

Statement of Geoffrey M. Lauer, Executive Director, Brain Injury  
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Testimony Before the Senate Committee on Health, Education,  
Labor and Pensions

Hearing on Overcoming Barriers to Economic Self-Sufficiency for  
People with Disabilities

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Introduction

Chairman Harkin, Senator Alexander, and Members of the Committee, I am Geoffrey Lauer, the Executive Director of the Brain Injury Alliance of Iowa, the Chairman of the Iowa Olmstead Consumer Task Force, and a member of the board of trustees of the United States Brain Injury Alliance. I have worked for more than 25 years as an advocate and service provider with and for individuals with disabilities. The organizations I am honored to work with also provide services, support and advocate for and with, hundreds of thousands of Americans with long-term disability from brain injury and other causes. Consequently I am keenly aware of many barriers with respect to economic self-sufficiency for persons with disabilities.

The Brain Injury Alliance of Iowa was the second chartered state affiliate of the Brain Injury Association of America, founded as the National Head Injury Foundation in the early 1980's by my friend and colleague Marilyn Price Spivak.

The Brain Injury Alliance of Iowa more recently is a founding member of the United States Brain Injury Alliance which, with its 21 member states, works to improve the lives of individuals with brain injury and their families through awareness, prevention, advocacy, support, research and community engagement.

Iowa's Olmstead Consumer Task Force was formed in 2003 via Executive Order by then Governor Tom Vilsack to advise the Governors' Office on strategies to remove barriers to community living to Iowans with disabilities and promote community integration through changes in state policy and programming.

There are a number of things that I hope to accomplish with my testimony today. However before I get into the specifics I wish to thank the Committee for their support of the Traumatic Brain Injury (TBI) Reauthorization Act of 2014. The TBI Act is the only federal law that authorizes agencies within the U.S. Department of Health and Human Services (HHS) to conduct research and public education

programs and to administer grants to states and protection and advocacy organizations to improve service system access and coordination for the 2.4 million civilians who sustain traumatic brain injuries in the U.S. each year. As a modest first step, the TBI act has been a tremendous success to catalyze systems change and improvement for Americans with brain injury and their families.

I also wish to thank Chairman Harkin for his superlative service to the State of Iowa and to our nation for more than four decades. His deep commitment as a champion for the civil rights of Americans with disabilities is deeply appreciated from Cumming, Iowa (his hometown) to every corner of this country.

Yet as the Chairman well knows there is much yet to do. Each day across our country millions of Americans with disabilities are faced with navigating a shifting maze of daily challenges related to both disability and income. These include an array of environmental, health care, social, economic, institutional and attitudinal barriers. These range from transportation to a job or to the grocery store to inexcusably low expectations for individuals with disabilities from the teachers and professionals that serve them.

## **Selected Barriers – General**

### **Asset Limits**

Federal programs of public assistance are essential in providing a safety net preventing many from falling into extreme poverty. However without question is the fact that many income and work support programs maintain eligibility requirements that serve as blockades to individual and family economic self-sufficiency. One of the most egregious of these eligibility requirements are impossibly low programmatic limits to assets. Asset limits for a number of federal programs have the effect of “trapping” individuals with disabilities in poverty. These limits have not only been ravaged by inflation, they are ridiculously low. For example the current limits for Supplemental Security Income, or SSI, which are set by the federal government have been, since 1989, set at \$2,000 for an individual and \$3,000 for a couple or a disabled child living with their parents. Had such limits been linked to inflation they would be more than \$8,500 for individuals and \$12,800 for both couples and families with disabled children today.

These low limits plague programs such as SSI even with well intentioned federal and state efforts to accommodate employment such as Social Security’s “Plan to Achieve Self Support” (PASS). In fact such programs require such level of sophistication to appropriately access, update, and respond to that many fear make critical errors in planning and implementing employment. Such errors often result in loss of benefits or having to return overpayments and in a belief that employment is not worth the risk of the loss of benefits.

Let me share a story about Jason, which is illustrative. Jason is a young man with a disability in Iowa. He receives SSI benefits and Medicaid. Jason began working at a local factory and his first check totaled \$400 a week gross. However when his local caseworker learned of this income the response was panic. The caseworker told Jason that with such income he would lose all of his benefits, including his Medicaid. This was shared with Jason despite there being available and well-documented state based options for him to retain his Medicaid while working towards genuine independence. Jason and his caseworker, like many others, were victims of the widespread belief that substantial work is much more a threat than an opportunity. Support staff, acting in what they feel is the best interests of their consumers are many times the ones that are limiting people with disability in their movement towards self-sufficiency.

