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Doing Things Better:

Long Term Care Solutions for Indiana

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Most of all, The Generations Project wants to thank senior citizens, persons with disabilities, family caregivers and home care workers for not giving up on themselves and others….for always being willing to advocate for the health care needs of everyone as they make their case for home and community based services (HCBS).

Finally, the Project wants to thank forward thinking private sector leaders, lawmakers, and providers, including nursing home lobbyists, that are endeavoring to work with consumers to establish a better system of HCBS in Indiana. Everyone acknowledges the present long term care system is not sustainable. Too many dollars and human lives are wasted. Consequently, it is in our collective interest to find workable solutions. Based on what we have learned from the real world experiences of consumers, The Generations Project believes those solutions are found within the framework of long term care rebalancing. Many of those solutions are identified in this white paper. They are people proven solutions that have worked in other states. They will work in Indiana.

John Cardwell, author of *Doing Things Better*
and director, The Generations Project

Doing Things Better: Long Term Care Solutions for Indiana

A Generations Project white paper regarding CHOICE and other home and community based solutions for Hoosiers October 2012

Since 1987, Indiana has been searching for ways to do things better for senior citizens, persons with disabilities, and family caregivers that struggle with long term care issues each and every day. Doing things better for our most vulnerable and valuable citizens, those good Hoosiers who are the carriers of generations of wisdom but who now need our help due to aging and disability, is simply good common sense and the right way to go.

In the fall of 2011, The Generations Project travelled the state, learning directly from Hoosiers what it means to do things better for persons needing long term care. They consistently expressed the desire for home and community based services rather than institutional care. Their ideas are incorporated into the comments that follow regarding how to do things better in Indiana.

The value of home and community based services (HCBS)

Home and community based services (HCBS) include in-home care for seniors and persons with disabilities of all ages. The vast majority of people considering and needing long term care do NOT need -- nor do they want -- care in a nursing home or other institution. Advances in therapy, medical technology, and a growing awareness of basic human rights make it clear that very, very few people should ever be placed in a nursing home. There is also a growing awareness that HCBS covers a wide variety of care models that including home nursing, home medical visits, housekeeping, home modifications, assisted living, self-directed care, personal needs assistance, transportation services, community social services, meals and meal prep assistance, respite services, combinations of the above, and other options. All forms of HCBS directly help individuals and couples maintain their independence, and enable many non-elderly persons with disabilities to continue to work, pay taxes, and to support their families. Publicly funded HCBS provide the level of services needed to maintain independence, health and safety for persons who do not have other means.

HCBS also play another critical role: providing the relief that is necessary for family caregivers, and caregiver friends, to keep them from burning out. That enables these unpaid caregivers to continue their caregiving, to continue their income producing jobs, and it keeps intergenerational families whole. It is hard to overvalue this service, and the *value and cost* of unpaid caregiving to the economy of the state and nation. In *A Business Issue: Working Caregivers & Long Term Care* (2008), The Generations Project found that unpaid caregiving was

worth $100 billion a year to the nation, and cost businesses over $33.6 billion in lost productivity by their employees.

The community side of HCBS includes local transportation services, access to facilities and public places, and a variety of other services that assist people with disabilities of all ages to continue to be participants in community life, work, education, and local governance. These services are good for local businesses and the state's economy, are significant factors in attracting new businesses to the state in terms of quality of life measures, and are very positive elements in terms of intergenerational education.

For senior citizens and persons with physical disabilities the following publicly funded HCBS programs are crucial: the CHOICE program, Medicaid aged and disabled (A&D) waiver, and the Medicaid traumatic brain injury (TBI) waiver. CHOICE and the A&D waiver constitute the core of Indiana's HCBS system. (Please note this paper does not comment on the Medicaid services for people with intellectual/developmental disabilities, nor does it address mental health services. Persons with developmental disabilities and persons with mental health needs, and the families of both, face tremendous challenges in Indiana but the study of their needs is beyond the capacity of The Generations Project, with its limited resources, at the present time.)

