

**TESTIMONY FOR
THE UNITED STATES CONGRESS
LONG TERM CARE COMMISSION,
DIRKSEN FEDERAL BUILDING
UNITED STATES CAPITAL COMPLEX**

Of

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TESTIMONY FOR THE UNITED STATES CONGRESS LONG TERM CARE COMMISSION

Part I: Recent Trends in Intellectual Disabilities Services in the United States (stateofthestates.org)

Declining Use of Public/ Private Institutions

During 2009-11, the census of state-operated Intermediate Care Facility for Persons with Intellectual Disabilities (ICF/DD) institutions for 16 or more persons declined 12%, falling from 33,746 to 29,574, an average annual percentage reduction of 6.4%. This exceeded the annual reduction rate during 2006-09 (4.4%). In 2009-11, 36 of the 38 states financing state institutions reduced their censuses. Alabama, Michigan, Minnesota, and Oregon terminated use of state-operated institutions during this period. Twelve states and DC no longer operate I/DD institutions. Only two states increased their public institutional census between 2009 and 2011: Colorado (+57 persons) and Nebraska (+110).

The census of privately-operated 16+ institutions fell 7% during 2009-11 and the I/DD nursing home census fell by 907 persons to 31,256, a 3% reduction. Twenty states, however, reported an increase in nursing home census during 2009-11. Thirty-five states and DC operated ICFs/ID for 7-15 persons. The nationwide census increased by 290 persons during 2009-11 (1%). In contrast, the census of 7-15 person group homes not certified as ICFs/ID declined by 1,232 persons to 35,533 residents in 2011 (-3%).

Expansion of Community Services

During 2009-11, total out-of-home Intellectual and Developmental Disabilities (I/DD) residential placements nationally increased by 30,776 persons to 613,184. This was an average annual increment of 2.6%, matching the average growth rate during 2006-09. Seventy-seven percent of the 613,184 persons with I/DD in out-of-home placements in 2011 were living in settings for six or fewer persons. Fifty-eight percent of the individuals in six or fewer settings were in supported living. The remaining 42% lived in small group homes including ICFs/ID, foster and host homes, and apartments. The number of individuals living in settings for six or fewer persons increased by 8.9% during 2009-11, an average growth rate of 4.4% per year, just below the 4.5% annual increase during 2006-09.

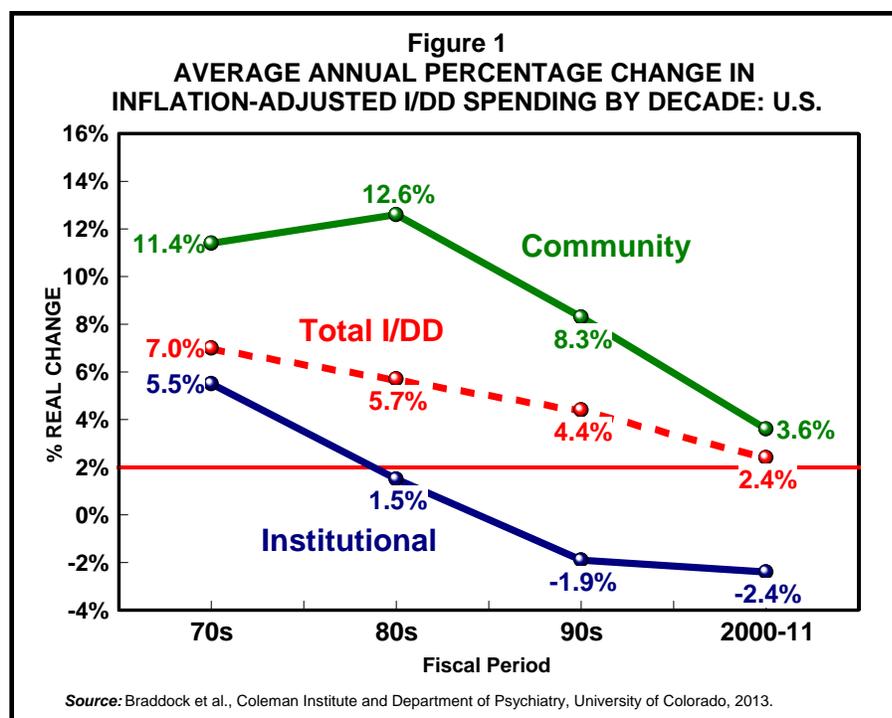
The Medicaid program continued to provide a large majority of nationwide I/DD funding in 2011 (77%). Spending for the Home and Community Based Services (HCBS) Waiver is the largest component of Medicaid I/DD spending. The Waiver grew from \$26.3 billion in inflation-adjusted federal and state spending in 2009 to \$27.9 billion in 2011 and supported 627,270 participants. Waiver spending, adjusted for inflation, increased 3% in 2009, 6% in 2010, and 1% in 2011. This

3% average annual growth rate was below the adjusted annual growth during 2006-09 (4%) and substantially below the average Waiver spending growth rate of 16% during 1993-2005.

In contrast to the continuing growth of HCBS spending nationally, adjusted ICF/ID program funding declined from \$12.9 billion in 2009 to \$12.6 billion in 2011. This 3% reduction in real spending was a product of the continuing nationwide decline in spending for public/private 16+ institutional services.

I/DD Spending Growth Continues To Slow Down

The average annual percentage growth in inflation-adjusted spending for consolidated I/DD services is slowing down. Institutional spending in the past two decades has fallen sharply. Growth rates in the community services component of I/DD spending continues to decline,



although it remains above the rate of inflation (Figure 1). Several factors are influencing growing demand for I/DD community services, including aging family caregivers, litigation promoting access to funding for community services, the increasing longevity of persons with I/DD, and the continuing downsizing of large public and private institutions.

A hallmark of the 2009-11 period was that continuing growth in community services spending, a general rule in previous studies, was reversed in many states. Twenty-five states saw real reductions in community spending in 2011, following reductions in 15 states in 2010 and in 18 states in 2009.

