

**WORKING AND AGING WITH DISABILITIES: FROM  
SCHOOL TO RETIREMENT**

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**HEARING**

BEFORE THE

**SPECIAL COMMITTEE ON AGING**

**UNITED STATES SENATE**

**ONE HUNDRED FIFTEENTH CONGRESS**

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## **WORKING AND AGING WITH DISABILITIES: FROM SCHOOL TO RETIREMENT**

**WEDNESDAY, OCTOBER 25, 2017**

U.S. SENATE,  
SPECIAL COMMITTEE ON AGING,  
*Washington, DC.*

The Committee met, pursuant to notice, at 2:32 p.m., in Room SD-562, Dirksen Senate Office Building, Hon. Susan M. Collins (Chairman of the Committee) presiding.

Present: Senators Collins, Tillis, Fischer, Casey, Nelson, Gillibrand, Donnelly, Warren, and Cortez Masto.

### **OPENING STATEMENT OF SENATOR SUSAN M. COLLINS, CHAIRMAN**

The CHAIRMAN. The hearing will come to order. Good afternoon.

Since 1945, October has been designated as National Disability Employment Awareness Month. Today we will examine a range of issues, including educational and vocational training and social and housing supports, that can help lead to a stable career and a more satisfying life for many people who are living with a disability.

Studies show that employing individuals with disabilities is not simply a social good. It is also good business. Individuals with disabilities offer many advantages, including a highly motivated workforce, lower rates of absenteeism and employee turnover, greater loyalty, and higher rates of satisfaction and productivity among the entire workforce.

I know these benefits from personal experience. Michael Noyes, who was born with disabilities, has been a caseworker in my Bangor, Maine, office for the past 20 years and worked for former Senator Bill Cohen before that. His excellent work has been recognized by numerous veterans' organizations, and he is appreciated by his coworkers and all those whom he has helped over the years. He is an extraordinary person who strengthens the services that my office provides.

While the business case is strong for employing individuals with disabilities, the unemployment data show that we can do better. While nearly three-quarters of Americans without disabilities are employed, only a third of those with disabilities have jobs.

The biggest barrier appears to be cultural—an implicit bias that is widespread. Avery Olmstead, a 46-year-old from Old Town, Maine, shared his experience with my staff of applying for a job. Avery has cerebral palsy and uses a wheelchair to get around. When he arrives for an interview, he says that he is often met with visible confusion and discomfort. He finds himself spending half of

his time trying to make the prospective employer feel more comfortable.

Yet Americans with disabilities are integral parts of our communities. They are our mothers and our fathers, our aunts and uncles, our children and our siblings, loved by family and friends. They are doctors, writers, researchers, artists, scientists, carpenters, counselors, and in just about every sector of our society. Every day individuals with disabilities dream, and they achieve their dreams and contribute to the workforce.

Depending on the specific disability, some individuals may require certain supports, ranging from help with basic daily activities to transportation and housing. With this assistance, we can break down barriers and move from exclusion to inclusion and recognition.

From housing and social supports to vocational training and employment, there are models of care and integration that work to ensure that each individual is valued as a contributing member of society.

With advances in medicine and technology, Americans with disabilities are living longer. This presents both unique opportunities and challenges as they prepare for their older years. For some with disabilities, the normal aging process can be exacerbated and complicated due to medications, reduced mobility, and their general health status.

Often, as these individuals age, so too do their family caregivers. Elderly parents who served as caregivers for their entire lives may find themselves in need of care. For some families, the caregiving situation flips: The adult with the disability becomes the caregiver for the aging parent. For others, caregiving needs double, as both the adult child and the parent require care, and siblings or other relatives may be called upon to help. It is so critical that we support our caregivers, who are an essential source of assistance, but respite care and other supports are often very difficult to secure, particularly in rural America.

We must better prepare for the retirement years of people with disabilities. Like many other older working Americans, they look forward to retiring. This desire, however, is complicated by the fact that many individuals with disabilities have experienced higher rates of unemployment and underemployment. Approximately 27 percent of Americans with disabilities live in poverty. That is the highest rate of any subgroup in our country.

Whether one is born with disabilities or acquires them as one grows older, aging is a normal part of the human experience. Older Americans with disabilities share the same hopes and aspirations of the average senior, and we must work to ensure that their distinctive needs are met as they grow older.

I am now pleased to turn to our Ranking Member, Senator Casey, for his opening statement.

**OPENING STATEMENT OF SENATOR ROBERT P. CASEY, JR.,  
RANKING MEMBER**

Senator CASEY. Chairman Collins, thank you for holding this hearing on disability employment. I want to begin today with an observation that I think all of us would agree with, which is that

all of us, in one way or another, cherish our own dignity. Many things contribute to our dignity, of course: keeping our word, our relationships, how we treat each other, for example. Work also contributes to our dignity. The 12th century Hindu philosopher Basava referred to the “dignity of work” and how work can make a person holy.

Our hearing today will cover how laws like the Americans with Disabilities Act, the Individuals with Disabilities Education Act, and the Rehabilitation Act have helped to make work dignifying for individuals with disabilities. This hearing will also examine what more we can do so that individuals with disabilities have a fair chance to attain financial security during their work years and in retirement.

With passage and implementation of the ADA, the IDEA, and the Rehabilitation Act, when you walk into a store or a restaurant or even a ballpark, it is likely you will see an employee with a disability. This is a great start toward fulfilling what the philosopher Basava said about the dignity of work.

However, for far too many individuals with disabilities, the dignity of work is still out of reach. When the Americans with Disabilities Act was signed into law in 1990, workforce participation for those with disabilities was at about 30 percent. Today that participation rate is still at approximately 30 percent.

The jobs individuals with disabilities hold and rates of pay may be better, but the overall participation rate has not changed. And it is not for lack of desire. A 2015 Kessler Foundation survey found that over 68 percent of people with a disability want to work.

We know that work has numerous benefits. I will just give you a few. First, it creates social networks. Second, it can be a pathway to better health, both physical and mental. Third, work provides dignity, as I said before, and a sense of self-worth. Fourth, work is the key ingredient to economic self-sufficiency. And, finally, work benefits the economy.

We, of course, need to address the barriers to employment. That is one of the reasons I worked hard to pass back in 2014 the ABLE Act. The ABLE Act made it possible for people with disabilities to save money and not put needed benefits, such as health care, at risk. I am pleased to report that, as of the second quarter of this year, over 10,000 ABLE accounts were open and over \$37 million was saved by individual account holders.

So as we break down financial barriers to employment, we must also ensure that individuals with disabilities are able to develop a strong foundation for success in the workforce. As a member of the committee that reauthorized the Rehabilitation Act in 2014, I worked to make sure that young people with disabilities get the experiences necessary to find a job. These experiences include learning soft skills, the type of skills that make it possible to have a successful interview and know how to interact in the workplace itself. It also means getting the chance to volunteer or to participate in an internship or even to have a part-time job.

It also means feeling confident about one’s abilities and one’s disability. Part of doing more includes making sure people with disabilities can find good-paying jobs working with their peers who do not have a disability. And it means benefits and supports such as

home and community-based services, making sure that those remain in place.

So I look forward to the hearing and hearing from our witnesses about strategies and policies that will make it possible for all Americans to realize the dignity of work.

Thank you.

The CHAIRMAN. Thank you very much, Senator Casey. I must say I have learned something already at our hearing today. I have used the phrase “dignity of work” many times. It is a philosophy that I really believe in, but I had no idea that it went back to a 12th century Hindu philosopher.

Senator CASEY. I did not either until recently.

[Laughter.]

The CHAIRMAN. You have good staff, clearly.

