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Economic Security and Health as People with Disabilities and Their Families Age

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Good morning. Thank you, Chairman Collins, Ranking Member Casey, and other members of the Senate Committee on Aging, for the opportunity to speak with you today about economic security and well-being for people with disabilities and their families. I am grateful to serve as a witness and share with you some of our research and provide information on the economic situation many people with disabilities and their families face as they age.

My name is Kelly Nye-Lengerman, and I am a researcher at the University of Minnesota's Institute on Community Integration (ICI), Research and Training Center on Community Living. ICI is Minnesota's designated University Center for Excellence in Developmental Disabilities (UCEDD). We are a research, training, and outreach center focusing on disability policy and services across the lifespan. A number of our current and past research projects have examined employment, economic outcomes, and well-being for people with disabilities and their families and caregivers.

Economic well-being includes a broad range of social, emotional, and health factors that extend well beyond how much money an individual or family has earned or saved. Millions of individuals with disabilities and their families are not able to access the American dream in the same way others do, as they do not have the same pathways to earning and saving. There are a number of significant obstacles they face, and cumulatively over a lifetime, these barriers make economic security later in life more challenging.

First, people with disabilities are more likely to be unemployed, underemployed, and living in poverty. "Disability is a cause of poverty as it is associated with job loss, reduced earnings, restricted opportunities to save or invest money, workforce entry barriers, and more limited access to education and jobs. Disability can also be a consequence of poverty because poverty limits access to healthcare, education, and jobs, or restrict the ability to save, all of which can adversely affect health and economic wellbeing necessary supports" (Vallas, Fremstad, & Ekman, 2015). People with disabilities are more than twice as likely to live in poverty compared to people without disabilities (27 percent vs. 11 percent), and people with cognitive disabilities, which include intellectual and developmental disabilities (IDD), are three times more likely (32 percent) to experience poverty (Erickson, Lee, & von Schrader, 2017). The labor force participation rate is the percentage of the population that is working or actively looking for work, and as of June 2018 was 33% for working-age people with disabilities compared to 78% of people without disabilities (Brennan-Curry, 2018). This employment gap between people with and without disabilities remains fairly consistent over time. Kraus et al. (2018) report that thirty-four states have an employment gap of 40 percentage points or greater, and only three states showed an employment percentage gap less than 23 percent.

Second, the act of caregiving for a family member with a disability creates many challenges to families that prevent them from having a regular income, accessing healthcare, or saving income for the future. An estimated 25 percent of American families include a member with a disability between the ages of 18-64, and that number rises to 43 percent of households include a member over the age of 65 with a disability. Nearly 40 million family members provide care for loved ones with a disability (Coughlin, 2010; Reinhard, Feinberg, & Choula, 2015). Caregiving duties range from simple to complex activities: such as assisting someone to go to the grocery store, physically transferring someone from a wheelchair to the tub for daily bathing or administering complex interventions such as tube feeding or suctioning. These responsibilities often increase as the family member with a disability ages and these support activities become harder to perform for family caregivers who are also aging.

The majority of caregiving provided by families is unpaid and not reimbursed through insurance or public support programs. In 2013, U.S. families provided an estimated 37 billion hours of care for people with disabilities of all ages, children, and older adults worth an estimated $470 billion (Reinhard et al, 2015). Many Americans over the age of 50 are what is sometimes referred to as “compound caregivers,” which means that they are providing care to a family member with a disability and an aging parent or relative simultaneously. Compound caregiving leaves little time for caregivers to take care of themselves and, as a result, these caregivers experience higher rates of stress, depression, and other physical and mental health issues from which there is often little reprieve (Perkins & Haley, 2010). This adds to challenges with being able to work, earn a living and save.

Family units that include a member with a disability are also more likely to live in poverty. The average household income for a family with a member who has a disability is nearly 45 percent less ($43,300 annually) than the average household income of a family without a member who has a disability ($68,700 annually; Erickson et al., 2017). In addition, households in which there is a member with a disability which have an income of $59,000 or less have reported higher negative social, emotional, and economic impacts of caregiving (Anderson et al., 2018). In sum, individuals with disabilities and their families have fewer economic resources in general than the average American family.