During fiscal years 2009-11, nationwide total adjusted I/DD spending growth per year decreased to 1.0%. Spending growth was 2.3% in 2010 and a negative 0.2% in 2011, the slowest growth rate in total national I/DD spending in the Project's 35 years of data collection.

Another important funding stream for I/DD services in a number of states that was impacted by the Great Recession was local funding. Local government I/DD spending declined 9% in real terms from 2009 to 2011. However, local governments, including counties, municipalities and special districts, accounted for only 3% of total I/DD spending in 2011.

Fiscal Effort Falls in 2011

Fiscal effort is defined as federal, state and local government spending for I/DD community and institutional services per \$1,000 of statewide personal income. Total I/DD fiscal effort increased 4% in 2010 but dropped 3% in 2011. Fiscal effort for consolidated I/DD services fell during the 1995-97 and 1997-99 periods by 0.6% and 0.8%, respectively. These were the only other periods in which fiscal effort levels declined during the 35 years of our data collection. Community services fiscal effort increased by 1.3% per year nationally during 2009-11. In contrast, fiscal effort for public/private 16+ institutions (excluding nursing facilities) declined by 2.4% per year during this period, and there were institutional fiscal effort reductions in 38 states during 2009-11.

Commitment to Supported Living Varies Across States

The average cost of care for persons in supported living, which is defined in different ways by states and serves persons with varying degrees of independence, is quite wide. Supported living spending per person ranged from a high of \$97,371 in Oklahoma to \$4,766 in South Dakota. The fifty states and DC all reported that they provided supported living and/or personal assistance services to 272,286 persons with I/DD in 2011. Adjusted spending grew by an average of 3% per year on a national basis during 2009-11, compared to a 5% annual growth rate during 2006-09.

Proportion of Workers in Supported Employment Continues to Decline

The proportion of supported employment workers in all day and work programs managed by state I/DD agencies fell to 20.8% in 2010 and 20.3% in 2011. These rates were the lowest since the peak of 22.8% was reached in 2000. States spent \$838 million in FY 2011 to support 101,505 workers--excluding 14,536 follow-along work support participants in 16 states. States are increasingly reliant on Medicaid HCBS Waiver dollars to fund supported employment initiatives. In 2011, the HCBS waiver program funded 64% of supported employment spending nationally, more than double the 27% rate 10 years earlier.

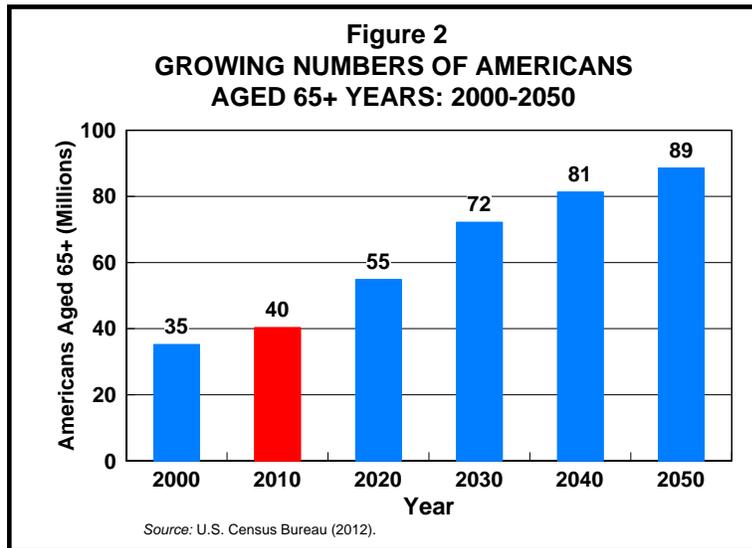
Families Supported Declines

Inflation-adjusted total family support spending stabilized at \$4.0 billion during 2009-11, but the number of families supported declined from 479,349 in 2009 to 467,958 in 2011. Cash subsidy payments to families were being provided in 19 states in 2011, down from 22 states in 2009. The average annual subsidy payment nationally was \$2,904 per family and ranged from \$344 to \$11,009. Kansas, New Jersey, Tennessee, and Utah no longer provide cash subsidies and Utah also ceased funding of non-subsidy family support services in 2010.

In 2011, the Home and Community Based Services (HCBS) Waiver financed 79% of family support services spending nationally. Family support spending, however, remains a small component of total spending for I/DD services: 7.1% in 2011, down from 7.3% in 2009. Moreover, state I/DD agency family support funding reached only 13% of the estimated 3.5 million I/DD family caregivers in the U.S. in 2011, down from 14% in 2009.

Aging Caregivers Double 2010-2040

The aging of our society directly influences demand for intellectual and developmental disabilities (I/DD) services because of the number of people with I/DD residing with family caregivers. As these caregivers age beyond their care-giving capacities, formal living arrangements must be established to support their relatives with disabilities (Braddock, 1999).



The aging of our society is the product of several forces, including the size of the baby boom generation (persons born during 1946-1964), declining fertility rates, and increased longevity. Baby boomers began to reach age 65 in 2011. The number of persons in our society aged 65+ years is projected by the U.S. Census Bureau (2012) to reach 55 million in 2020 and 89 million in 2050 (*Figure 2*). Currently, 13.3% of the U.S. general population is aged 65+ years. In the U.S., 37% of persons 65 years of age and over have one or more physical disabilities as

opposed to 11% of the population under age 65 (Schiller, Lucas, Ward, & Peregoy, 2012).

Americans 80 years or older are expected to be the fastest growing age group. Estimating the impact of aging on the increased demand for intellectual and developmental disabilities services in the states requires data on the prevalence of developmental disabilities in our society. Based on the 1994/95 data from the National Health Interview Survey-Disability Supplement (NHIS-D), Larson et al. (2001) recommended using a rate of 1.58% to estimate prevalence for persons with intellectual disability, cerebral palsy, autism, epilepsy, and other childhood disabilities originating prior to 22 years of age.

