



## *The Moving Forward Series – Part 5*

### caretaker support & quality management

*This is the fifth of a six-part series concerning the implementation of Senate Enrolled Act (SEA) 493, a law passed by the Indiana General Assembly in 2003 to expand the availability of community-based care in Indiana. Unpaid family caretakers provide the vast majority of the care and support that the frail elderly (and disabled) need to live independently in their own homes within the community. For people who rely on this unpaid family care – and for those receiving care in all other types of long term care settings – a defined quality management structure that is responsive to the rights and prerogatives of consumers must be in place to better accommodate the needs of a growing number of consumers who prefer to receive care in non-institutional settings.*

*The typical long term care user receives a mixture of services from a variety of providers – including unpaid family caregivers, services paid for through private resources, and those paid for with state and federal dollars. Any system designed to support caregivers as well as monitor and improve overall system quality must take this fact into account. Part 5 of the Moving Forward Series focuses on the work Indiana must do to ensure that long term care rebalancing will occur with a solid quality management structure already in place, and that all new initiatives and program expansions will include necessary quality features – including those that support caretakers.*

#### ***Designing a system of caretaker support***

According to *Moving Forward*, “Nationally, nearly one out of every four households (22.4 million) is involved with caretaking of a person aged 50 and over. Nearly one fifth of unpaid caregivers spend more than 40 hours per week providing care, with the average caretaking span covering 4.5 years.”

The contributions of unpaid family caregivers are of tremendous value to both individuals receiving care and larger society. If the 29 billion hours of care given per year by the nation’s 27 million caretakers are accounted for, they represent more than \$257 billion in market value. In Indiana, in the year 2003, it was estimated that more than 586,000 caregivers provided 628 million hours of care per year at an annual market value of more than \$5.5 billion.

In short, the ability of any state to maintain a comprehensive system of home and community based services is substantially improved if that state invests in a system of caretaker support. The failure to employ such a system of supports often results in unacceptable consequences for caregivers and those receiving care that include: loss of employment, loss of home, inadequate care, increased cost for state and federal taxpayers, and increased placements in institutional care settings.

*Moving Forward* recommends that Indiana implement the caretaker support provisions of SEA 493 in order to provide the following five basic services for family caregivers:

1. Information to caretakers about available services;
2. Assistance to caretakers in gaining access to supportive services;
3. Individual counseling, support groups, and caretaker training to assist caretakers in making decisions and solving problems relating to their roles;
4. Respite care to temporarily relieve caretakers from their responsibilities; and
5. Supplemental services, on a limited basis, to complement the care provided by caretakers.

Primarily through funding through the Older Americans Act, Indiana does have in place several caretaker supports that are primarily administered through its 16 area agencies on aging. The full implementation of SEA 493 will further strengthen these supports and continue to build on the valuable services unpaid family caregivers provide to their families and communities.

### ***Ensuring quality in our long term care system***

According to *Moving Forward*, “Full compliance with SEA 493 depends on a quality management infrastructure that is flexible enough to adapt to the shift in service delivery from institutional to community-based settings.”

Quality management in long-term care service delivery has come to mean many things to many people. From a consumer perspective, quality management represents consumer choice, safety, independence, dignity and protection issues, emergency response, and provider qualifications and compliance with established standards. For institutional and community residential providers, quality management takes the form of survey and certification processes, and general compliance with provider standards. For the State, quality management means all those things and more, such as assurance in quality of service delivery, positive and improved health outcomes of beneficiaries, fiscal accountability, and program administration, monitoring and oversight.

According to the Centers for Medicare and Medicaid Services, there are three main components of program quality. These are:

1. Quality system design
2. Quality assurance
3. Quality improvement

The first, quality system design, provides a foundation for the others. By specifying methods for how monitoring activities will be carried out, it provides the framework by which quality assurance and improvement can occur.

All three components appear to embody the full scope of requirements and mechanisms necessary for assuring that consumer rights and preferences are protected and that all home and community-based services programs (regardless of funding source) include proper safeguards, meet accountability requirements and expectations, and maintain timely and thorough response capabilities. Each of these components is discussed in detail in *Moving Forward*.

“As Indiana begins to implement SEA 493, expand available home and community based services, and expand eligibility to those services, it must also build out a system of quality management reflective of those changes,” according to John Cardwell, director of The Generations Project. “While building this system,” Cardwell concluded, “It is critical that the rights and prerogatives of consumers drive this process.”

The full *Moving Forward Report* is available at [www.generationsproject.org](http://www.generationsproject.org)