I am now very pleased to turn to our panel of witnesses. I want to begin by first recognizing my colleague Senator Donnelly to introduce our first witness, who is from Indiana.

Senator DONNELLY. Thank you, Madam Chair, and I would like to thank the Ranking Member for the history lesson on 12th century Hindu philosophy. It is greatly appreciated.

Madam Chair, it is my pleasure to introduce a fellow Hoosier, Dr. David Mank. Dr. Mank is an Indiana University School of Education professor emeritus and former director of the Indiana Institute on Disability and Community, where he currently serves as a consultant. In these roles, Dr. Mank has focused on special education and employment opportunities for individuals with disabilities. He has also served in leadership positions at the American Association on Intellectual and Developmental Disabilities and the Association of University Centers on Disabilities.

Throughout his career, his research and leadership has helped improve the lives of individuals with disabilities in Indiana and across our land. Dr. Mank recently served as Chair of the Advisory Committee on Increasing Competitive Integrated Employment of Individuals with Disabilities. This committee was established by the Workforce Innovation and Opportunity Act to identify barriers to employment and ways of increasing employment for individuals with disabilities. Our hearing today will review the advisory committee’s report and its recommendations for the Federal Government.

Many challenges still remain to ensuring that all Americans with disabilities have the resources and support necessary to lead healthy and productive lives. Dr. Mank’s work is helping address this important issue, and we are fortunate to have the chance to hear his expertise today.

Dr. Mank, I want to thank you for your lifetime of work on this issue and for your willingness to testify before the committee. I look forward to your testimony.

Thank you, Madam Chair.

The CHAIRMAN. Thank you, Senator.

Next I would like to introduce our second witness, Dr. Tamar Heller. Dr. Heller is the head of the Department of Disability and Human Development at the University of Illinois at Chicago. She is also the co-founder of the national Sibling Leadership Network for brothers and sisters who have a sibling with a disability.

Third, it gives me great pleasure to introduce Eric Meyer from Portland, Maine. Mr. Meyer is president and CEO of Spurwink, a nationally accredited nonprofit serving Mainers with disabilities of all ages. Spurwink is one of Maine's largest providers of behavioral health and educational services for children, adolescents, adults, and families. Under Mr. Meyer's leadership, Spurwink provides services for nearly 7,000 Mainers at 35 locations around the state as they age in and out of federally based programs.

I am very pleased that you are able to be with us this afternoon, and I look forward to your testimony.

I am now going to turn to our Ranking Member, Senator Casey, to introduce our witness from his state.

Senator CASEY. Thank you, Chairman Collins. I am pleased to introduce Jeff Smith from Bryn Mawr, Pennsylvania. Jeff is a senior mail clerk at Arkema, which is a multinational chemical company located in King of Prussia, Pennsylvania. He will tell us about his experiences in the workforce and why his job is important to him.

I hope I am allowed to say this, Jeff, but I understand that you are engaged?

Mr. SMITH. Yes, sir.

Senator CASEY. I am glad I checked with you first, right?

[Laughter.]

Senator CASEY. He is engaged to be married, and his fiancée, Phyllis, is here with us today. Phyllis, I did not have a chance to say hello before. Thanks for being here.

Jeff, we look forward to your testimony, and thanks for your presence here.

Mr. SMITH. Thank you.

The CHAIRMAN. Dr. Mank, we will start with you. Thank you.

**STATEMENT OF DAVID MICHAEL MANK, PH.D., PROFESSOR EMERITUS, INDIANA UNIVERSITY, BLOOMINGTON, INDIANA**

Mr. MANK. Thank you, Chairman Collins, Senator Casey, and thank you for the kind introduction, Senator Donnelly.

I would like to focus my remarks today on the Workforce Innovation and Opportunity Act and its implementation going forward.

This act established employment of people with disabilities as a national priority in a way that is more clear than has ever been done before in this country. The goal of this act is to increase employment of people with disabilities in competitive integrated employment and significantly limit placements in subminimum wage, sheltered workshops.

Competitive integrated employment is defined as paying people with disabilities at least the minimum wage or the wage that any other person would be paid for doing the same kind of work. It must be performed in settings where people without disabilities work and the opportunity to interact with others and provide the opportunities for career advancement that anyone else would receive in that workplace.

Let me be clear about several things that are well established in the research that we have in this country. We know that people with disabilities want good jobs in integrated settings and with good wages. We know that people with disabilities want to pursue

careers. We know that people with the label of “very significant” disabilities are fully capable of working productively in competitive integrated employment when and if provided with supports individualized to their interests and their needs. This has long been established in research and emerging practice.

In addition, in research specifically in Indiana, when asked, two-thirds of the people in sheltered workshops wanted to try competitive integrated employment in community jobs. We know that when people leave day programs and sheltered workshops and go into integrated employment, they have greater variety in their jobs, they pay more taxes and receive more employer-sponsored benefits. This is the kind of research we did at Indiana University and as a part of the Association of University Centers on Disability.

Senator Donnelly mentioned that I was appointed to the Committee for Increasing Competitive Integrated Employment for People with Disabilities. This committee was established by the Workforce Innovation and Opportunity Act, and it had two very specific charges. The first charge was to advise the Secretary and Congress on ways to increase competitive integrated employment for people with intellectual and developmental disabilities. The second charge was to advise Congress and the Secretary on the use of subminimum wage certificates in this country that makes it possible for people to be paid less than the minimum wage in any state or the nation. After appointment to that committee, I was later elected Chair. This committee was important for a couple of other reasons.

Number one, its composition was unique inasmuch as it was comprised of perspectives across the disability spectrum. There were advocacy organizations. There were disability law attorneys. There were Government representatives from four different departments of Government. There were academic representatives. There were people with disabilities. There were family members of people with disabilities. And there were providers of services, both of competitive integrated employment as well as sheltered workshops.

The committee report and recommendation, which I submitted with my written testimony, were recommendations arrived at by consensus, without minority report and without objection. We worked really hard to get that consensus in those committees. I will highlight just a few of those today.

Number one, align funding of employment services with outcomes. Too often in disability services, we pay for services, and yet do not get employment outcomes. There are ways in federal and state government to craft funding formulas that reward outcomes, and we have specific recommendations about that.

Number two, create incentives to states to transform their system from sheltered work in day programs to a competitive employment system. We know that we have emerging opportunities in states to do that right now, yet more attention and assistance will be needed.

Number three, address the issue of subminimum wage. Our recommendation was that Congress should amend the Fair Labor Standards Act to allow for a “well-designed, multi-year phase-out” that results in people with disabilities entering integrated employment. It is no achievement to eliminate subminimum wage without offering something better, and our recommendation is focused on

the need to make sure that we offer something better along with the supports to make that possible.

We also made recommendations about assistance and incentives to the business community in order to expand employment of people with disabilities. You can read those recommendations in my report, and I thank you for this opportunity to testify today.

The CHAIRMAN. Thank you very much, Dr. Mank.

Dr. Heller, welcome.

**STATEMENT OF TAMAR HELLER, PH.D., PROFESSOR, DISTINGUISHED PROFESSOR AND HEAD, INSTITUTE ON DISABILITY AND HUMAN DEVELOPMENT (UNIVERSITY CENTER OF EXCELLENCE IN DEVELOPMENTAL DISABILITIES), DEPARTMENT OF DISABILITY AND HUMAN DEVELOPMENT, UNIVERSITY OF ILLINOIS AT CHICAGO**

Ms. HELLER. Thank you very much, Senators Casey and Collins, for highlighting the issues of people aging with intellectual and developmental disabilities as part of this hearing.