CHOICE

The Community and Home Options to Institutional Care for the Elderly and Disabled Program, or CHOICE, was established by the 1987 General Assembly and passed that body 149 to 1, despite opposition from the nursing home industry. Republican and Democrat lawmakers joined a wide coalition of Hoosiers to make CHOICE a reality, and Governor Robert Orr signed the act. One of the program's key strengths has always been its strong bipartisan support, which stems from a simple fact: this program works.

CHOICE allows persons to get HCBS if they are found to be unable to perform two (2) activities of daily living and have impairments that place them at risk of losing their independence. That means persons in the CHOICE program are at real risk of being placed in a nursing home if they do not get assistance with their home care needs. CHOICE clients do not pay for their services if their incomes (calculated after existing and ongoing medical expenses are deducted), are at 150 percent of the federal poverty level (FPL) or below. CHOICE consumers above 150 percent of FPL must pay one (1) percent of their cost of CHOICE funded services for every two (2) percentage points their income exceeds 150 of FPL. For example, a CHOICE consumer with an income of 250 percent of FPL would pay fifty (50) percent of the cost of his or her CHOICE funded services. A CHOICE consumer with an income of 350 percent of FPL would pay all of the costs associated with his or her services. In reality, the vast majority of CHOICE consumers have incomes below 150 percent of poverty level. While in recent years, some political leaders and

state officials have said or implied there are significant numbers of people getting CHOICE services with middle class or higher incomes, that is simply not true.

CHOICE represents a huge monetary opportunity for local communities and the state of Indiana that has never been fully realized.

CHOICE was designed to utilize a minimum of bureaucracy and a maximum of common sense in how it is operated. First, CHOICE is designed to fund comprehensive HCBS with minimum bureaucracy, i.e. very little overhead. Because the program is designed in statute to fund what is needed, and uses a unique comprehensive assessment tool (that is referenced in statute) the program is very versatile. Second, CHOICE is the funder of last resort: by statute this means CHOICE funds services only after any and all other funds available to the CHOICE client have been used. (This does not mean Medicaid funds that are theoretically available to FSSA at some point in the future.) Third, CHOICE is designed to supplement, not replace, family caregiving. Fourth, CHOICE care plans are designed in partnership between the consumer and a professional case manager from the local area agency on aging (AAA). Fifth, the AAA case manager is supposed to broker the best and most affordable package of services that are available in the local community. That could and should include the use of independent providers (IPs). An IP is an individual qualified as an appropriate caregiver who can be contracted by the local AAA to provide specified HCBS for an individual. High quality and flexible HCBS programs in other states utilize IPs as well as licensed home care agencies to insure the availability of skilled home care workers whenever and wherever they are needed. Bottom-line, these features, if used in constructing and maintaining a CHOICE consumer's package of services, produce a plan of care that is both cost effective and satisfactory to the consumer. These features also make it possible for the AAA and consumer to develop a plan of care that keeps family members and friends engaged in the consumer's care, and a plan that uses the most cost effective services in the community without sacrificing quality.

From the delivery of the first CHOICE funded services in July of 1988 through 2005, the above model for the CHOICE program worked very well. Unfortunately, the Daniels administration has worked very hard to change how CHOICE works. The current administration has worked to make CHOICE function like Medicaid and to defund the program. As a result, the program has seen a notable decline in quality and outcomes in the past six to seven years. The problems stem almost entirely from the arbitrary policies and practices imposed on CHOICE and the AAAs by the Daniels administration. (See *A Failure to Play by the Rules and the Rule of Law*, The Generations Project, June 2012.) ***If the harmful Daniels era administrative and budgetary actions directed against the CHOICE program are stopped and reversed there is every reason to believe the CHOICE program can flourish again.***

CHOICE is a locally based program and has been entirely free of corruption. The sixteen area agencies on aging administer the program. As designed in law, CHOICE was created to utilize

local providers. As designed in law, CHOICE was designed to function as a partnership between each consumer that uses CHOICE funded services and the local AAA. Very importantly, consumers get no money through the CHOICE program. CHOICE funds the services but the providers are enrolled by the local AAA. Each CHOICE consumer only gets services after that consumer has been assessed face to face by the local AAA. Professional medical assistance may also be utilized in the assessment process when necessary. Consequently, the means and the motivation for gaming the system are minimized if not entirely eliminated in the CHOICE program.