Many countries will be affected by this demographic trend, particularly Brazil, China, India, Indonesia, and Japan. For example, the UN estimates that, by 2050, the percentage of Japan's citizens over the age of 60 will have increased from 30% to 44%. At least 16% of their population will be over age 80 (United Nations, 2009). Europe now has the oldest population, with a median age of nearly 40 years that is projected to reach 47 years in 2050. On a global basis, life expectancy at birth was 68 years in 2005-10, and is projected to be 76 years in 2045-50 (United Nations, 2009).

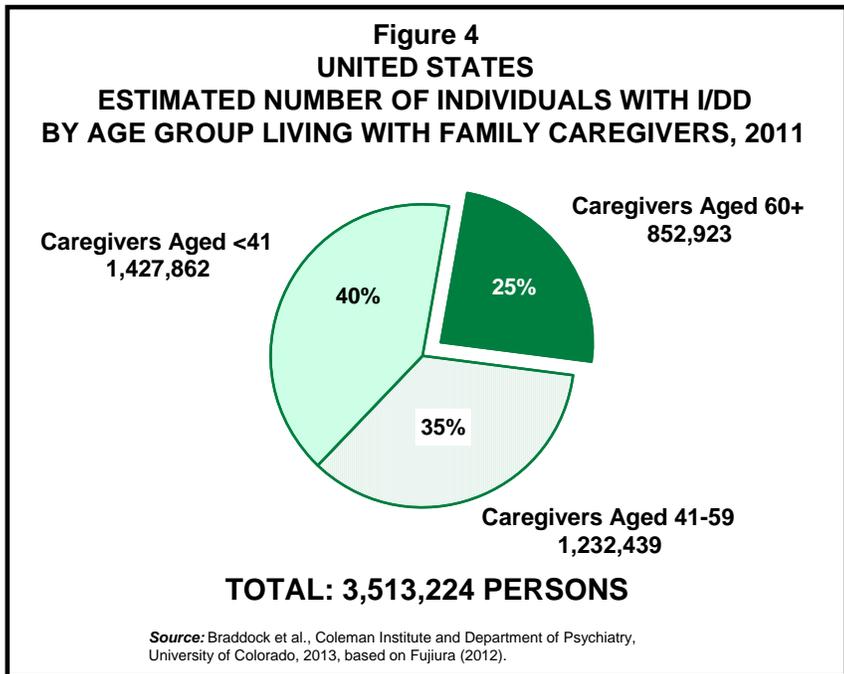
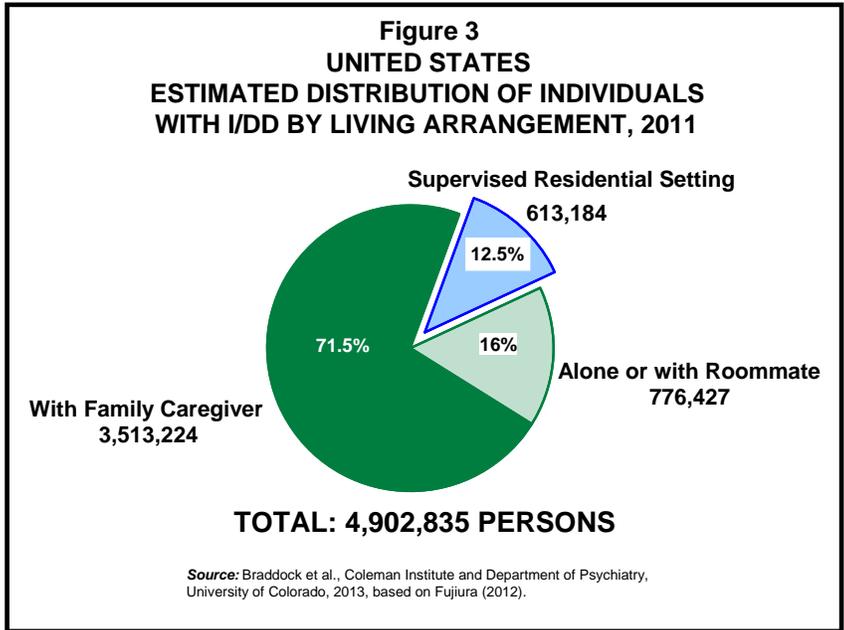
Fujiura (1998, 2012) determined that in 2010, 71.5% of persons with developmental disabilities in the U.S. resided with family caregivers, and 28.5% lived on their own or within the formal out-of-home residential care system in the states. We updated Fujiura's analysis using data pertaining to the 2011 out-of-home residential system, and the U.S. general population in 2011.

The results are presented in *Figure 3*, which indicates that 3.51 million of the 4.90 million persons with intellectual and developmental disabilities in the U.S. population in 2011 were

receiving residential care from family caregivers. This “informal” system of residential care served nearly six times the number of persons served by the formal out-of-home residential care system (613,184 persons). Fujiura (1998, 2012) determined that 25% of individuals with developmental disabilities in the U.S. lived with family caregivers aged 60+ years, and an additional 35% were in “households of middle-aged caretakers for whom transition issues are near-term considerations” (Fujiura, 1998, p. 232).

In *Figure 4*, we further examined the data in the previous figure to draw specific attention to the size of the aging family caregiver cohort (852,923 persons) in 2011. How large is the aging caregiver cohort in each of the states?

State-by-state estimates can be generated by taking into account differences in states’ utilization of out-of-home placements and the number of the states’ caregivers who are over age 60. For example, an estimated 5% of persons with I/DD in Arizona and Nevada live in out-of-home settings while the figure is 23% in Oregon. The percentage of individuals over age 65 in the *oldest* state, Florida (17.6%), is over two times the percentage of older individuals in the *youngest* state, Alaska (8.1%) (U.S. Census Bureau, 2012).