I am currently director of one of the University Centers of Excellence on Developmental Disabilities, part of one of 67 centers, and I also direct two rehabilitation research and training centers, both funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) and the Administration on Community Living, one that addresses developmental disabilities and health and the second one that addresses family support. I previously directed the Rehabilitation Research and Training Center on Aging with Developmental Disabilities. So bridging aging and disability I see as a very important issue.

As Senator Collins noted, people who are aging into disability and people who have long-term disabilities have many similar needs, and they are also both experiencing transformation in the way health care and long-term services and supports are being delivered. We see more managed care and more integration of or at least attempts to integrate health care and long-term services and supports.

There is a growing population of people with intellectual and developmental disabilities, partly because they have longer life expectancy than it used to be. So we are estimating a growth from 850,000 people with intellectual and developmental disabilities in 2010 to about 1.4 million in 2030.

I would like to focus my testimony on three main areas—looking at health-related changes, family caregiving issues, and retirement issues.

We know that there is earlier aging and mortality, particularly for certain groups of people with intellectual and developmental disabilities. For example, people with Down syndrome are more likely to experience Alzheimer's disease about 20 years earlier. In fact, I just last week was at an NIH summit on dementia care and had the opportunity to speak about the work that we are doing in regard to the National Task Group on Intellectual Disabilities and Dementia, that is looking at the special care issues for that group. By the way, it is co-led by Matt Janicki, who is from Maine. You might be interested in that.

They also develop chronic diseases earlier, such as diabetes and osteoporosis, two areas. Their health behaviors—they tend to be more sedentary with poorer health, resulting in higher rates of obesity, and health care access is an issue, and we see much later diagnoses of cancer.

So what can we do about that? We have some very good interventions that have been developed for people who are older, such as chronic disease self-management, and now there are adaptations that have been made for people with—or at least the beginnings of that for people with intellectual and developmental disabilities, for example, in the area of diabetes as one area. Our center has developed this program called “Health Matters,” exercise and nutrition health education for people with developmental disabilities, and it is being rolled out throughout states and all over the country, and we are testing different ways of disseminating it.

In the area of long-term services and supports, we know that people with intellectual and developmental disabilities are likely to live with their families most of their lives. Seventy-one percent live with family, and 24 percent of those are living with parents who are 60 years and older. So you can imagine with these long waiting lists that we have for residential services of over 100,000, that is a big issue.

Particularly, long-term caring has an impact on mothers in regard to income and to their restricted social networks, and we see for minorities also health issues for people who are caring for people with intellectual and developmental disabilities.

Another issue is that siblings end up playing a larger and larger role. I myself am a sibling, and I have a sister with intellectual and developmental disabilities, and I see the many issues that she is facing.

Only 15 percent of those caring at home receive any kind of public family supports. There is a national project that is funded called the “National Community of Practice for Supporting Families,” and that is trying to make a difference in many different states in terms of looking at different ways of supporting families. And also we have the Research and Training Center on Family Support that is looking at research and public policy across both disability and aging.

In regard to retirement, people with intellectual and developmental disabilities, whether they are in integrated settings or in non-work facilities, which many are in, do look for retirement options. For people who are working, it is especially important to look at accommodations for people. Especially assistive technology and inclusive transportation are two areas that I think are especially important. And we need to look at individualized retirement options that take into account helping to support people in decision-making and helping them plan for the future and looking at ways to have meaningful lives in inclusive communities.

I have specific recommendations that summarize what I have just said in my report that you can look at.

Thank you.

The CHAIRMAN. Thank you very much, Dr. Heller.

Mr. Meyer.

**STATEMENT OF ERIC MEYER, LCSW, MBA, PRESIDENT AND CHIEF EXECUTIVE OFFICER OF SPURWINK SERVICES, PORTLAND, MAINE**

Mr. MEYER. Chairman Collins, Ranking Member Casey, and distinguished members of the Senate Special Committee on Aging, thank you for this opportunity to testify today. I am Eric Meyer, president and CEO of Spurwink Services in Portland.

Long before the closure of Maine's only institution for individuals with intellectual disabilities, Spurwink recognized the importance of connection to community and began providing integrated services outside the confines of segregated institutions for people with intellectual and developmental disabilities, or IDD.

Spurwink began with one house serving eight boys on Riverside Street in Portland in 1960. Today, as you mentioned, Senator Collins, we serve more than 7,000 people each year across the State of Maine, with more than employees doing the amazing work that we are committed to.

Our mission and our vision remain the same: providing exceptional and evidence-based behavioral health and education services for children, adults, and families with disabilities so that they can lead healthy, engaged lives in our communities.

At Spurwink our therapeutic model is built on preparing young people with disabilities for a successful transition into adulthood and for adults with disabilities to live healthy, engaged lives. Our person-centered planning model is driven by clients and their families—creating individualized goals, planning with their teams where they will live, the type of work they want to pursue—all informing the supports that our team will provide to help them meet their goals.

People with disabilities can and do work, and we believe it is not only the role of Spurwink but of our country to support adults with IDD to live meaningful and productive lives.

While few of our clients go on to higher education, many benefit from learning a trade or skill. For example, our small engine repair program at our Chelsea campus gives students an opportunity to work on tractor motors, small boat engines, and snow blowers for local neighbors and businesses. And with the season that is right around the corner, snow blowers in particular are very popular this time of year. In our experiential learning setting, students learn not only practical skills in small engine repair, but about responsibility, perseverance, patience, and cooperative work. They build confidence in themselves, and that confidence translates to all parts of their lives.

Riley, one of our former students with autism in Portland, started his career journey at in-house school jobs, moving on to community-based training folding laundry at The Cedars Nursing Home, shelving and alphabetizing books at the Falmouth Library, and preparing orders for distribution at Planet Dog Warehouse. After graduation he successfully worked in the warehouse at Micucci's Wholesale Foods. His parents stated, "The Spurwink vocational program exposed our son to a range of work environments and responsibilities with the full support of a job coach, which was not available in our public school. He was able to build work skills and confidence thanks to the Spurwink vocational team's experience."

Spurwink does not receive state or federal funding for these pre-vocational programs, yet we are committed to making them available. We believe that it is absolutely crucial that students leave Spurwink with the skills and experience needed to lead healthy and productive lives.

We also believe that it makes good economic sense, much as you have said, Chairman, for the State of Maine. It is no secret that recruitment and retention of employees is a major priority area for Maine businesses, Spurwink included.

In addition, young people who are employed in appropriate work are more stable financially and less likely to require additional economic supports in adulthood.

For our adult population, ages 18 to 84, Spurwink provides residential and community supports. Key to our services is self-determination, individual choice, and the dignity of work. There is that term again. This includes access to continuing education and/or meaningful employment, a place to call home, robust community involvement, and other components of a meaningful life. Without this, there is no community integration.

Employment should be an option for all who want to and can work, and it is never too late to open this door. For example, Robert, age 57, has a mild intellectual disability and mental health challenges. He spent many years in a group home setting and had dabbled in employment, but intrusive thoughts and lack of focus always led to dismissal. Robert made the decision to move into a Spurwink shared living home, and in the new home, he began to thrive and develop a stronger sense of self-advocacy. He decided to try employment again, and for months now, he has been working several hours a week, stocking coolers at a small store. He has done his job well, often offering customers anecdotal comments about the additives of carbonated beverages. Despite his past unsuccessful attempts at employment, he is now considered a valued employee, connected to his community, and his job is a boon to his self-esteem. Let us work together to make community integration and employment for people with disabilities the norm in the United States—for people with disabilities, for the strength of the economy, and for the vitality of our communities.

We thank you again for this opportunity to testify. I look forward to your questions.

The CHAIRMAN. Thank you very much, Mr. Meyer.

Mr. Smith, welcome. We are glad to have you with us today.