Individuals with Social Security Disability Insurance (SSDI) also face significant asset limits that act as barriers to self-sufficiency. SSDI recipients frequently describe a fiscal or financial “cliff” when seeking to escape public support.

For example Tom is an Iowan who experienced a disability after many years working in the IT sector. He and his children receive more than \$3,000 per month in support from SSDI. He relies on Medicare for his health care. He is finishing a Masters Degree in Rehabilitation Counseling and has a goal to start a small business providing computer repair and assistive technology design. However with his benefits threatened with termination if, and when, he earns more than \$1,000 per month he stands at a “fiscal cliff” in that if he is not able to earn in the range of \$40,000 - \$50,000 per year he risks a significant cut to his ability to support his family. Tom and hundreds of thousands of others like him would benefit greatly from the option of having their benefits reduce in relation to their income vs. dropping off at an unreasonably low, fixed level. They also need the ability to retain their Medicaid and/or Medicare coverage as they re-enter the workforce vs. current program rules, which drop such coverage when asset limits are met.

Across the States asset limits are inconsistent, and many times set at very low federal levels, for other federal programs including Temporary Assistance for Needy Families (TANF), the Supplemental Nutrition Assistance Program (SNAP), and the Low Income Home Energy Assistance Program (LIHEAP).

The result of such limits is an inability to develop and/or retain a modest amount of savings to mitigate against financial set-backs that can result in dire outcomes such as eviction or having utilities shut off. Savings are also key for individuals with disabilities whose goal is self-employment, starting and running a small business, or paying for essential medical or assistive technology products not covered under insurance.

The complexity of the income and health insurance systems results in many feeling as if it would take, as one individual shared with me, “six attorneys and an estate planner” to successfully navigate the impacts of earned income on benefits.

Consequently there is a clear and pervasive perception among individuals with disabilities, their families and service providers that trying to become economically self-sufficient, within the current asset limit caps, simply presents too high a risk of losing essential medical coverage through Medicaid or Medicare as well as income supports through such programs as SSI.

### **Recommendation – Asset Limits**

1. Congress should significantly increase the outdated SSI asset limits and index them to inflation. The SSI asset limits have not increased for more than 25 years, effectively shrinking the amount of money that recipients can hold in savings. Bringing the limits to at least \$10,000 for individuals, \$15,000 for couples and families with disabled children, and then indexing these limits to inflation would alleviate needless economic insecurity among individuals with disabilities and their families.
2. Congress should address the “fiscal cliff” for individuals utilizing SSDI and, in addition, allow an extension of medical benefits for individuals working toward self-sufficiency.
3. Congress should remove asset limits for TANF, SNAP, and LIHEAP. This would create a uniform national standard and remove complexity and variability across states. It would enable families to receive benefits when they fall upon hard times and would enable recipients to build savings and plan for the future.
4. Congress should increase support for disability resource facilitation, navigator, and aging and disability resource center programs.

### **Long Term Services and Supports**

Long-term services and supports (LTSS) in state Medicaid programs are a means to provide medical and non-medical services to seniors and people with disabilities in need of sustained assistance. Medicaid LTSS includes services to aid individuals with activities of daily living (ADL) and instrumental activities of daily living (IADL). ADLs include eating, grooming, dressing, toileting, bathing and transferring. IADLs include meal planning and preparation, managing finances, shopping for food, clothing and other essential items, performing essential household chores, communicating by phone or other media and traveling around as well as participating in the community. LTSS are provided both as part of state Medicaid programs as well as within Home and Community Based Service Waivers.

There are two major dimensions of long-term services and supports that I wish to highlight. First are the fiscal limitations of state and federal programs (asset limits)

that support LTSS essential to economic self-sufficiency and independent community living for individuals with disabilities. Many individuals face a devastating reduction in funding for LTSS if they become substantively employed. The costs of LTSS are seldom sustainable at, or modestly beyond, the current asset limits and therefore result in millions of persons with disabilities concluding that such personal and financial goals are not worth the risk of losing such supports.

The second dimension of LTSS I wish to highlight has to do with unreasonably long waiting list for LTSS via the Medicaid Home and Community Based Services Waiver programs that States are allowed to operate. These programs are intended to waive a Medicaid bias towards institutionalization. In 2012 there were more than half a million Americans on waiting lists for an average of more than 27 months (PAS Center, UC / San Francisco, 2013). Many States are not providing funding to keep HCBS waiting lists “reasonable” and are inconsistent in their scope of prioritization for services. In fact one third of states are without a process to prioritize services. The result is decreased recovery for individuals with disability from brain injury and increased nursing home placement, increased incarceration, and increased homelessness for individuals with disabilities.