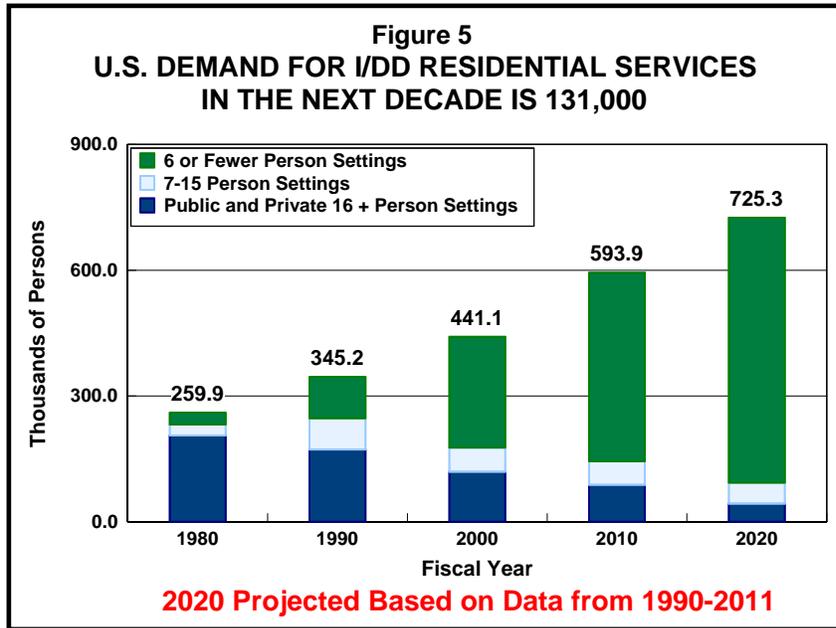
Increased Longevity

A second factor contributing to the growing demand for I/DD services is the increase in the lifespan of individuals with intellectual and developmental disabilities. The mean age of death for persons with developmental disabilities was 66 years in 1993, compared to 59 years in the 1970s and 33 years in the 1930s. The average longevity of people with Down syndrome increased from nine years in the 1920s to 31 years in the 1960s to 56 years in 1993 (Janicki,

Dalton, Henderson, & Davidson, 1999). The mean age at death for the general population in 1993 was 70 years (Janicki, 1999).

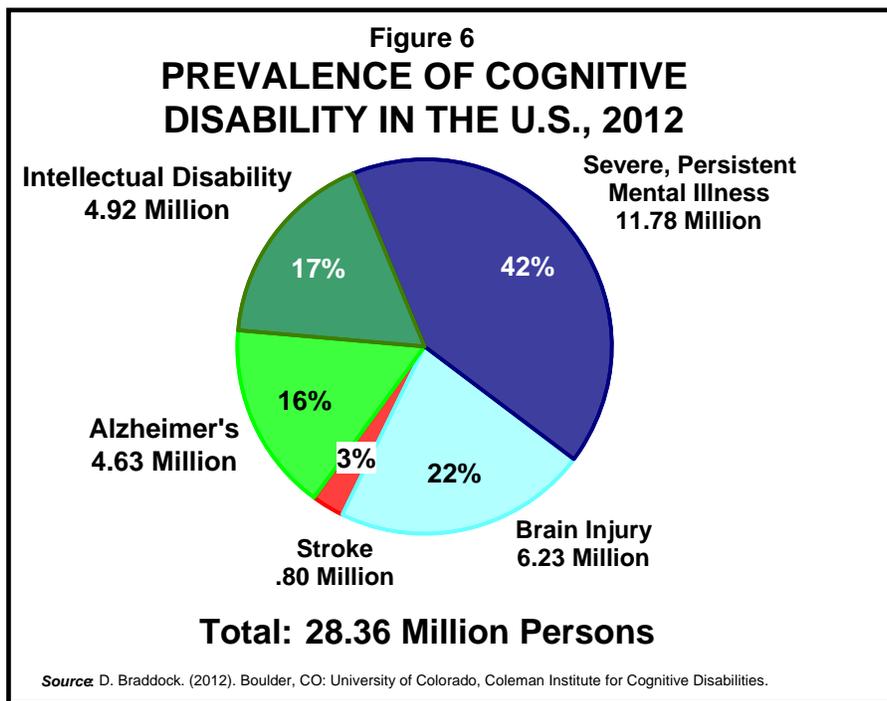
Growing Demand for Residential Services

Based on the growing number of baby boomers nearing retirement age, including aging caregivers of individuals with I/DD, and the past trend in growth of residential services, we have estimated the future requirement of different sizes of community residences to meet growing support need (*Figure 5*). The figure takes into account the trend during 1990-2011 in residential settings for 6 or fewer persons (growing), and for 7/15 and 16+ person settings (declining).



Part II: Coleman Institute for Cognitive Disabilities

The Coleman Institute for Cognitive Disabilities is a resource in cognitive support technology for people with intellectual and developmental disabilities. The Institute’s mission is to catalyze and integrate advances in science, engineering, and technology to promote quality of life and independent living for people with cognitive disabilities. There are an estimated 28.5 million citizens with cognitive disabilities in the U.S., as illustrated in *Figure 6*. Grants are provided by the Institute to faculty on the four campuses of the University of Colorado—in Boulder, Denver, Colorado Springs, and the Anschutz



Medical Campus in Aurora—and to CU faculty collaborators in research universities and industry throughout the U.S.

Confluence of Advances in Technology¹

The use of computer-related technologies for communication, education, health and work has become ubiquitous in developed countries, but the inaccessibility of such technologies to people with I/DD has created a new meaning for the term *digital divide* (Rizzolo & Braddock, 2008). Cognitive support technologies can take many forms (LoPresti, Bodine, & Lewis, 2008). Adapted personal digital assistants (PDA) and smartphones can be used as a prompting or memory aid and can enhance the ability of a person with an intellectual disability to perform job tasks, remember the steps to prepare a meal, and promote a healthy lifestyle. PDA-based and smartphones systems with Global Positioning System (GPS) technology can enable a person with I/DD to navigate a bus route independently (Davies, Stock, Holloway, & Wehmeyer, 2010). E-mail programs using pictures and voice-driven messaging can facilitate communication (Braddock et al., 2004; Bryen, Carey, & Friedman, 2007; Davies, Stock, & Wehmeyer, 2001).

Universal design principles applied to technology benefit not only persons with I/DD, but also aging individuals and the general public. For example, web access has become a critical information resource as well as a transactional methodology. People with cognitive disabilities need to be able to access the Internet with an appropriate level of simplicity regarding navigation and information translation (Lewis, 2007).