**STATEMENT OF JEFF SMITH, SENIOR MAIL CLERK, ARKEMA,  
KING OF PRUSSIA, PENNSYLVANIA**

Mr. SMITH. Good afternoon. My name is Jeff Smith. I am 63 years old and live in the Philadelphia suburbs. I am excited to be here today to tell you about me. Thank you to Chairman Collins, Ranking Member Casey, and the Special Committee on Aging for inviting me.

My mother is 94 years old, and she could not come with me today to Washington, but I know she is watching me on TV. I have a brother named Tat who lives in Toronto and a sister named Carol who lives in New Mexico, and they also could not come. I have a fiancée in Philadelphia named Phyllis. She is here with me today,

and so are Stacy Levitan and Dave Mytych from Judith Creed Horizons for Achieving Independence (JCHAI), which helps over 130 people with disabilities like me to live independently.

I have worked at Arkema for 39—almost 40—years delivering the mail as a senior mail clerk. I have my own apartment where I live by myself, and I do not need help from my mother or my family.

I get help once a week from Dave Mytych, my social worker, who works at JCHAI. JCHAI helps me to be independent and has changed my life. JCHAI helps me feel more positive about life because they help me have more friends and I see how happy everyone else is. Everyone I know has changed because of the help they get from JCHAI. JCHAI helps me with shopping, keeping my apartment clean, and cooking. Dave was a cook before, and he helped me cook fish. We are going to try a new recipe next time that he says will make the fish taste even better.

Because of JCHAI, it is a whole new way of life. I am treated better by everyone at work and in my life, and it is because I am so happy.

I am very proud that I have been able to work at Arkema for all these years. Working at Arkema is great because I love delivering the mail. I go to a lot of different places all over our campus, which is one square mile. I get to do a lot of walking, which clears my mind, and I can think of different ways that I can help the world. I like to meet different people at work and from all over the world, like from Japan, Korea, Vietnam, and China. I also have a lot of friends since I have been working there so long. I even have some friends who have been there almost as long as I have.

I like that I have my own salary that lets me go to the laundromat, the market, and I can take Phyllis on dates or trips with JCHAI. Sometimes we even go out of state on some of the trips, like to New Hampshire, Connecticut, and Massachusetts—all over the eastern seaboard.

One of the things I like to do in my free time is work on my rock collection, which I have gotten rocks from Colorado, Pennsylvania, Texas, and Arizona. I especially like quartz. The rocks give me a neat feeling when I look at them. I also collect coins from all over the world. I get them from change that I get when I buy things, and sometimes I go to coin shops in Philadelphia and get coins there. Even the Natural Science Museum helps me. I can afford to do all these things because I have my own money that I earn from my job.

Having my own job and support from JCHAI means that my mother does not have to worry about me anymore. She knows that I do great on my own. And if I need help, I do not have to get it from her. I know who to call, which is Dave and the people at JCHAI.

Getting older is really just a part of life. It is an interesting facet of life. When I was 30, I thought, “I have so many more years of my life.” Now I can look back and say that is gone, but I am still working hard, making a living, I still have friends, I have help with everything I need, and it is really a tribute to how good life is.

In the future, I will retire when I am 66 because I will have a full pension, and I will be able to live on that. When I retire, Phyl-

lis and I will be able to spend a lot of time together, and we will live our own life. We will do a lot of things with each other. We will go on trips and go around together. We like to go to the movies and out to dinner, lunch, and breakfast. We go all over Philadelphia. I am looking forward to the next part of my life.

Thank you for letting me talk to you today.

The CHAIRMAN. Thank you very much, Mr. Smith. We very much appreciate your being here and sharing your personal story.

Dr. Mank, I want to start with a question for you to make sure that everyone understands a phrase that you used, and that was "competitive integrated employment." I believe that most people are familiar with sheltered workshops, for example, but you are talking about something quite different. Could you explain to us what you mean by "competitive integrated employment"?

Mr. MANK. Yes, indeed. Thank you for the question. Competitive integrated employment means a job in a business, public sector or private sector, that anyone would have access to that pays a wage rate that is the competitive wage. So accountants have—there is a competitive wage for accountants. There is a competitive wage for mechanics. And people with disabilities should have access to those same kind of jobs at the same wages.

Integrated means jobs in the public sector and private sector that are not segregating people with disabilities into a given setting, but instead are the employers of everyday life, the cleaners, the retail stores, the offices where everyone else works, that people with intellectual and developmental disabilities are now just getting access to as opposed to primarily having access to segregated settings where it is mostly or primarily people with disabilities working, many times earning not only less than competitive wages but less than the minimum wage of the country.

The CHAIRMAN. Thank you. That is very helpful. So instead of talking about a work environment where, say, most of the individuals have disabilities, you are talking about a regular work environment where there are some people with disabilities, some people without disabilities, and they are all working together and being paid comparable wages.

Mr. MANK. Exactly. Sometimes we speak of natural proportions. It is like in any given setting, what percentage of people might have a disability in a given environment? You know, depending on the definitely of disability, 6 percent, 8 percent, 10 percent; if you include older people, more. But the point is not forcing a segregation of a population by virtue of the label of disability.

The CHAIRMAN. Thank you. And in some ways, it reminds me of the transition that we have gone through in special education where we try to integrate children with special needs into a regular classroom. It sounds like a similar approach.

Mr. Meyer, you told a very inspiring story about Riley, and in the packet of information that you left with me this morning, I read all of Riley's story. And it is really wonderful how he progressed to take jobs of increasing complexity through the help of a job coach, as you said, and other supports. And that is a wonderful story. That is exactly what one would hope to see, and I appreciate your sharing it with us.

Our state is a very large and rural state. What would you say are the biggest obstacles in rural areas in particular that are barriers to employment for adults with disabilities?

Mr. MEYER. Am I live?

The CHAIRMAN. You are.

Mr. MEYER. Hot mic. So as you say, with any rural state like ours, transportation is a key factor and a key challenge. So, in particular, we see situations where there are individuals who are making progress like Riley did, rise to a certain level, and maybe stop qualifying for assistance with transportation, and then they really have no way to continue their employment. So there ends up being artificial cliffs that interrupt the progress that folks make. So transportation is key.

The other part for us continues to be the development of workplaces where employers are open to employing people with intellectual disabilities. We have worked really hard developing this at Spurwink, and I think some of the examples I gave and some of the ones from Riley's own experience were about relationships that we have really nurtured with employers who have been fantastic. They have been really open to it. But others are not sure. You know, they need help in understanding it. They want to know that we are going to be there to support. We need more employers to be willing to engage with us around that. So the availability of employers, and access to transportation, are essential supports for folks in the workplace. And I would say that stagnant wages have made it so that we are not competitive on hiring and then we have trouble maintaining staff. So that is another barrier for us in our rural state.

The CHAIRMAN. Thank you.

Senator CASEY?

Senator CASEY. Thank you very much.

Jeff, I will start with you and ask you a couple of questions about your experience. You shared with us what you like about your job.

Mr. SMITH. Yes.

Senator CASEY. And it is good to hear that. And you also shared with us some of the things that your job makes it possible for you to do, whether that is going to restaurants, going on trips, being able to buy things that you want to buy, especially those that support your rock and coin collection, among others. These are things that are part of what we might describe as a full life, and that is why it is so important that you are providing this testimony today.

I guess I wanted to ask you to think for a minute what your life would have been like if you were not able to have this job or any job and how you have felt—or I should say how would you have felt if you were not able to have the work that you have and if you could not, in fact, work? Can you imagine that, or can you give us a sense of that?