Third, as individuals with disabilities and their family members age, they can become more reliant on public support programs such as Medicaid, Medicare, Supplemental Nutrition Assistance Program (SNAP) and/or Supplemental Security Income (SSI). With life expectancies increasing for people with and without disabilities and the changing demographics of the workforce (i.e. worker to retiree ratio), the demands and needs for these supports have never been higher.

Adding to this complexity, many public support programs inadvertently keep individuals and families in poverty in order to maintain eligibility. Two examples include: substantial gainful activity (SGA) limits earnings over $1,180 for non-blind individuals ($1,970 for blind individuals) for some support programs like SSI, and the $2,000 asset the limit for eligibility for other support programs like Medicaid. Support programs are critical lifelines for individuals and families but do little to assist in lifting them out of poverty long-term.

Collectively, these circumstances leave people with disabilities and their families in a difficult situation, having to make no-win decisions. An aging parent may ask, “Do I take early retirement to stay home with my son to provide care?” An adult with a disability may think, “I want to work but I’m not sure how taking this job might affect my healthcare benefits.” In our research at the Institute on Community Integration, we’ve tried to better understand the experiences of family caregivers and people with disabilities in order to inform practice and policy solutions. The following findings include a small sample of work by various researchers at our center about out of pocket expenses, living environments, workforce challenges, respite needs, and retirement for people with intellectual and developmental disabilities (IDD).

Finding 1. Without paid employment, people with disabilities do not retire, nor have savings for later in life. One study we have conducted examines retirement for people with IDD. This research revealed that most people in this group are not actually retiring because they have not participated in paid employment over the course of their adulthood. Instead there is significant increase in facility-based, not community-based, day services as individuals with IDD age (Stancliffe et al., 2018). For people the few people with IDD who did retire, their entry into retirement was not gradual over time, as is typical of the general aging population, but instead is sudden, working one day and fully retired the next day. In the general aging population, people often decrease the number of hours they work each week as they age, gradually engaging in retirement. The pattern of sudden retirement for people with IDD, however, is characterized by an age-related decline in the percent of people working, without a marked age-related change in hours of work for those who remain employed. In this research, there was a segment of people with IDD who participate in paid employment that work well beyond age 65, which is also true for the general aging population. While we still know very little about retirement for older adults with disabilities, these findings highlight the fact that people with disabilities are less likely to be working and, therefore, likely have little to no savings from earnings, which limits their ability to retire in the same way that people without disabilities retire. With secured funding, our future research seeks to analyze other national data sets, including the Health and Retirement Study, and to examine healthy retirement planning and strategies for people with disabilities.

Finding 2. Families with a member with a disability have a drastically reduced ability to earn income and save due to high caregiving demands. Caregiving affects opportunities for economic mobility for both people with disabilities and their family members. We recently conducted a study, in partnership with The Arc of the United States, of family caregivers who provide support to individuals with intellectual and developmental disabilities. We found that 90 percent of respondents reported annual out of pocket expenses related to caregiving. Twenty percent reported having out of pocket expenses ranging from $5,001-20,000 each year, and 17 percent reported spending more than $20,000 in out of pocket expenses each year. Another study found the average annual medical expenses for a family that included a person with a disability were 300 percent higher than for families without a member with a disability (Altman et al., 1999). When most Americans, disability or not, only have savings of about $500 to $5,000, out-of-pocket expenses related to a disability can be financially devastating.

Solutions for this situation come not only from public support programs, but employers and businesses play a role too. Benefits offered by employers such as paid time off, flexible work schedules, healthcare, employee assistance programs, flexible spending accounts, and supportive supervisors have been identified by family caregivers as essential to help keep them working while caring for a loved one with disabilities.