***CHOICE is a state funded program and is entirely budget driven*.** CHOICE can only fund services to the extent it is funded by the General Assembly. CHOICE is not an entitlement. Nobody has a legal right to CHOICE services and qualifying for CHOICE does *NOT* make a person eligible for Medicaid state plan services. (In recent years, certain political figures have implied that persons on CHOICE are also drawing down Medicaid state plan services. That should not be the case for persons who are CHOICE only clients. It is possible there are individuals on Medicaid waivers that have their services supplemented by CHOICE in order to make them more functional.)

CHOICE costs very little when compared to other HCBS and other long term care services, such as nursing home care. If FSSA's current manipulated numbers are used then the total public cost of a person to be on the Medicaid aged and disabled waiver for a year is over $41,000 and the like cost for being on Medicaid in a nursing home is around $45,000. (Many observers believe FSSA's reported costs for the A&D waiver are too high because of the state's bias for using expensive agency based care, and FSSA's reported costs for Medicaid nursing home care are simply a misrepresentation of fact since the agency refuses to report all publicly incurred costs associated with that care.)

The Division has recently misrepresented the cost of the CHOICE in reports to the General Assembly. In November 2010 the Division of Aging (DOA) reported the annual per person cost of the CHOICE program to be $4,000. That was a historic low for the cost of CHOICE services. Based on the inputs reported in the CHOICE annual report that number was probably correct, but it also verified the impact of the Daniels administration's efforts to devalue the services provided through CHOICE. However, in the draft annual report that was due in the fall of 2011 the DOA reported the costs for CHOICE to be $7,596 per year, per person on average. The draft report also stated the CHOICE program had served 7,093 individuals with total expenditures of $27,845,391. Those numbers simply did not add up. The math actually produced an average annual cost of $3,925 per person. Those numbers were challenged by advocates in a public meeting of the CHOICE board. The board then asked DOA officials to meet with advocates and HCBS professionals. In the meeting that followed with representatives from the Indiana Home Care Task Force, area agencies on aging, and a CHOICE board member, a DOA administrator

admitted the CHOICE dollars diverted from the program for Medicaid match had been double counted as CHOICE expenditures. Nonetheless, on the FSSA website the CHOICE annual report for the fall of 2011 still contains the wrong numbers for the fiscal year that ended June 30, 2011 despite the objections that were raised before the CHOICE board. On September 20, 2012 the DOA presented to the CHOICE board the draft annual report for CHOICE for the fiscal year ending June 30, 2012. Once again the CHOICE cost numbers were misrepresented. DOA is now reporting the average annual cost of serving a CHOICE client to be over $9,300 yet the data in the report suggests that number should be under $5,500. The CHOICE board withheld approval of the draft report and has asked DOA to rework its calculations.

Prior to the Daniels administration, the average annual cost of a CHOICE client had been reported in the $6,500 to $7,000 range for virtually the entire history of the CHOICE program. Based on interviews with HCBS professionals throughout the state, and reviews of the program by The Generations Project, CHOICE costs should still be around $6,000 to $7,000 per year per person. Those historic numbers were generated when the state was making no attempt to arbitrarily limit the application of CHOICE services. FSSA and the Division of Aging under the Daniels administration have aggressively acted to make it harder to receive CHOICE services and to limit the scope and effectiveness of the services. In the past two years, DOA and FSSA have been trying to grossly over report the cost of CHOICE in an effort to make it appear to be more expensive than the Medicaid A&D waiver. It is important for policy makers and the public to understand, by any *accurate* measure of costs, CHOICE remains far cheaper than other forms of long term care in Indiana.