**Recommendation - Long Term Services and Supports:**

1. In addition to the recommendations in the section on Asset limits (above) Congress should strive to decouple LTSS from other supports such as TANF, SSI or Medicaid. The goal must be that if you need LTSS you can access them. The sustained availability of LTSS will open the door for many individuals who seek to achieve increased self-sufficiency. These services should be a basic right in support of community living with copayments beginning only after significant income.
2. Congress should direct the Center for Medicare and Medicaid Services (CMS) to require reasonable movement on waiting lists for HCBS Waivers and to deploy consistent methods to prioritize such waiting lists based on risk to the individual as well as amount of services needed.

**Transportation:**

As we approach the 25<sup>th</sup> anniversary of the ADA millions of Americans with disabilities lack access to affordable and available transportation. This is especially true for individuals who live in rural communities. Across Iowa and across much of the country lack of access to regular, reliable and affordable transportation to access basic services, education, appointments, health care, and employment is still a major barrier to individuals with disabilities. You cannot participate if you cannot “get there”.

## **Recommendations - Transportation**

1. As Congress works to address how best to rebuild and repair our nation's roads, bridges, railways, and ports, and where and how to prioritize investments in public transportation, it is vital to take into consideration the needs of people with disabilities.

## **Selected Barriers – Brain Injury**

The United States Brain Injury Alliance (USBIA) represents 21 state members including the Brain Injury Alliance of Iowa. Through member states and their individual members and constituents USBIA works to provide basic information and resource for community level services and supports. Brain Injury is one of many disabilities that can strike at any age. The U.S. Centers for Disease Control and Prevention estimates that there were 2.4 million emergency department visits, hospitalizations, or deaths associated with TBI alone or in combination with other injuries in the United States in 2009. Brain Injury is a leading cause of death and disability in the United States that affects persons of all ages, races/ethnicities and incomes. Any injury to the brain – regardless of type, cause or severity – can change the way a person moves, talks, thinks, feels and acts. TBI can cause epilepsy and increase the risk for Alzheimer's disease, Parkinson's disease and other brain disorders that become more prevalent with age.

As a result of brain injury being the “signature injury” of war fighting in the past decade, combined with the increased awareness from sports related brain injury in professional and youth sports, one might think that awareness of the medical and disability needs of this constituency would be better positioned for response. Sadly this is not yet the case.

Many of the barriers to self-sufficiency for individuals with disability from brain injury are those faced by individuals with disability from other causes. However brain injury presents a unique set of features that demand recognition and response.

The nature of brain injury is highly variable. Injury is often characterized as mild, moderate to severe and outcomes from these injuries are variable as well depending on a host of features unique to each individual injured, the nature of the injury and the speed and acumen of immediate and subsequent response.

However those of us providing lifelong information, navigation and support for individuals with brain injury recognize that on the medical front the length of stay for essential acute and post-acute rehabilitation has been pared to a paltry 18 – 21 days on average. Limitations on rehabilitation are pushing individuals with brain injury out of rehabilitation and into the community “quicker and sicker” than ever

before. In too many cases discharge is not even to community but to long term institutionalization lost to any system of care or account.

These limitations often result in prolonged disorders of consciousness. Families and communities are not prepared to cope with the needs, supports, and changes resulting from brain injury and far too many experience financial ruin, homelessness, incarceration, and death. A survivor of brain injury stated to me recently that we are no longer the “silent epidemic” – we are the “throw away group”.

All too frequently individuals with brain injury are faced with seeking services and supports within systems of support that were developed for other populations of persons with disabilities and which are resistant to expanding to include brain injury. Support staff often does not understand or address the cognitive and behavioral challenges associated with brain injury. Agencies and programs are resistant to funding services for this population, as they are struggling to address their mandated and/or priority populations.

Clearly more funding at both the federal and state level is necessary to deploy needed medical and long term service and supports for Americans who have disability from brain injury

### **Recommendations - Brain Injury**

1. Congress should pass the TBI Reauthorization Act of 2014.
2. Attached please find a set of recommendations to strengthen existing legislation and programs for individuals with brain injury developed by the “One Voice for Brain Injury Consortium” in the fall of last year. In this document seven national Brain Injury organizations present considered Congressional responses to the gaps and needs facing Americans with brain injury.

Thank you for the opportunity to testify today. I look forward to answering your questions.