Finding 3. Supporting people with disabilities to live in family homes or their own homes is significantly less costly to society than housing them in group or institutional facilities. Where a person lives can provide insight to caregiving capacity and needs. Today, more than any other time in history, people with disabilities are living in the community, most often in a family home. Data from our Residential Information Systems Project (RISP), which annually reports on Medicaid Long Term Services and Support (LTSS) data for people with IDD reveals that most of these individuals are living with their families and require both formal and informal caregiving. In 2014, of the nearly 1.4 million people with IDD who were served by state IDD agencies, 57 percent lived in the home of a family member, 11 percent lived in a home they owned or leased, and 5 percent lived in a host home or with a foster family (Larson et al., 2017).

While there is a narrative that suggests "group housing," or keeping people with disabilities together in one home, can save costs and reduce family caregiving, our research has found the opposite to be true. Living in the community in family- or self-owned homes is less expensive than institutional or nursing home settings. Institutional settings for adults with IDD cost an average of $128,251 annually, compared to $50,705 annually for care in family homes. The same is true for children with disabilities, with institutional settings costing $118,540 annually versus $18,531 annually for services provided in the family home (Larson et al., 2017). Community settings save money for both Medicaid and tax payers. We also know that, when asked, most people with disabilities and their family members prefer to live in and be a part of the community, which includes being part of their family in their home. Current estimates suggest that 25 percent of family caregivers in these homes are over the age of 60 (Heller & Factor, 2004). Given the vast majority of people with IDD live with aging caregivers, it is critical that Congress find ways to support family caregivers.

Finding 4. Family caregivers are in urgent need of relief and support. Families report that respite care provides them with much needed relief and space to attend to life's other issues. Respite care is temporary planned or emergency care provided to care caregiver. As family caregivers age, the desire for respite care to balance caregiving and personal needs increases. Our Family Individual Needs Study (FINDS), in partnership with The Arc of the United States, found that over half of families used respite, and of that group 92 percent reported they had trouble finding respite care staff of providers (Anderson et al., 2018). Families rely on the direct support workforce to fill respite and other care needs. Interestingly, 50 percent of respondents in this study were caregivers between 50-64, 15 percent ages 65-74, two percent and were over the age of 75.

The current direct support workforce shortage, which include respite care, nationally has surpassed a crisis point. A series of recommendations on how to address this crisis is outlined in our recent publication: *Report to the President 2017 America's Direct Support Workforce Crisis: Effects on People with Intellectual Disabilities, Families, Communities and the U.S. Economy* (Hewitt et al., 2018). Selected recommendations include: providing sufficient funds for Direct Support Professional (DSP) wages and compensation packages in Medicaid rate-setting methodologies; providing technical assistance and financial or programmatic incentives to states to promote the use of technology solutions to create efficiencies; reduce costs and support community living; expand utilization of self-direction so that family, friends, and neighbors can be hired as DSPs; and investing in nationally recognized specialized credentials and professional development opportunities for DSPs. The implementation of these recommendations (and others from the report) are essential to stabilize the direct support workforce and provide aging family caregivers relief and support so that a family member with a disability may continue to live at home or in their own home.

Key take-away messages from the body of research on the economic well-being of people with disabilities and their families include:

- Invest in and support employment for people with disabilities so that they can earn and save for the future. Current investments in employment for youth with disabilities today can lead to increased saving and decreased governmental support program expenses in the future.
- Support growth in flexible saving options, like ABLE accounts, to create safe spaces for families and individuals with disabilities to save funds without endangering eligibility in important support programs.
- Support family caregivers so they can stay in the workforce, maintaining access to healthcare, benefits, and retirement savings through their employers.
- Support and invest in a stable and competent direct support workforce to supplement family caregiving.
- Incentivize and support people with disabilities and their families in integrated community settings (i.e., their family home or their own home).