CHOICE is cheaper than the A&D waiver but the selection of a funding stream should be determined by the needs of each consumer who qualifies for publicly funded HCBS. If a person needs the medical coverage provided through Medicaid in addition to HCBS, and qualifies for the A&D waiver, then that person should be on the wavier. It would be terrible public policy to deny a person access to needed medical care. Persons that only need HCBS because their medical needs are being met by Medicare or private insurance should be able to use the CHOICE program. In either case, the public interest is best served by meeting the HCBS and medical needs of persons who don't otherwise have the means to access those services.

CHOICE promotes personal and family responsibility. By encouraging family members and friends to continue their caregiving for an individual who qualifies for publicly funded HCBS services, CHOICE is uniquely designed to promote individual responsibility. CHOICE can also be used to encourage family members and friends to become caregivers. The area agency on aging in Dillsboro, for example, has long practice in encouraging and growing family caregiving. The result is often significant savings and a workable home care solution for the family. This is just one example. When allowed to implement the CHOICE program as enacted and intended by the General Assembly, area agencies on aging throughout the state have been able to find

cost savings and responsible solutions to the home care needs of individuals and families in the communities they serve.

Indiana passed a law to ***re-balance*** its long term care system in 2003, but SEA 493 has never been implemented and that failure is costing Indiana hundreds of millions of dollars in excess Medicaid costs, and harming tens of thousands of Hoosiers, each year.

The combined effect of not implementing SEA 493 is an economic, health and societal disaster for Hoosiers that remains grossly under reported. Long term care re-balancing started in Oregon in the early 1980s where it has been a great success. In 1991, the state of Washington began its long term care re-balancing program with even greater success. In the early years, these re-balancing efforts produced large surpluses in the states' Medicaid budgets. These surpluses were used -- in part -- to fund public education and to buy out nursing homes that were not needed.

Long term care re-balancing is a simple concept; here is how it works. Each year a state budgets X number of dollars for Medicaid funded nursing home care. With re-balancing, the state adopts the policy to promote HCBS as a replacement for a specified number of nursing home beds. For each person that is diverted from going into a nursing home, and for each person that is brought out of a nursing home, dollars that were budgeted for their nursing home care are applied to purchase HCBS for that person and others, since HCBS is usually between one half to one third of the cost of nursing home care. Once this process starts, more and more people can be diverted or shifted into HCBS and the funding for doing this comes from the Medicaid dollars that would have been budgeted for their nursing home care. This self-funding mechanism works IF the state truly uses the saved dollars to continue to grow HCBS. However, in the early years of a re-balancing program, because of the pent up need for HCBS including low-cost HCBS, surpluses (or savings) can be generated out of a state's Medicaid budget so quickly that dollars can be available for other programs. For a period of time in Washington the LTC re-balancing program produced such savings that were then applied to public education.

In Indiana, SEA 493 was passed in 2003 by a combined final reading vote of 148 to 1. But the law has never been implemented because the self-funding mechanism in SEA 493 was an optional provision in the law. Governors and state budget directors have never opted to use it. Hence, the re-balancing could not happen because there was no means to start, grow and continue the self-funding process.

***The SEA 493 re-balancing opportunity could still be used in Indiana by a new administration. The steps that follow would greatly enhance its effectiveness*.**

One, *Indiana should implement an **independent provider** (IP) program* that could potentially make available a network of hundreds, if not thousands, of qualified home care workers who would be directly contracted by the state, or locally contracted by area agencies on aging, to provide in-home services through the Medicaid waivers and CHOICE.