Market forces will drive advances in cognitive technologies as our nation ages, but regulatory policies and standards have not kept pace with the growing need for more broadly inclusive accessibility standards. Organizations such as the U.S. Access Board and the World-Wide-Web Consortium have begun to address web accessibility, but the principles of the Americans with Disabilities Act (ADA) are unrealized with respect to technology access for people with cognitive disabilities (Karreman, van der Geest, & Buursink, 2007).

The Coleman Institute has offered recommendations pertaining to the advancement and diffusion of cognitive support technologies for people with I/DD in the United States (Braddock et al., 2013). One key recommendation is developing several university-based *Centers on Cognitive Technology Research, Development and Dissemination* modeled after the existing national network of University Centers for Excellence in Developmental Disabilities (UCEDDs). Core funding for a UCEDD-based cognitive technology initiative might include resources from federal agencies such as the U.S. Administration on Developmental Disabilities, the National Institute on Disability and Rehabilitation Research, and the U.S. Department of Commerce. Corporate and foundation partners, persons with I/DD and their families, and community service providers would participate in this collaborative effort as well.

Industry standards in cognitive support technology, such as the AIMS prompting standard (LoPresti, Bodine, & Lewis, 2008) should also facilitate reuse and dissemination of standards-based content. This will entail dissemination and technical assistance to professional associations and other standards-setting groups to incorporate the needs of people with cognitive disabilities

¹ This section is based in part on a summary and update of an article appearing in the *Journal of Special Education Technology* (Braddock et al., 2004, 19(4), 49-56) and in Testimony to the Interagency Committee on Disability Research (Braddock, 2004).

in standards and personnel training. Funding eligibility also needs to be clarified in state Medicaid plan amendments to assure reimbursement of smart home and individualized cognitive support technologies throughout the states.

A recent Coleman Institute Conference on Cognitive Disability and Technology explored an important issue for persons with I/DD: Whether a “right to technology access for people with cognitive disabilities” is analogous to the right to education and habilitation. Research support by the Coleman Institute is being completed on this topic.²

Cognitive technologies have the potential to help persons with cognitive disabilities, and those with age-related cognitive decline, to achieve greater independence, productivity, and quality of life (Eisenberg, 2002; Hammel, Lai, & Heller, 2002; Merritt 2003; Simpson, Koester, & LoPresti, 2010). Product engineering is evolving from stand-alone devices and applications to distributed, connected, integrated, and multi-technology systems. Electronic products are becoming "smart" and software systems are becoming adaptive and personalized. The movement toward smaller, easier to use, micro-technologies, with larger-scale integration, increased performance, and reduced price not only benefits the general population, but also has the potential to benefit those with cognitive disabilities. Three arenas of technology advancement in cognitive disability are described below: personal support technologies, assisted care systems technologies, and virtual technologies.

Personal Support Technologies

Personal Support Technologies (PST), such as personal digital assistants (PDA's), have the ability to greatly enhance the independence, productivity, and quality of life of persons with cognitive disabilities. For example, parents or caregivers can pre-program a PDA or desktop software with educational, vocational or daily living tasks to prompt individuals with cognitive disabilities to perform a wide variety of well-defined vocational and independent living tasks (Palmer, Wehmeyer, Davies, & Stock, 2011; Davies, Stock, & Wehmeyer, 2002a).

Specialized PDA software is currently available for enabling individuals with developmental and other cognitive disabilities to manage personal schedules with much greater independence (Davies, Stock, Holloway, & Wehmeyer, 2010; Davies, Stock, & Wehmeyer, 2002b), for helping direct individuals during their work tasks (Davies, Stock, & Wehmeyer, 2002a; Furniss et al., 2001; Furniss & Ward, 1999), and for assisting with activities of daily living (Lancioni, O'Reilly, Seedhouse, Furniss, & Cunha, 2000). PDA's can also interface with wireless communication protocols to track and monitor an individual's daily activities, and provide prompts to the individual as needed to complete educational or work tasks (Furniss et al., 2001; Kautz et al., 2001; O'Hara, Seagriff-Curtin, Davies, & Stock, 2002).

Computer Assisted Learning and Communication

Other personal support technologies include specialized computer training programs (Stock, Davies, Davies, Wehmeyer, & Lachapelle, 2011; Davies, Stock, Wehmeyer, 2003, 2004; Simpson, Koester, & LoPresti, 2010), voice interfaces (Barker, 2002), picture based email programs, and adapted web browsers such as WebTrek (Stock, Davies, Wehmeyer, & Lachapelle, 2011; Davies, Stock, Wehmeyer, 2001). Wearable computers can also assist students

² See the Institute's website for more information about the recent Conferences, and the agenda for the forthcoming 2013 Conference (colemaninstitute.org).

with cognitive disabilities. For example, a wearable data glove has been developed by an engineering student at the University of Colorado that translates American Sign Language and transmits this information wirelessly to an electronic display (Patterson, 2002).

Access to personal support technologies can benefit individuals in the classroom to remain on task, remind them of pending assignments, and provide access to information on the computer or the internet. Computer-based learning techniques for students with cognitive disabilities has been documented. Despite the benefits to be gained, however, studies indicate access to computers and the internet for persons with cognitive disabilities in the classroom and at home lags continue to lag behind access for persons without disabilities. The rates of access for persons with cognitive disabilities are undoubtedly even lower than the above cited statistics, which apply generally to persons with disabilities. Some researchers, however, posit that with advances in computer power and declining costs, increasing numbers of students with disabilities will have appropriate access to necessary technologies. However, education tends to follow well behind other sectors of society in terms of technology utilization. In addition, this problem can be exacerbated in special education because it comprises a small market relative to general education.