Mr. SMITH. Well, yes, I can imagine that. Well, of course, over the years—I have been with this group for 7½, almost 8 years right now, and I have changed completely from—I was almost a know-nothing man, I can say, up to what I am now, I am a positive—you know, I am positive on almost every matter of the things that I do every day. And so I can say that if I did not have, you know, a job right now or if I did not have payment or if I did not

have anything good for me, I would be inundated with sadness or inundated with malfunction or, you know, with difficult ways of getting around, because, you know, life today is no easy matter, as you know. I mean, whoa, there is a lot—I mean, I hear it all the time on TV on the news, on various programs, on various ways. I hear it from different people that, you know, it is so much involved. Just think of all the many ways around the United States that things are done differently by different people. And for one thing, the lesser talented people, you know, do not get the appreciation they need, but, you know, with my working hard and my—when I started working, I was, oh, I could not believe where I was, you know? I was working in Pennwalt Corporation in Philadelphia, and I was down at one end of the hallway, and I said to myself, “I want to go to the other end of the hallway and see what is up there.” So I went up there, and then I got up there, and I said right away, “This is where I belong.” So I stayed up there with the cooperation or with the coordination of the people from the floor, you know, that could help me out.

And then I said to myself, “The mail is not being put in any natural way.” So I said, “I will deliver the mail.” So I started delivering the mail, and that is where our company has taken off from. Right now we have so much mail coming in daily, you know, we get like—oh, I will give you a fact—well, yeah, I could say we get at least 80 packages of mailing a day, 80 packages of mail, and they are from all around the world, and they go to everybody—well, not everybody, but they go to certain places around the company. And they are delivered to the mail room, but then they are also delivered to the loading dock, which takes care of certain mail because it is either large or it is marked for different people that do not work where I work or, you know, do not work in the area that I work in, and so, but—

Senator CASEY. Well, you have got a busy job, right?

Mr. SMITH. Very busy, yes, but I do enjoy it. It is totally mindful and it is heart-warming, and it is very soothing to know that I am out there doing my part for the country and the country is doing its part for me.

Senator CASEY. Well, we are glad you are doing that, and I am glad you are here today to share that.

Mr. SMITH. Yes.

Senator CASEY. I will maybe follow up with Dr. Mank in a moment. But, Doctor, I guess—and I know I am almost out of my time, but the reauthorization of the Rehabilitation Act—that took place in 2014—included a definition of “competitive integrated employment,” that phrase that you referred to, for people with disabilities. It emphasized paid work. It is either at the minimum wage or the prevailing wage and work that takes place with others who do not have a disability.

Why are both “competitive” and “integrated” important characteristics of employment for people with disabilities? And I am over time, so if you can be brief.

Mr. MANK. Very briefly. “Competitive” is important because it is at full wage. We know one of the most likely characteristics of life in this country, if you have an intellectual or developmental disability, is poverty. And so a competitive wage is a requirement.

“Integrated” wages, of course, working alongside where everyone else would do that kind of work. We would not think of segregating others by some other personal characteristic. Why would we in schools or in employment segregate on a characteristic called “disability”?

Senator CASEY. Thanks, Doctor.

The CHAIRMAN. Thank you.

Senator FISCHER, welcome.

Senator FISCHER. Thank you, Madam Chairman, and thanks to the panel today.

One issue facing individuals with intellectual and developmental disabilities is having a reliable caregiver. More than 70 percent of individuals with these disabilities, they live with family members, most frequently their parents. The impact of these situations can adversely impact a caregiver’s health. They have a higher prevalence of diabetes, high cholesterol, and arthritis.

Ms. Heller, since you touched on this issue in your testimony, can you describe in a bit more detail the importance of having a reliable caregiver and how often this caregiver is a family member? And then if other panel members would like to answer, I would welcome that. Thank you.

Ms. HELLER. Right. Obviously, the family is the strongest. Even when a person does not live at home, families continue to have a really big role, and I could give you an example even with my own sister, who was languishing in a nursing home. She had developed some age-related conditions that were really bad, and she ended up in a nursing home, and I could not get her out. I finally was able to get her out of the nursing home, and I can tell you that without my advocacy, she probably would have died in that nursing home. So siblings and parents play a huge role in regard to caregiving.

One of the aspects that I have been recommending and I know the AARP is very interested in also is making sure that the voices of families are included, both in health care and long-term services and support, particularly as managed care organizations, that they really try to involve people, families, because families play such an important role. They also play a very important role in helping the person with the disability make decisions because often they need some help with that. With respect to self-determination, they also need support from families.

Senator FISCHER. Thank you. Yes?

Mr. MEYER. Senator, if I could just add, just in conjunction with what you were saying, one of the ways that we approach our adult services as Spurwink is we refer to them as “adult and family services,” really with the assumption and expectation that we strongly support family engagement. Even if we have professional staff that are providing primary care, family involvement is critical.

And then there is the important nature of the long-term relationships. So many of the folks that we serve with intellectual and developmental disabilities thrive with consistent support over time. We have many staff that have been working with the same individuals for 5 to 10 years or more, and we always see the best outcomes for consumers when we are able to support that. That, of course, ties back to what I mentioned before about the importance of funding for these programs.

Senator FISCHER. When you talk about the programs that you have where it brings in the entire family, do you address health concerns for family members? And could you talk to us a little bit about that as well for the caregivers themselves? Do they seek your advice or do you reach out to them when you see maybe they are taking on too much responsibility? The weight of it all affects a caregiver's health, too.

Mr. MEYER. In particular, aging and co-morbid medical conditions and those sorts of complications, we do. I mean, we have to be aware and part of the conversation is being aware of where the boundaries are. So if their son or daughter is our client, the parent may not be our client, but we develop relationships with them. Then we make sure that they are referred to appropriate medical or other kinds of supports and that we are attending to the levels of stress that they experience in those relationships. So we see that as part of our responsibility even while we try to make sure that we do not cross boundaries where we should not.

Ms. HELLER. I would like to add about a program that our center has done called "Taking Care of Myself" that Sandy Magana has headed up, and it is training promotoras, which is like peer parents that are Latino or African American, to go into the home of parents of people with intellectual and developmental disabilities and address health care and making sure they take care of their own needs also.

Senator FISCHER. Thank you very much.

Thank you, Madam Chair.

The CHAIRMAN. Thank you, Senator.

Senator Warren?

Senator WARREN. Thank you, Madam Chair. I taught special needs children when I was much younger and just out of college, and when you spoke at the beginning of this hearing about the importance of making sure that everyone has opportunities and that everyone is treated with dignity, as Senator Casey did, I just want to say, yes, that is a measure of who we are as a people. And I very much want to associate myself with your comments on that. I think it is right. So I am glad you are holding this hearing today.

In doing some research for today's hearing, my staff came across a few reports about working conditions of individuals with intellectual and developmental disabilities. In Rhode Island, Pedro, a 25-year-old man with an intellectual disability, spent three years sorting and packing buttons. Pedro's boss described him as an "excellent worker." He was paid 48 cents an hour.

In New York, workers with disabilities package pharmaceuticals at a nonprofit organization. They were paid 33 cents an hour. The CEO, by the way, was paid more than \$400,000.

In Iowa, dozens of adult men with intellectual disabilities worked at a turkey processing plant. They began work every day at three o'clock in the morning, and they were housed in a crowded schoolhouse together. They were paid \$2 a day.

Now, Dr. Mank, you are an expert on the labor market for individuals with intellectual and developmental disabilities. Congress has passed labor laws, civil rights laws, and other laws protecting Americans with disabilities.

It is 2017. Can you explain why wages this low are not illegal?

Mr. MANK. I can explain it. I cannot defend it.

Senator WARREN. Could you turn on your mic there?