Two, *Indiana should seek authority from the federal government to expand the **A&D waiver** and the **TBI waiver** for a re-balancing program that would also include **CHOICE** for persons that only needed HCBS and not Medicaid state plan services. Like the IP network, this would also save the state tremendous sums of money*.

Three, *Indiana should include in its re-balancing program an **aggressive expansion of self-directed care*** as an additional source of savings and as a means to enhance the quality and reliability of HCBS for many persons with disabilities who have the capacity to self-direct their caregivers.

Four, ***Indiana should aggressively implement the clients' rights and empowerment provisions of SEA 493 in any re-balancing regime***, including the provision requiring Medicaid waivers to function like the CHOICE program, as a means of strengthening and improving the quality of care, and to make Indiana a leader in promoting the human rights of long term care users.

Five, ***Indiana should use re-balancing to aggressively reduce the use of publicly funded, expensive and inappropriate nursing home care. Rebalancing means serving far more people with less expensive and appropriate HCBS.*** Rebalancing can entail promoting the use of innovative "small houses" that dramatically redefine the concept of nursing home care and investing more dollars in the quality of care provided in the nursing homes that remain open. Rebalancing can entail buying out nursing homes, and incentives for owners to convert to other forms of long term care or to simply leave the business. Rebalancing must include the closing of bad nursing homes. Bad players should have nothing to do with the provision of long term care. If excess nursing homes go away their expensive beds cannot be refilled at a future date.

Six, *re-balancing would take off the table the threat of any **Olmstead,** civil rights litigation against the state of Indiana*. Presently, Indiana is considered one of the most likely states to be sued for violating the rights of persons with disabilities under the Americans with Disabilities Act for its failure to provide access to appropriate and timely HCBS.

Seven*, enroll people into services in a timely manner and stop the practice of unnecessarily holding persons who need CHOICE or waiver services hostage to the Medicaid eligibility determination process.* Forcing persons to go through the state's arbitrary Medicaid eligibility

process that can take months, when skilled area agency on aging case managers can quickly and accurately determine if a person qualifies for Medicaid, is a bureaucratic waste of taxpayer dollars and increases the likelihood that those people will be further harmed or forced into a nursing home. For re-balancing to be effective, people need to be enrolled in HCBS in a timely manner.

Eight, ***grow CHOICE no matter what is done in terms of Medicaid funded HCBS*.** There is a huge demand for CHOICE, it is incredibly cheap, and has been demonstrated to keep large numbers of people out of nursing home. Simply put, CHOICE saves money, keeps people at home, and families whole. CHOICE is also free of the negative restrictions and the stigma that are associated with Medicaid programs.

Nine*, use and enhance the area agencies on aging single point of entry system for long term care re-balancing, and look for ways to strengthen the rights of citizens that use long term care services.* The more control that citizens have in terms of the care they receive and its quality the better and more cost effective that care will be over time. Indiana should clearly be moving to a system of long term care that is defined by people of all ages, backgrounds and incomes being able to protect and grow their human rights. The current legal mechanisms for protecting the rights, health and wellbeing of long term care consumers in Indiana are very poor.

Ten, *stop or severely limit attempts by for-profit corporate managed care entities to take over long term care management, including case management for home and community based services.* The HCBS consumer experience with managed care in terms of citizen rights and the quality of service has been mixed, at best. We need to strengthen the area agency on aging system, and the system of centers for independent living in this state before considering for-profit corporate-based solutions that often put the rights of citizens at risk. It should be noted that area agencies on aging were designed to implement the provisions of the Older Americans Act. The OAA promotes the health, wellbeing and continued engagement of seniors in civic life. That is a far better model for serving the common good than the narrow profit defined practices of managed care corporations.

Eleven, *utilize the provisions of the congressional Affordable Care Act that are designed to expand the use of home and community based services through a variety of means that include promoting individual responsibility and preventative care.* Over time, these features will improve the health of Hoosiers and save money for citizens, the state and the federal government.