. 2005.

AARP: *Hoosiers Speak Out: Indiana's Health Care System Needs Reform*. AARP Knowledge Management. Washington, D.C. 2008.

AARP: *Across the States; Profiles of Long-Term Care and Independent Living.* Washington, D.C. 2009.

AARP Public Policy Institute: *Valuing the Invaluable: The Economic Value of Family Caregiving, 2008 Update*. Washington, D.C. 2008.

Administration on Aging: *National Family Caregiver Support Program Complete Resource Guide*. Washington, D.C. 2004.

Aging and Disability Resource Center Technical Assistance Exchange: *Aging and Disability Resource Center Successes, March 2009*. www.adrc-tae.org accessed 10/25/09.

Better Jobs, Better Care, Institute for the Future of Aging Services: *Solutions You Can Use: Transforming the Long-Term Care Workforce*. Washington, D.C. 2008.

Centers for Medicare and Medicaid Services: *State Efforts to Rebalance Their Long Term Support Systems and Enable "Money to Follow the Person"*. Washington, D.C. 2003.

Crowley, J.: *Vermont's Choices for Care Medicaid Long-Term Services Waiver: Progress and Challenges as the Program Concluded its Third Year.* Kaiser Commission on Medicaid and the Uninsured. Washington, D.C. November 2008.

Donelan, K. et al: *Challenged to Care: Informal Caregivers in a Changing Health System*. Health Affairs 21:222-231. 2002.

Eiken, S.: *Technical Assistance Guide to Assessing a State Long-Term Care System*. Thomson Reuters. Cambridge, MA. 2006.

Flood, P.: *Shifting the Balance, Act 160*. Presentation to the National Academy for State Health Policy Conference. Nashville, TN. 2005.

Health and Human Services, U.S. Department: *Informal Caregiving: Compassion in Action*. Washington, D.C. 1998.

Hewitt et al: *A synthesis of direct service workforce demographics and challenges across intellectual/developmental disabilities, aging, physical disabilities, and behavioral health*. National Direct Service Workforce Resource Center. November 2008.

Indiana Division of Aging: *Balancing Long Term Care-Phase 2*. Indianapolis, Indiana. September 2009.

Indiana Division of Aging: *Financial Review (July 1, 2008-June 30, 2009)*. Indianapolis, Indiana. 2009.

Indiana Division of Aging: *Indiana ADRC Semi-Annual Report*. www.adrc-tae.org accessed 10/24/09.

Institute of Medicine: *Retooling for an Aging America: Building the Healthcare Workforce (Chapter 5)*. Washington, D.C. 2008.

Kane, R. et al: *Rebalancing Long-Term Care Systems in Washington*. Centers for Medicare and Medicaid Services. Washington, D.C. 2006.

Laird, Faith: *Letter to All AAA Directors and Waiver Liaisons*. Indianapolis, IN. December 3, 2009.

Larson and Hewitt: *Staff Recruitment, Retention and Training Strategies from CMS Direct Service Workforce Demonstration Promising Practices in Marketing, Recruitment and Selection Interventions* (Background Section). University of Minnesota, Research and Training Center on Community Living in partnership with The Lewin Group. 2006.

Lee, S. et al: *Caregiving and Risk of Coronary Heart Disease in U.S. Women: A Prospective Study*. American Journal of Preventive Medicine 24: 113-119. 2003.

Mollica, R.: *Expediting Medicaid Financial Eligibility*. Community Living Exchange Collaborative. New Brunswick, N.J. 2004.

Mollica, R.: *Fast Track, Presumptive and Expedited Eligibility*. National Academy for State Health Policy. Portland, ME. 2005.

National Alliance for Caregiving and AARP: *Caregiving in the U.S*. Washington, D.C. 2004.

NCB Development Corporation: *Arkansas Case Study*. Prepared for the State Leadership Symposium on Coordinating and Leveraging Long Term Supports with Affordable and Accessible Housing. Washington, D.C. November 2005.

NCB Development Corporation: *Vermont Case Study*. Washington, D.C. 2007.

*New Jersey Department of Health and Senior Services: Independence, Dignity and Choice in Long-Term Care Act Report*. Trenton, N.J. 2007.

New Jersey Office of Legislative Services: *Background Paper: Nursing Home Alternatives and Their Impact on Medicaid Nursing Facility Expenditures and Utilization*. Trenton, N.J. April 2008.

Reinhard, S. and Polansky, P.: *New Jersey's Community Choice Counseling Program: Past, Present and Future*. Presentation to the Nursing Home Transition Summit, Rutgers Center for State Health Policy. September 2005.

Seavey, D.: *Engaging the public workforce development system: Strategies for investing in the direct care workforce*. Better Jobs, Better Care, Institute for the Future of Aging Services. Washington, D.C. 2006.

Spector, W.D. et al: *The Characteristics of Long Term-Care Users*. Agency for Healthcare Research and Quality. Rockville, MD. 2000.

The Medstat Group: *Promising Practices in Home and Community-Based Services*. Centers for Medicare and Medicaid Services. Washington, D.C. 2002-2005.

Vermont Division of Aging and Disability Services: *Choices for Care, Quarterly Data Report*. Montpelier, VT. July 2009.

Washington State Department of Social and Health Services, Aging and Disability Services Administration*: An Introduction to ADSA*. Olympia, WA. 2009.

Washington State Department of Social and Health Services: *Fact Sheet: A Successful Vision*. Olympia, WA. July 2009.

Wisconsin Department of Health and Family Services: *Family Care Quality, CMO Member Outcomes: Round 4*. Madison, WI. 2004.

Wright, B.: *Strategies for Improving DSW Recruitment, Retention, and Quality*. CMS National Direct Service Workforce Resource Center. October 2009.

www.aarp.org/research/longtermcare

www.aging.state.pa.us

www.aoa.gov

www.cms.hhs.gov

www.dhs.wisconsin.gov/ltcare

www.dswresourcecenter.org

www.in.gov/fssa/da

www.aging.pa.us

www.state.nj.us/health/senior/choice