Mr. MANK. I can explain it, but I am not defending it. The legislation, the original legislation, was passed in 1938 that allowed payment of subminimum wage. This was somewhat updated in 1966. But because of a section of the Fair Labor Standards Act, Section 14(c), it is perfectly legal to measure someone's productivity and say, "You work at 50 percent; you get 50 percent of the raise."

Having said that, it is often unnecessary when people are matched with the right kind of work. We have something—well over 250,000 people in the country. It is hard to know exactly because the hard count is on organizations that hold the certificates, of which there are more than 2,000.

Senator WARREN. I just want to make sure, though, that we are following this. I want to ask this question very clearly. A worker with a disability can be paid less than a worker without a disability for doing exactly the same job?

Mr. MANK. That is correct.

Senator WARREN. Wow. You know, I do not think most Americans know that this kind of discriminatory treatment is perfectly legal. But I will bet that if they did, they would agree that individuals with disabilities ought to be paid fairly for their work.

So, Mr. Smith, let me ask you, if I can—I want to thank you for coming before this committee today to share your testimony. And I hope we can take your comments into consideration as we make policy that will affect employment for people with disabilities. I understand that you are a mail clerk. Could you just say a word about what that job means to you?

Mr. SMITH. Ever since the beginning, when I was working at Pennwalt Corporation, right down 17th Street, I was—I thought, "Where am I going to go in this world?" I started out in my job, and I thought, "Where am I going to go? What is going to go on?" But I wanted to go higher and higher and higher and work—you know, I did not know how high I would get, but, I mean, I wanted to get very high. And so right now, as I know, I am a part of human resources. I am also a part of the whole company, and I am a natural asset to it that is really helping me out in a lot of ways, and I am helping them out in a lot of ways. And I do see that the work that I am doing there is very demanding, but it is not too much for me. I mean, I do not feel any difference in it than other work because it is—it is really—okay, it is hard, yes. I mean, first of all, my memory is good, and I have a large—knowing where-about people sit, where people are throughout the company. I mean, we have had many moves and changes throughout the company, and I am just able to pick up on where the people sit and where they—and so I am able to do my work that way.

Senator WARREN. Could I ask you, do you think Americans with disabilities should be paid less than their coworkers for doing the exact same jobs?

Mr. SMITH. No. I really do not, because they deserve—see, they are people, they are American people. They are truly a part of our nationality, and they serve a purpose. They serve a natural purpose on this land. A lot of people around me—I am not saying any-

body here, but, I mean, a lot of people do not perceive as good or as nourishing or as helpful to us.

Senator WARREN. I really appreciate that. Thank you, Mr. Smith. I am over my time, but if I could make one point since I will not have time to ask the question, that the Advisory Committee on Employment for Individuals with Disabilities that Dr. Mank chaired recommended that Congress pass a well-designed, multi-year phase-out of the subminimum wage. It is pretty amazing to me that in 2017 the law in America still allows employers to exploit some workers with disabilities, paying them pennies on the dollar. And I support phasing out the subminimum wage and look forward to working with my colleagues on this committee.

Thank you.

The CHAIRMAN. Thank you.

Senator Tillis?

Senator TILLIS. Thank you, Madam Chair. I am sorry I am late. We had a conference with the Senate Armed Services Committee. I am a conferee.

This is actually a subject matter that I have spent a fair amount of time with. My wife serves on a board for an organization in the middle part of the state called "Industries for the Blind," where literally blind persons, ironically, are making eyeglasses for persons with sight. In fact, if you come to my office, you can see we have got a display dedicated to it.

I have also spent some time in western North Carolina where we have an organization called Industrial Opportunities Inc. (IOI), which has persons with disabilities doing just incredible work, including sewing and making products that are ultimately sold to the DOD. In fact, tourniquets that go into almost every EMT facility now was initially a collaboration between a firm or special operator and folks at IOI.

And then I personally have served on a board that oversaw Lifespan, which is a work skills training entity in the middle part of North Carolina that actually does in-source work to give people job skills and gives them an opportunity to go work with the businesses.

And, finally, just about three weeks ago, I was at a place called Bitty & Beau's, and it is a coffee shop in Wilmington, North Carolina, that has gotten a lot of attention recently. Thirty-nine, the vast majority of their staff, are persons with disabilities. And if you want a battery charge, go to Bitty & Beau's and get a cup of coffee first. It is a great cup of coffee. Rachael Ray, it is her official coffee now. They are about to open a facility in Charleston.

I tell you those stories to tell you that really getting in and seeing how these operations work and the challenges that they have, you have to really understand the inner workings, how the economics work, how they can actually create a business model that is sustainable because, quite honestly, if we want to attack the challenge of the disproportionately high number of people who are underemployed or unemployed, persons with disabilities, we have got to be smart about it, and we have got to work with businesses to be absolutely certain that we are compensating persons for the skills that they do, they need to be paid whatever the market rate would be for those skills, regardless of who is doing it.

By the same token, I think we have to take a look at how many of these—and I would probably point to IOI out in western North Carolina, about how they are also trying to provide a service and really Lifespan, not only for those who can work and be in compensated jobs, but enrichment centers and engagement with other persons with more severe disabilities where they may not have that opportunity in the community but for these businesses, these private sector enterprises, that they may be in underserved communities.

So we have to get it right and not necessarily jump to an extreme to where we pass a well-intentioned law that, on the one hand, looks good on paper but, on the other hand, creates barriers so that these private sector solutions can no longer thrive and grow, like the Bitty & Beau's that is in Wilmington and now about to open one up in Charleston.

So then that is a lead-in to my question. How do we as a matter of public policy look at the things that we should be doing to incentivize more Industries for the Blind, more IOIs, more Lifespans and more Bitty & Beau's versus a well-intentioned person who thinks it is now time to nationalize this and make it a big Government-regulated entity which will almost certainly reduce the leverage and the opportunities for persons with disabilities? That is the only question I have. I would like a response from anybody here who would like to talk about it.

Mr. MANK. I would be happy, Senator, to answer your question. I think at the end of the day, employment for anyone, and certainly employment for people with disabilities, is about being matched up to work you are interested in and can do well. And I think part of what is incumbent on communities, society, and businesses is to discover one person at a time, what are the interests and talents that a person has and can we get them matched up with that work.

I guess I would argue that many of us, maybe most of us in this room could name 15, 20, 50 jobs that we would not be very good at, and we spend a fair amount of time trying to get matched up with work that suits us, that we can be both productive, contributing, and happy. And sometimes I think with people with disabilities it takes a little while to discover that, and that it is worth the discovery to try to get that match right.

Mr. MEYER. If I could, Senator, add to something that I had said earlier, part of Spurwink's approach has been the cultivation of relationships with local businesses. So we spend a lot of time helping raise awareness, helping a business to feel comfortable bringing in somebody with an intellectual disability when they have not thought of it in advance, and so there really is a partnership that develops. In terms of a model or a direction for this, I would say that local partnerships are critical being able to help increase understanding and acceptance of people.

And then I think to your point, Dr. Mank, the whole fit for individuals and having some patience, but also a process to be able to help folks identify the jobs that are a good fit for them, is part of the solution.

Senator TILLIS. Well, having been Speaker of the House before I came up here 2½ years ago, one thing I am really encouraged to see, if you go out and you go into the community—and I have lit-

erally gone—we call it Manteo to Murphy, that is the span of the state. I have literally been in several facilities across the state, and the most inspiring ones that I have seen are when private enterprise, state government, and local government entities and organizations supporting persons with disabilities come together. And I think our role is to figure out how we can facilitate that, not supplant it, and be very mindful of well-intentioned policies that could ultimately have the reverse effect in terms of the opportunities, and we should have increased opportunities for persons with disabilities.

Thank you all for being here.

The CHAIRMAN. Thank you very much, Senator Tillis.