Universal Design

Universal design principles are necessary to ensure that persons with cognitive disabilities are able to utilize common technologies available to the general public. Universal design intends that products -- especially software and computers -- provide an interface that is suitable for *all* potential users, including persons with disabilities. Web standards, such as User Agent Accessibility Guidelines (Festa, 2002), federal regulations - such as section 508, and public/private initiatives, such as the World Wide Web Accessibility Initiative (WAI) of the World Wide Web Consortium (W3C), promote access to software and the internet for people with disabilities (Friedman, & Bryen, 2007).

Assisted Care Systems Technology

Another area of emerging technology for persons with cognitive disabilities is assisted care systems technology. These technologies are designed to assist caregivers of individuals with cognitive disabilities, and can range from simple monitoring devices to complex assisted care systems (ACS) integrated into the infrastructure of a building. These technologies can assist in promoting the independence and health of persons with disabilities -- including persons with cognitive disabilities-- while maintaining safety.

Smart Houses

One example of an assisted care system is the “smart” home. Smart homes and rooms combine tracking technology and environmental control to provide robust prompting, including environmental cues such as adjusted lights, and simplified operation of household systems and routines (Lancioni, O'Reilly, Singh, Sigafoos, Campodonico, & Oliva, 2009). Many companies, such as Microsoft, Honeywell, and Intel, and universities such as MIT and Georgia Tech, are researching smart home technology as beneficial examples of ubiquitous computing. Research at the University of Colorado at Boulder is also underway to apply similar “smart supports” technology to community and family-based settings for persons with developmental disabilities (Stock, Davies, Wehmeyer, & Lachapelle, 2011; Taylor, 2003).

Residential assisted care systems integrate indoor/outdoor tracking systems, bio-sensors, building automation, databases, computer networks, and potentially, learning algorithms. Assisted care systems could provide numerous benefits for persons with cognitive disabilities, their families, and caregivers. For example, tracking systems can provide feedback to direct support employees and relatives on daily living activities. Pattern-recognition and learning software can be used to alert direct support employees of impending risks or adverse events, including social isolation and abnormal behavior. Building automation can simplify or control operation of household systems, including disabling an appliance or unlocking a door when a resident reaches their room. Though the research to date has focused on how these systems can promote independence in residential settings, the technology has the potential to be applied to other environments including the work site and the classroom (Stock, Davies, & Wehmeyer, 2009).

Smart Transportation/Tracking Technology

Another example of smart technology is the smart transportation system. This system can assist persons with cognitive disabilities with mass transportation by utilizing wireless technologies and personal digital assistance devices (Fischer & Sullivan, 2002). Travelers can be alerted when their GPS-equipped bus is arriving, and caregivers can be notified if the traveler has boarded the wrong bus. The availability of reliable and safe transportation options can be an essential precursor to the successful transition from school to work (Lancioni, Singh, O'Reilly, Sigafoos, Alberti, Scigliuzzo, & La Martire, 2010; Stock, Davies, Wehmeyer, & Lachapelle, 2011).

Tracking technology is also a potentially useful ACS strategy to address wandering. Over 50% of respondents in a survey by the National Down Syndrome Society (2001) identified wandering as a significant problem. Many of the respondents indicated that wandering behavior occurred at night. Companies have developed both personal devices and home-based systems to address this need (Digital Angel, 2002). Utilizing GPS or local tracking data, monitoring devices can also alert caregivers in the event of a fall or unusual activity, or help locate persons who wander.

Personal Robots

Robots have also emerged as a novel way to supplement the role of caregivers (Dario, Guglielmelli, Laschi, & Teti, 1999). Researchers at Carnegie Mellon and the University of Pittsburgh have developed a nurse robot (Nursebot) to assist elders with activities of daily living including prompts to perform certain tasks and medication administration (Rotstein, 2004; Stresing, 2003). The role of robots in the provision of care to the elderly and persons with cognitive disabilities will increase as the general population ages, the need for long term care increases, and the pool of potential caregivers declines. Analysis of data from the National Long Term Care Survey showed that utilization of assistive technologies was associated with fewer hours of personal assistance (Hoenig, Taylor, & Sloan, 2003). Future research should investigate the role these technological assistants can play in the school environment.

Despite the progress made in I/DD services to supplant segregated public and private institutions with individualized supports in community living, work, and recreation, there is much still to be done. Personal support technologies are becoming well established, but are

available to only a small number of all individuals with I/DD requiring support. The Great Recession and the economic uncertainties it has spun has given rise to a heightened sense of urgency and concern about demographic, legal, economic and political forces currently impacting demand for residential and community services for people with disabilities in the United States. Class action litigation remains a strong force in the states in shaping the provision of services for persons with I/DD, and could well become even more pervasive in near future.

Aging caregivers from the Baby Boom generation, the large number of persons with I/DD dependent on aging caregivers, and increased longevity of persons with I/DD will contribute to substantially increased demand for improved systems of support in the years ahead. People with disabilities are a significant proportion of those Americans impacted most negatively by economic uncertainty and growing income equality in our country. Even though we have made significant progress in disability rights and the provision of services in recent decades, current economic challenges in the United States place millions of people with disabilities in great jeopardy.

Despite the potential of emerging technologies to help persons with cognitive disabilities to become more independent and productive, significant practical impediments must be overcome in commercialization, consumer abandonment, and in the design, development, and delivery of useful products to consumers. For example, existing barriers to widespread commercialization of emerging technologies include regulatory burdens imposed by the FDA and the economically disadvantaged status of many persons with cognitive disabilities -- combined with limited private insurance and Medicaid/Medicare coverage and payment policies. These problems are chronic but they are not irresolvable.

Barriers also exist in terms of the financial and organizational feasibility of specific envisioned products, and their limited potential to reach the consumer market. Innovative engineering approaches, effective needs analysis, user-centered design, and rapid evolutionary development are essential to ensure that technically feasible products meet the real needs of persons with cognitive disabilities. The obsolescence of most technological devices after only a few years presents a significant barrier to persons with cognitive disabilities. Efforts must be made by advocates, designers and manufacturers to promote better integration of future software and hardware systems so that forthcoming iterations of personal support technologies and assisted care systems technologies do not become obsolete quickly. They will need to operate seamlessly across multiple real-world environments in the home, school, community, and workplace.