These issues represent tremendously complex policy and system challenges. However, there are a number of policy pathways and investments that can increase the economic well-being of individuals and families by supporting saving for retirement in older ages, helping people with disabilities stay in their own home, and bolstering assistance for aging family caregivers. Congressional action has provided the formative foundation for many programs which have benefited people with disabilities and their family caregivers. The Institute on Community Integration’s research, policy advocacy, and engagement work inform the following recommendations:

1. **Support pathways to savings for individuals with disabilities and their families.** The Achieving a Better Life Experience Act (ABLE) of 2014 led to the creation of ABLE accounts which are now held by more than 21,000 beneficiaries in the U.S. (Strategic Insights, 2018). These tax-advantaged savings accounts for individuals and their families recognize the extra costs of living with a disability. Various ABLE programs through STABLE, the National ABLE Alliance, and others represent nationwide access for families. With annual contributions of up to $15,000, the beneficiary of the account (i.e., the person with a disability) is the account owner, which represents an important shift. The first $100,000 in an ABLE account is exempted from the Supplemental Security Income (SSI) resource limit. ABLE accounts, although not yet widely adopted by families and individuals, are a tool for a significant, positive shift in economic well-being of people with disabilities and their family caregivers. The ability to save without penalty or ineligibility for other support programs opens new doors for individuals and families financially and provides a more equitable footing from which to save for the future, while potentially reducing the need for public support programs in years to come. Increasing the age of eligibility to those acquiring their disability before the age of 46 (from the current age of 26) would be welcome, along with additional investments to support family education about these accounts in order to increase enrollment and utilization. Growth of ABLE can be achieved through building trust with beneficiaries and their families through face-to-face interactions;

eliminating barriers to accessing ABLE; and making information about ABLE more accessible to families and beneficiaries from economically, linguistically, and culturally diverse communities.

2. Keep employment policies and investments for workers with disabilities strong. The Workforce Innovation and Opportunity Act (WIOA) is landmark legislation that is designed to strengthen and improve our nation's public workforce system and help get Americans, including youth and people with significant barriers to employment, into high-quality jobs and careers, while helping employers hire and retain skilled workers. WIOA further establishes competitive, integrated employment for people with disabilities as a clear national priority, built on the goal of economic self-sufficiency. Opening WIOA regulations under a recent notification issuing a Notice of Proposed Rulemaking (34 CFR part 361) has the potential to undermine implementation. Additionally, Promoting Readiness of Minors in Supplemental Security Income (PROMISE) grants highlight a joint national demonstration effort between the Social Security Administration and the U.S. Departments of Education, Health and Human Services, and Labor, with a goal of improving employment and educational trajectories of youth with disabilities. The research focus of PROMISE is examining various interventions with youth and families to support post-secondary education and employment. Lessons learned and findings from PROMISE may illuminate promising ways forward that will increase employment and education, while decreasing participation on other support programs.

3. A strong direct support workforce provides essential services to individuals with disabilities and their families. The direct support workforce is one of the highest in-demand professions in the U.S. The direct support workforce provides essential services to people with disabilities so they can live, work, and participate in the community, while also providing much-needed respite for family caregivers. Solutions to the direct support workforce challenges are complex, but one important way to address the current workforce crisis is through the expansion self-direction in long-term services and supports (LTSS) so that family, friends, and neighbors can be hired as Direct Support Professionals. Paying family members for caregiving can relieve economic burdens on a family and can be a particularly helpful option to older family members who are entering their retirement years.

4. Family caregivers and employed people with disabilities benefit from time off and support from employers. Access to paid leave is recognized as a critical component of being able to keep and maintain a job when complications of a disability or family member needs arise. Despite the presence of the Family Medical Leave Act (FMLA), an estimated 40 percent of all Americans cannot access this benefit because they work for small employers, lack longevity in a job, or have not worked enough hours (Jorgensen & Appelbaum, 2014; National Partnership for Woman and Families, 2013). FMLA could be significantly strengthened through legislation, eligibility requirements, or employer participation to accommodate the needs of individuals with disabilities and their families so that they can retain their employment and stay in the workforce despite the demands of caring for a family member with a disability.

In closing, I would like acknowledge the research of my University of Minnesota colleagues whose research was cited today: Drs. Amy Hewitt, Sheryl Larson, Sandra Pettingell, and Roger Stancliffe, and Ms. Lynda Anderson. Funding from numerous federal agencies including the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), Administration on Community Living (ACL), and others make research our possible.