I want to note that Senator Gillibrand was here and very patiently waiting but had to leave, and Senator Nelson as well.

Dr. Heller, I want to go back to the issue of transitions. We all hope that the number of people with disabilities will go up—the number who are working will increase. And that means that we are all of a sudden going to have many more individuals with disabilities who have worked many years, like Mr. Smith, who has worked nearly 40 years, who are going to be facing the issue of transitioning into retirement.

So what are the features of a successful transition into retirement for individuals with disabilities? This is not something we thought of probably 20 years ago.

Ms. HELLER. I think, first of all, there needs to be some education and some planning around it, as we all need to do. Actually, a while ago, we developed a curriculum called “person-centered planning for later life” for people with—at that time we called it “mental retardation.” And the main idea was to—we really adapted it from retirement curriculums for the general population—but looking at how to try to find out what people really want, number one. And as we know, you get older, you get more and more life yourself, and more different than others, and I think we will see with this population also in terms of really coming up with individualized approaches and looking at who the support network is, doing training with the people with disabilities about various options. Sometimes they do not know what is out there, what is possible. Looking at options like part-time for a start. Transitioning the retirement into other kinds of—and sometimes it is a real issue for people who live, for example, in group homes where they do not have staff around during the day, and figuring out how to deal with that transition. Those are some of the issues that are really important in terms of planning for retirement.

The CHAIRMAN. Thank you.

Mr. Smith, you have worked nearly 40 years. Work is clearly a very important part of your life and has been really helpful to you in so many ways, not just financial but in the friendships that you have made and the confidence that you have built. Are you worried about retiring?

Mr. SMITH. No. I find retirement right now is just another point of life, you know, another way of life, because when I retire, I am going to build my own house, and I am going to move in with my fiancée, and we are going to live a fine life together. But there will be things that I will be doing. You know, I mean, I am not going

to sit still all by myself and not do anything because, no, I believe that getting out and working in this world is far better than sitting down and doing nothing, you know, because, I mean, there is so much that you can do out there today. And I know I can do a lot for the world, and I have done a lot for the world, and I want to continue doing more for the world that I can.

The CHAIRMAN. Thank you.

Senator Cortez Masto? By the way, Mr. Smith, I think you are going to be just fine in retirement.

[Laughter.]

Senator CORTEZ MASTO. Thank you. First of all, let me just say thank you for this important hearing. I had another hearing on Indian Affairs so I could not be here for your testimonies, but thank you for the written testimony. It has been very helpful.

Let me start with Dr. Mank and Dr. Meyer. Just today I had the opportunity to meet with some constituents and persons with disabilities from Nevada, and they told me very clearly that they want to work and provide for themselves. However, one issue they had was finding reliable transportation to get them to their jobs on time and back again. Even when they are able to receive state-funded transportation, it is often unreliable, causing them to be late to work, and sometimes potentially costing them their jobs.

What are some of the best practices you have seen by states and local government to get people with disabilities the transportation that is important for them to be mobile and independent?

Mr. MANK. Well, thank you for the question. I am certain it is a problem in Nevada, and I am sorry to say it is a problem everywhere; that reliable transportation for people that do not drive, whether by virtue of disability or poverty, do not have a car, public transportation, getting to work on time is a major problem. So it certainly is a problem where I come from in Indiana. We have many rural parts of the state. Even in the cities there are limited public transportation routes.

I do not think the disability community is going to solve this one because it is a community problem, much broader than the number or percentage of people with disabilities.

I lament the problem in my state and in other places that I have visited. I have seen occasions when disability-oriented nonprofits actually took over a small town's transportation system themselves in the interest of people with disabilities and people who were older or poor to try to be something of a measure of responsiveness. But I do not have a solution, and I do not know where one exists to the extent that you speak.

Senator CORTEZ MASTO. And let me open it up to the other panel members. Are you aware of any best practices or what we can be doing at the federal level to help address the transportation needs?

Mr. MEYER. A few minutes ago, I did talk about exactly this barrier as one of the key issues and challenges for people to maintain employment for individuals with intellectual and developmental disabilities. So, yes, in our rural State of Maine, transportation is uneven and cannot be relied upon. At this point we do not have good solutions. We try to cobble together the best supports we can. We work with family members. We work with employers who are

creatively accommodating transportation schedules. But it is very piecemeal, and not adequate.

Senator CORTEZ MASTO. Okay. I appreciate that. Thank you. That is disheartening. This is an issue we need to address. Literally, I talked to a young man from Nevada who is able to get to work, but that is all he can do because there is a point system, and he can use his points to get to work and home. But then if he wants to go out and visit friends or go to a movie, he does not have transportation. So I think this is something that really we should be looking at to address in working with so many across the country and in our communities to address it. I appreciate that. Thank you.

Ms. HELLER. I just wanted to add that it is important that public transportation is accessible, and including cab services. I know that in Illinois there has been a lawsuit with Uber to make sure that they have accessible rides available. That is another way to go at it.

Senator CORTEZ MASTO. Thank you. Thank you. I appreciate the conversation and really appreciate you being here today and working with us. Mr. Smith, it is a pleasure to have you here. All of you, thank you so much for your willingness to come to Washington and work with us and help educate us as well. So thank you.

Mr. SMITH. You are welcome.

The CHAIRMAN. Senator, I am just going to interject because the transportation issue is such a major barrier. In Portland, Maine, there is a program that is called "ITN," and it was started originally by a volunteer whose child was hit and almost killed by an older driver who should not have been driving but really had no other choice as far as how to get around. And she has built up an extraordinary program. Back in the good old days of earmarks, I was able to get her a little bit of help in getting it off the ground. But what people do is turn in their cars in some cases, and volunteers provide the transportation, they do the driving. It is mainly aimed at seniors, but a lot of seniors have disabilities and a lot of them are not able to see or have mobility challenges. So I think it also would apply to the population of individuals with disabilities, and it is really this wonderful program.

There is often a very small charge for the ride, but it is something that has been replicated in other states, and I will see that we get you some information about it. It is something that I wish we could expand to rural Maine because it is really more in the urban southern part of the state. And since you two have a state with a lot of rural areas, and a big state, I can imagine that this is a real challenge as well. But I just wanted to mention that before calling on Senator Casey. Thank you.

Senator CASEY. Thanks, Madam Chair. I know we have to wrap up soon. I guess I wanted to end with thanking the panel for your testimony. But if you could encapsulate just briefly what you hope we would do to move forward, because we have set forth a lot of challenges that folks with disabilities face in the context of employment, and there might be a long list of action items or there might be a shorter list in terms of your own perspective. But what do you think is the most important thing we can do to remove some of these barriers? It does not have to be a long list, although it could

be. If you want to supplement it in writing, you can do that. But I just want to give everyone a chance to give kind of their own summary of what we could do to remove those barriers. I will just go left to right. Dr. Mank?

Mr. MANK. Thank you, Senator. The first thing that I would say is to look at the funding contingencies for employment-related programs now and seek incentives to produce employment outcomes. We spend a lot of money on many kinds of services, day services, even employment services. But effectively getting that is creating incentive to get outcomes, namely, integrated jobs. Thank you. That is the first thing I would do.

Senator CASEY. Thank you.

Ms. Heller?

Ms. HELLER. I think it is important to make sure that we have enough—

Senator CASEY. Turn on your mic.

The CHAIRMAN. Could you turn your mic on, please?

Ms. HELLER. I think it is important that we have enough financing for assistive technology for people as they age and universal design and inclusive transportation that we have just been talking about.

I would also like to emphasize support for families, and I know this is a big priority area now, to make sure that there is funding and also to endorse, for example, Lifespan Respite Act programs, as one example, or the National Family Caregiver Support Program is another example. Thank you.