An extremely important concern in current systems of supports nationwide is the inadequacy of direct support staff wages. The American Network of Community Options and Resources (ANCOR) has led a National Advocacy Campaign and endorsed legislation sponsored by Representative Lois Capps (D-CA) and Representative Lee Terry (R-NE), the Direct Support Professionals Fairness and Security Act of 2009. That proposed legislation would have given states an enhanced Federal Medical Assistance Percentage (FMAP) for addressing the issue of chronically low direct support staff wages and benefits. The National Advocacy Campaign was delayed during the Great Recession, but recently re-launched as a priority by ANCOR. This is an extremely important initiative to reduce turnover in community facilities and improve the quality of care.

It is my understanding that the National Council on Disability has recently provided four recommendations to the Long Term Care Commission. These include:

1. Decoupling eligibility for Home and Community Based Services (HCBS) under an HCBS Waiver from a determination of nursing home eligibility. Remove the institutional bias in the Medicaid program to give Medicaid beneficiaries greater choice in where they live and how financial assistance is provided to cover a range of LTSS.
2. Increasing support for families and significant others in their role as informal and unpaid caregivers.
3. Improve the supply, retention, and performance of direct support workers to meet increasing demand. Funding should be authorized for collaborative demonstration projects between the U.S. Departments of Labor and Health and Human Services that promote collaboration between community colleges and disability-related organizations to develop a high-quality set of competencies to be taught in a new support worker certificate program that expands supplies of quality workers to meet market demand in home and community-based settings.
4. Mandate coordination and collaboration among federal agencies to align public policy and transform infrastructure to be responsive to consumer needs and preferences by a comprehensive system of LTSS.

I also support these recommendations, and in conclusion, I would like to propose an initiative for "Research Centers of Excellence in Technology and Cognitive Disability."

Part III: Proposed Research Centers of Excellence in Cognitive Disability and Technology³

The costs of cognitive disability in American society currently exceed \$165 billion per year in income maintenance and long term care. People with cognitive disabilities substantially lag behind all other groups in our society in the utilization of technology. This is a critical issue because, increasingly, technology is a major contributor to the independence, productivity and quality of life for nearly all segments of our society today. People with cognitive disabilities are extremely underserved in accessing such technologies not only compared to non-disabled citizens, but also compared to persons with physical and sensory disabilities, themselves an underserved group.

I am proposing the creation of a national network of "Research Centers of Excellence in Technology and Cognitive Disability" to address this issue. The explicit purpose of these Centers will be to conduct research and develop and disseminate new technologies to improve the quality of life and independent living of people with cognitive disabilities in American society.

The proposed Centers on Cognitive Disability and Technology will advance the independence and quality of life of individuals with cognitive disabilities through technology

³ The Centers were initially proposed in April 18, 2002 testimony to the U.S. Department of Education Hearings on Reauthorization of the Vocational Rehabilitation Act (Braddock, 2002).

research and development, foster public-private partnerships in the development, commercialization and dissemination of new technologies pertinent to cognitive disabilities, and thereby contribute to the nation's economic productivity while reducing income maintenance and long-term care costs to federal and state governments and families.

- The Initiative should authorize core administrative funding and research resources across the nation for 10 “Centers of Excellence in Technology and Cognitive Disability”;
- The Centers would be located in multidisciplinary, university-based settings and closely linked functionally to commercial enterprises and to private foundations interested in technology and cognitive disability. The Coleman Institute will consider providing planning grants for prospective applicants for federal funding;
- Core disciplines would include, but not be limited to, computer science, electrical and computer engineering, biomedical engineering, psychology, imaging science, rehabilitation science, and special education;
- Centers would involve consumers with cognitive disabilities and their families, service providers, employers, and schools to facilitate the development and dissemination of viable new technologies to increase the social, economic, and educational participation of persons with cognitive disabilities. Centers would also advance scientific knowledge about cognitive disability and technology;
- Centers would compete for and secure research and development funding and related resources from Interagency Committee on Disability Research (ICDR)-related units at the National Institutes of Health, National Institute on Disability and Rehabilitation Research, the U.S. Departments of Education, Labor, and Transportation, the National Science Foundation, Administration on Developmental Disabilities, state governments, private industry and foundations;
- The Centers would coordinate their activities with entities such as existing federal technology laboratories, engineering research centers, rehabilitation research and training centers, Technology Act information and technical assistance grantees in the states, the nation's ten Regional Disability and Business Technical Assistance Centers on the Americans with Disabilities Act, University Centers of Excellence in Developmental Disabilities, independent living centers, and federally funded Mental Retardation and Developmental Disabilities Research Centers.

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Revised

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APPENDIX 1

Frequently Asked Questions about Cognitive Disability

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1. What is a cognitive disability?

- Cognitive disabilities include intellectual disability (previously referred to as "mental retardation") and other developmental disabilities such as autism spectrum disorders; severe and persistent mental illness, brain injury, stroke, and Alzheimer disease;
- Cognitive disability entails sub-average intellectual performance and limitations in adaptive behavior;
- Cognitive disability can originate at or before birth, during the neonatal or developmental period (through age 21), during adulthood, or during later life;
- Approximately 28.4 million persons, or 9.1%, of the U.S. general population of 312 million currently experience significant cognitive disabilities. Approximately 76% of persons with cognitive disabilities are adults (see **Attachment 1**);
- The cost of cognitive disability to the U.S. economy, not to mention to individual and family well-being, is substantial. In 2011:
 - ✓ \$67 billion annually in income maintenance funds
 - ✓ \$98 billion in long term care costs
 - ✓ With special education and health care spending included, the total public cost of cognitive disability exceeded \$236 billion
 - ✓ Added billions of dollars in lost productivity
- We live in a society heavily dependent on cognitive functioning: sequencing and planning thoughts and actions, interpreting subtle social cues, manipulating numbers and symbols;
- Our intellectual or cognitive styles are highly personalized, and this is equally true for people with cognitive disabilities;
- Personalized software can aid people with cognitive disabilities by prompting and otherwise supporting communication and interaction with the world around them.