As an addendum to my testimony, I have provided the committee with four family profiles that include their perspectives on policies that support economic security for people with disabilities and family caregivers. I hope you will take a moment to read recommendations from the Rigotti, Harris, Hilgart, and Hofer-VanNess families. Policies that make it possible for people with disabilities to work, save, and plan for their older years have long-term benefits that make it possible for us all to do better. Thank you again most sincerely for the opportunity to provide testimony and for your interest in this topic. I am happy to answer any questions the committee may have or provide additional resources.

Respectfully submitted by,

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Nye-Lengerman Testimony Supplement

Family Experiences and Thoughts: Improving economic security for people with disabilities and their families

In preparation for my testimony, I reached out to four families who provide support to their family member with a disability. Most of these family caregivers are over the age of 50 and have concerns about what their family member's life as they age.

Meet the Harris family. Josh (26), Debbi (60), Victor (69), Nicholas (28), and Jonathan (31). Victor served in the U.S. Marine Corp., CWO-4, for 33 years and was deployed multiple times in his military career. Debbi has provided full-time care for Josh in their home for almost his entire life. She left the workforce at age 38 to protect and preserve Josh's quality of life. Josh requires 24-hour nursing care. While Josh has access to skilled nursing services covered through Tricare, private insurance, and Medicaid, his family members work regular around-the-clock shifts to support Josh and fill gaps in coverage. In addition to Debbi, Victor, Nicholas' shift, Josh's 85-year-old grandfather and 58-year-old uncle work weekly shifts providing care as well. Josh's oldest brother, who has a family of his own, comes home every other weekend to provide care for Josh during overnight shifts. Josh's other brother lives with Josh, Debbi, and Victor in the family home and also supports Josh throughout the week. Josh's care and support is a family affair and, though difficult, they have made it work. Debbi says, "We're not a family without Josh, and if we didn't have him we'd be broken." Their suggestions for reducing caregiving challenges and economic burdens include:

- Competitive pay for in-home nurses (as they don't earn as much as nurses in other medical settings) so that families can keep consistent, high-quality staff. Good staff help keep Josh alive.
- Invest in the workforce development (i.e., competitive wages, benefits, incentives, professional status, etc.) of nurses and direct support workers so they stay in the field. The lack of a consistent workforce puts the lives of people with disabilities at risk and increases family stress exponentially.
- Close loopholes in Tricare that make getting skilled nursing services covered. Hoop jumping, excessive paperwork, and lack of payment to nursing providers leads to unnecessary stress and trauma for families.
- Allow Reservists who are called to active duty without permanent change of station orders to be able to immediately access nursing or homecare benefits for their family member in order to prevent hardship for other families in the future.

Meet the Hofer-VanNess family. Andy (29), Brian (67), and Jody (63). Andy is a young man, who, when properly supported, lives, contributes, and thrives within his local community. He also lives with an intellectual disability. As a family, this has not come without a cost. Andy's family has worked together to create both long- and short-term support plans for Andy later in life, and as his parents age. Whereas his family feels fortunate to have the services that support Andy in reaching his goals, his care has required one family member to forego the workforce to manage his services and provide critical transportation across his lifespan. Flexible tax credits for all income brackets for out-of-pocket costs associated with supporting a family member with a disability would have made a significant difference in the economic and emotional well-being of his family. Today, as they move toward a new system of supports based on Andy's individual wishes, they find their family has had to have an ongoing financial commitment in the process. Thinking outside the current social service delivery box, with a focus on a community living, supporting Andy's goals can be a win/win for all. For his goals to be fully realized, however, and for the family supported in moving forward, certain funding mechanisms are required. As an adult, Andy's transportation, as well as wages and benefits that are commensurate with a job, are critical in his achieving fiscal independence, thus, allowing him to rely less on public support programs. Andy's family has also experienced tremendous gains by nurturing natural supports that already exist in places Andy wants to belong to help him engage and work in his local community. This has allowed his family to share his support needs with a greater community while decreasing the burden on government to provide paid care. Andy's family has worked tirelessly to find and nurture people of like mind, but not all families have this capacity. Funds are needed to support community training and a shift in culture and understanding around the role individuals with disabilities play in the world. So much more can be accomplished and money saved with a person-centered approach, but families need more flexible funding and options that support community integration. Andy's family is pleased and hopeful that you are addressing these disparities. In their experience, some of the greatest areas of growth and promise are:

- Individualized budgeting and consumer-directed supports through Home and Community Based Services (waivers) should be expanded.
- Information about ABLE accounts should be accessible to all family types in various economic circumstances. Some state-level rules regarding ABLE accounts can be overly burdensome.
- Investment priority should be given to public programs and services that promote and provide incentives for competitive, integrated employment. Providers are often not sufficiently motivated to shift their services to support employment in the community. Rather, more public funds are available for segregated services. We have struggled to find quality providers and staff to support Andy in community employment.
- Sub-minimum wage for people with disabilities should be eliminated. Everyone has a right to earn a fair wage.

Meet the Rigotti family. Nick (23), Joe (21), Cindy (51), and Mark (55). Mark and Cindy are both small business owners in rural Minnesota. They are also both over the age of 50 and actively involved in their community. Nick lives at home, and they are happy he is there. It's where Nick wants to be too. Since he was young, Mark and Cindy always expected that Nick would work in the community. They spent years working with multiple school districts to provide Nick with the experiences he needed to join the workforce. Several years post-graduation, the Rigotti's are still struggling to find the right job supports for Nick. Staff turnover in Vocational Rehabilitation and in provider agencies has created discontinuities in service which have compromised Nick's success on the job. As a result of Nick's experience, Cindy started her own non-profit that provides work experiences to youth with disabilities, which has been extremely well received in her community. Mark and Cindy identified a few areas where the right policies could benefit Nick and their family's economic well-being as they, and Nick get older; they suggest:

- Improved, coordinated long-term job supports that would assist people with disabilities, like Nick, in finding and maintaining a job in the community, earning his own wages. The supports they received under WIOA from Vocational Rehabilitation and employment service providers could be greatly improved with quality, well-trained staff direct support staff who are consistent. Nick wants to work!
- Public and on-demand transportation in rural areas is non-existent. The Rigotti's and their extended family have spent hours driving Nick into the city for work experiences, appointments, and activities. Nick is capable of using public transit as he did so successfully when he was in school in a larger city but they simply do not exist where he lives now. Investment in public transit infrastructure would be helpful to them and reduce the significant costs they've invested private transportation.
- The Rigotti's save money for Nick's future but would like more saving opportunities. SSI limits what Nick can earn and save. They have used multiple different strategies to save for Nick, despite Nick not being the direct beneficiary of the account to safeguard some types of benefits. They would like other families have access to information and outreach about saving for future care needs for their child or family member. They are looking into an ABLE account in the future.

Meet the Hilgart family. Ben (6 months), Jackson (3), Michele (39), and Andy (39). The Hilgart's are an active and busy family. There are play dates, family gatherings, and lots of appointments. Ben was born with Down Syndrome. After his birth this February, he and his mother both met their out-of-pocket maximums in before the end of the month. Ben is benefiting from birth-to-three early intervention services and is already making progress! The Hilgart's pay $200 per month for early intervention supports. Michele had to go back to work after twelve weeks to maintain family insurance coverage, but her employer provided her with a customized position so she could meet Ben's care needs and maintain employment. In her newly created position, she works full-time from home, with 50 percent of her weekly hours (20 hours per week) fulfilled at any time, day or night. This benefit has allowed Michele to say in the workforce, keep her insurance, and provide care to Ben. They currently have a 529 account for their son Jackson and will soon open an ABLE account for Ben. As a family new to the disability community they suggest:

- Access to high-quality early intervention services for all eligible children and families. Ben made measurable progress in just two weeks.
- Healthcare access is important for all people. Out-of-pocket expenses have to be manageable for families in different types of circumstances.
- Ensure information about ABLE accounts are available to all different types of families, are easy to understand, and aren't overly burdensome to maintain with excessive paperwork requirements.

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