

**Comments on Behalf of The Generations Project Regarding Home and Community Based Services in Indiana as Requested by the Indiana Family and Social Services Administration Pursuant to HEA 1493**

Today, we are representing The Generations Project as members of its governing board. The Generations Project was founded in 2001 to do advocacy education and research for consumers of all ages in Indiana that need publicly funded home and community based services.

Per the general provisions of HEA 1493, and as requested by the Division of Aging and FSSA, we would like to make the following comments on behalf of the consumers of long term care (LTC) services, specifically, those individuals and families that use home and community based services (HCBS) or long term services and supports (LTSS).

Across the nation the trend in state LTC programs has been to invest more money and human resources in HCBS and LTSS, and less in institutional care. The reasons vary for this trend but they generally fall into four categories: cost containment, quality care outcomes, consumer preferences, and legal exposure.

We think these motivations are all important. However, they are not given equal weight among the states. For example, Indiana continues to trail the rest of the states in terms of implementing these changes: so much so that Indiana is now ranked 51<sup>st</sup> in the nation by AARP in terms of overall LTC measures and outcomes. This is unacceptable.

We do appreciate the questions being examined in these hearings by FSSA and the Division of Aging. We appreciate the statutory objectives in HEA 1493. We also appreciate being invited to participate in this process and the willingness of state officials to dialogue with us.

However, we also appreciate that Indiana is not doing enough to address the needs of Hoosiers who need home and community based services. For too long we have talked about addressing the chronic challenges facing disabled citizens of all ages. We must get beyond talk. We need action.

Here are our recommendations.

One, catalogue the provisions in Indiana law since 1987 that mandate the provision of HCBS and LTSS (or simply LTSS for the purposes of this paper), or which directly support the provision of these services. Match these legal tools with the population of Hoosiers who are not served and who are under-served in terms of LTSS and then put in place an aggressive program to use these tools. We believe you will find in the provisions of the CHOICE statute and SEA 493 from 2003 most of the tools that other state use to implement top notch LTC programs that focus first and foremost on the use of LTSS.

Two, look at the federal tools that are available now in terms of court rulings, such as Olmstead, and in federal Medicaid laws and regulations to aggressively grow LTSS.

Three, do an accurate assessment of the number of Hoosiers who need publicly funded LTSS.

Four, look at your rates and reimbursement levels. If they are not enough then change them.

Five, you can manipulate with good intentions laws, regulations and programs, but you will not succeed unless your programs are designed by and for consumers and their families in a manner that purposely exploits all the programs and services that are available through federal and state laws, the funding streams associated with these laws, and the full array of civil and human rights that pertain to citizens with disabilities under federal and state law as written in statute and applied by the federal courts.

Presently, Indiana has created a nightmare for an underdetermined number of its citizens who are qualified for home and community based services under

Medicaid prior authorization and waiver programs. These include citizens that have long attempted to get by on what Indiana offers, and citizens who are fully qualified for these services but cannot access them for various reasons. In either case, too many citizens are being denied the Medicaid funded care for which they are qualified and as a result are being forced into nursing homes and other institutions against their will, or are simply going with few to no services in their own homes. Consequently, these are citizens who are being placed in great jeopardy by the state's failure to act to provide their care.

We believe the failure by the state to serve these citizens is a violation of federal Medicaid law and a violation of federal civil rights law as confirmed in the ruling of the U.S. Supreme Court in the Olmstead case in 1999 and in other federal cases since that decision.

We have learned that various reasons have been given for not serving these citizens, but the violation of the basic civil rights of persons with disabilities should not and cannot stand. Our own examination of state law finds no statute that legally justifies these violations of civil rights and the denial of critical long term care services.

FSSA should act on these cases immediately. We have raised these issues for many years. Action is needed now.

We will conclude with these two recommendations.

One, FSSA should act immediately to restore HCBS and LTSS to persons who are qualified for those services but who are being denied those services. FSSA should do whatever is necessary to do these things including saying unequivocally to the Governor and the State Budget Agency that the courts, federal and state law, and our humanity demand that we restore these services without further delay.

Two, FSSA should begin a process now, such as the process outlined in this paper, to identify and then act without further delay on what can already be done to build out a system of home and community based services in Indiana that is truly consumer defined and driven. Such approaches have saved taxpayers countless

billions across Americas. Hoosiers who need these services, as well as taxpayers, need Indiana to take these recommended actions.

Thank you.

John Cardwell, Member

The Governing Board of The Generations Project

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