2. What is a significant cognitive disability?

- A disability having a substantial impact on a person's major life activities such as educational performance, capacity for employment, receptive and expressive language, capacity for independent living and economic self-sufficiency;
- For persons with intellectual disability, those whose intelligence level is measured at two or more standard deviations below the mean (i.e., an IQ of approximately 70 or below) on standardized tests of cognitive functioning (i.e.,

Stanford-Binet, Wechsler Adult Intelligence Scale, Wechsler Intelligence Scale for Children) and who also experience significant limitations in adaptive behavior.

3. What is a developmental disability?

- The federal Developmental Disabilities Act defines developmental disabilities as:
 - (A) In general. The term "developmental disability" means a severe, chronic disability of an individual that
 - (i) is attributable to a mental or physical impairment or combination of mental and physical impairments;
 - (ii) is manifested before the individual attains age 22;
 - (iii) is likely to continue indefinitely;
 - (iv) results in substantial functional limitations in 3 or more of the following areas of major life activity:
 - (I) Self-care.
 - (II) Receptive and expressive language.
 - (III) Learning.
 - (IV) Mobility.
 - (V) Self-direction.
 - (VI) Capacity for independent living.
 - (VII) Economic self-sufficiency; and
 - (v) reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.
 - (B) Infants and young children. An individual from birth to age 9, inclusive, who has a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting 3 or more of the criteria described in clauses (i) through (v) of subparagraph (A) if the individual, without services and supports, has a high probability of meeting those criteria later in life.

4. What about adult/aging/trauma induced cognitive disabilities?

- Brain injury and stroke can cause significant limitations in cognitive functioning during the developmental period (0-21 years) or in adult life or old age.

5. Are learning disabilities cognitive disabilities?

- Learning disabilities are cognitive disabilities to the extent that they impact upon major life areas including educational performance, capacity for employment, receptive and expressive language, capacity for independent living and economic self-sufficiency.

6. How are the schools and special education teachers involved?

- In 2011, there were 6.14 million children in the United States receiving special education services, including 1.4 million children with intellectual disability (including autism spectrum disorders and developmental delay) and 375,000 with emotional disturbance. These 1.8 million children form the core of children with cognitive disabilities in the schools. They present some of the greatest challenges to special education teachers, and, as students become adults, in the transition from school to work.

7. Is Alzheimer disease a cognitive disability?

- Yes, Alzheimer disease leads to cognitive disability, and due to the aging of the U.S. population, there is likely to be increases in the number of individuals experiencing Alzheimer disease.

8. What are the important policy issues at the local and state level around cognitive disabilities?

- Stigma and discrimination;
- Lengthy waiting lists for long term care services in community and family settings;
- There are inadequate financial resources for community-based programs, and inadequate wages and other problems affecting the recruitment and retention of qualified staff to work with persons with cognitive disabilities;
- Despite recent initiatives to finance supported employment programs, persons with cognitive disabilities have vastly higher unemployment rates than other Americans, and many are substantially underemployed; poverty is a serious problem for most persons with cognitive disabilities.

9. How does the ADA relate to cognitive disabilities?

- The Americans with Disabilities Act (ADA) promotes equal access in employment; state and local government activities; public transportation; public accommodations; and telecommunications for people with cognitive disabilities, just as it does for all people with disabilities.

10. What are some issues faced by those living with cognitive disabilities?

- Social isolation, unemployment/underemployment, higher prevalence of emotional problems than the general population, difficulty communicating with others, lack of community services, and lack of support for families;
- Absent affirmative efforts to "level the playing field," people with cognitive disabilities face increasing challenges on many fronts as the world becomes more technology-reliant;

- Access to appropriate technologies, however, can mean greater participation in employment, social and recreational activities, and other activities of daily life and community living.

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ATTACHMENT 1

Number of People with Cognitive Disability in the United States By Age and Type

2012 Update: UNITED STATES								
Age	General Population ¹	Intellectual Disability ²	Emotional Disturbance ³	Severe and Persistent Mental Illness ⁴	Traumatic Brain Injury ⁵	Stroke ⁶	Alzheimer's Disease ⁷	Total
Under 5	20,162,058	318,561	1,449		403,241			723,251
5 to 17	53,772,214	849,601	370,049		1,075,444			2,295,094
18 and over	237,657,645	3,754,991		11,407,567	4,753,153	800,000	4,628,027	25,343,738
Total	311,591,917	4,923,152	371,498	11,407,567	6,231,838	800,000	4,628,027	28,362,083
Population %		1.58%	0.12%	3.66%	2.00%	0.26%	1.49%	9.10%
Sources								
1 US Census Bureau (2012) http://www.census.gov/popest/								
2 National Health Interview Survey - Disability Supplement; includes closely related developmental disabilities (1.58%); Larson et al., 2001. NOTE: an additional 2.894 million children are receiving special education services due to a diagnosis of learning disabilities								
3 26th Annual Report to Congress on Implementation of the Individuals with Disabilities Education Act (3-5, 1,449 + 6-21, 370,049).								
4 U.S. Department of Health and Human Services. (2010). <i>Mental Health: A Report of the Surgeon General</i> . Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institutes of Health, National Institute of Mental Health, (estimated at 4.8% of adults, 18 +, p. xxi).								
5 Thurman, D., Alverson, C., Dunn, K., Guerrero, J., & Sniezek, J. (1999). Traumatic Brain Injury in the United States: A public health perspective, <i>Journal of Head Trauma and Rehabilitation</i> , 14(6), 602-15. (Estimated at 2.0% each age group).								
6 Kelly-Hayes, M., Robertson, J.T., Broderick, J.P., Duncan, P.W., Hershey, L.A., Roth, E. J., Thies, W.H., & Trombly, C.A. (1998). The American Heart Association stroke outcome classification, <i>Stroke</i> 29, 1274-1280. (Est. 4,000,000 alive have stroke & 15-25% cognitive deficits, pp. 1274, 1276).								
7 U.S. Department of Health and Human Services., 1999, p. 359 (estimated at 11.5% of population aged 65 +).								