Senator CASEY. Thank you.

Mr. Meyer?

Mr. MEYER. Thank you. I would encourage the committee to launch from the good work of today to continue awareness raising and to continue moving to a shift in understanding across our country about employment for people with all sorts of disabilities and certainly with intellectual and developmental disabilities.

And then from my perspective, while I really liked Dr. Mank's suggestion, I also think that not only should we make sure that we are spending the money wisely, but we also should make sure that we are keeping up with very tough job markets and be able to pay staff in a competitive way to allow them to maintain a career in supporting and assisting with vocational success.

Senator CASEY. Thanks very much.

Jeff, any suggestions?

Mr. SMITH. Well, I have been thinking about that, and it dawned on me that this country is so well put together, there is so much about it, you know, that we can say is "A-1". But as I know it, from what has been said here today and from what I have learned from the past, the care and everything given to these people, given to needful people, is not totally helpful and is not totally responding. So I think in some way we ought to all step out and do something about it rather than sitting on our cans and not doing what we think, you know, can be done for these people, because, you know, I have a fiance here who had a deeper problem when I met her, and now she has stepped up to a much better way of life. And I know a lot of people that I have been friends with over at her apartments have done that same thing, too. But they are in a dif-

ferent needful way. But there is not much—well, there is things being done, but, I mean, there is not as much as we can do for them around this country.

Senator CASEY. Well, we hope today we have come up with some new ideas and, if not new ideas, at least the examination of some of the problems. Thanks for your testimony.

Mr. SMITH. You bet.

The CHAIRMAN. I, too, want to thank all of our witnesses today for this excellent hearing. I think you have helped raise awareness, as Mr. Meyer suggested, that individuals with disabilities can play such an important role in the workforce, and we have only to listen to Mr. Smith's experience, where he reorganized the entire mail delivery system and improved it, to know that that is the case. And I believe that individuals with disabilities just like everyone else can thrive in work environments in which their individualized strengths are accommodated and appreciated. And we are going to see the employers call more and more on the population of individuals with disabilities because they need that talent, they need those workers.

We have also learned more about the transition that more and more people with disabilities are making between work and retirement, not an issue that years ago we even thought much about. I am still troubled by the poverty rate being so high among that population. But if we can have more and more individuals working for 40 years, that issue will also greatly improve.

So thank you all for being here today, for increasing our understanding, and for helping us chart a path forward for a better life for those with disabilities, whether they were born with them or acquired them later in life.

This hearing record will remain open for another week until Friday, November 3rd, in case any committee member has additional questions for the record.

This concludes the hearing. Thank you for being here.

[Whereupon, at 3:59 p.m., the Committee was adjourned.]

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## **APPENDIX**

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**Prepared Witness Statements**

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**Prepared Statement of David Michael Mank, Ph.D., Professor Emeritus,  
Indiana University, Bloomington, Indiana**

Good morning, I am David Mank, Ph.D., Professor Emeritus of Indiana University. I am formerly the Director of the Indiana Institute on Disability and Community and Professor in Special Education and Rehabilitation. The Institute is one of the nation's university centers for excellence in developmental disabilities research, education and service. The Institute is a member of the Association of University Centers on Disabilities (AUCD). As a national resource, AUCD's mission is to advance policies and practices that improve the health, education, social, and economic well-being of all people with developmental and other disabilities, their families, and their communities.

Late in the year of 2014, I was appointed by the Secretary of Labor, to the Advisory Committee on Increasing Competitive Integrated Employment for Individuals with Disabilities (ACICIEID). This committee was created in the Workforce Innovation and Opportunity Act of 2014 (WIOA). Subsequently, I was elected Chairperson by the committee. In September 2016, this committee completed its work and delivered its final report and recommendations to the Secretary and to Congress. I am submitting this committee's report as a part of my written testimony.

WIOA established employment of people with disabilities as a national priority. The goal of WIOA is to increase employment of people with disabilities in competitive integrated employment (CIE) and significantly limit placements in subminimum wage sheltered workshops. WIOA defines CIE as a job that (1) pays people with disabilities at least the minimum wage and not less than the wage paid to people without disabilities for the same or similar work; (2) is performed in a location where the employee interacts with co-workers without disabilities; and (3) provides workers with disabilities the same opportunities for career advancement as their non-disabled co-workers.

WIOA was passed by Congress in 2014. It was also the subject of a bipartisan and bicameral congressional hearing held earlier this month. The congressional briefing was sponsored by Senator Bob Casey and Senator Maggie Hassan, in cooperation with the House of Representatives Bipartisan Disabilities Caucus, Chairs Representative Gregg Harper and Representative Jim Langevin.

We know that people with disabilities want good jobs, in integrated settings, and with good wages. We know that people with disabilities want to pursue careers. We know that people with significant disabilities are fully capable of working productively in CIE when provided with supports individualized to each person's talents and needs. This has long been established in research and in emerging practice. In addition, in a research study in Indiana, when asked, two thirds of the adults in sheltered workshops are interested in CIE. Research shows that when people with disabilities leave day programs and sheltered work settings, they earn more money, are more fully integrated in communities, work in a greater variety of jobs, pay more taxes, and receive more employer sponsored benefits. Research studies about the preferences of people with intellectual or other developmental disabilities in sheltered workshops show that a large majority of these individuals would prefer competitive integrated employment. One such study is submitted with my written testimony.

WIOA's major substantive provisions include:

- Significant limits on the use of subminimum wage sheltered workshops, particularly for transition age youth. WIOA requires that anyone under 24 explore and try CIE before they can be placed in a subminimum wage setting, prohibits schools from contracting with subminimum wage providers, and requires at least annual engagement of anyone in a subminimum wage setting to discuss CIE alternatives.
- Requires state agencies—including Medicaid, intellectual and developmental disabilities (I/DD), vocational rehabilitation, and education—to enter into cooperative agreements to prioritize CIE.
- Requires that at least 15 percent of vocational rehabilitation funding be used for pre-employment transition services.
- Extends post-employment services from 18 to 24 months.
- Requires that at least half of states' supported employment grant funds be used for youth (up to age 24) with the most significant disabilities.

WIOA stands is a rich line of national developments, the Rehabilitation Act, the 1998 Workforce Innovation Act and the Americans with Disabilities Act, and more, that establish employment and full integration of people with disabilities in all aspects of community life.

In addition to WIOA's substantive provisions, the law also created a Federal Advisory Committee on Increasing Competitive Integrated Employment for Individuals

with Disabilities. WIOA charged the committee with developing findings, conclusions and recommendations for the U.S. Labor Secretary and Congress on: (1) ways to increase employment opportunities for people with intellectual or developmental disabilities (I/DD) and other individuals with significant disabilities in CIE; and (2) the use of subminimum wage certificates under 14(c) of the Fair Labor Standards Act (FLSA) for employing people with I/DD and other significant disabilities, including ways to improve oversight of such certificates. The committee was comprised of federal official members from key agencies representing four federal departments, representatives of national disability advocacy organizations, self-advocates, providers of employment services (both supported employment and sheltered workshop providers), employers, and academic experts.

The committee issued its final report to the Labor Secretary and Congress on September 15, 2016. The report was issued following ten public meetings held between January 2015 and August 2016. Hundreds of people testified or submitted written comments to inform the committee's work. The committee received more than 2,000 letters, e-mails, and video messages about employment of people with disabilities and the work of the committee. The committee was attentive to the broad scope of the ideas and comments from the public through the course of its work.

In accordance with the rules governing federal advisory committees, the findings, conclusions and recommendations contained in the final report were developed by consensus of the committee. This committee report is especially important in several ways. First, the committee was comprised of individuals outside and inside the Federal Government, representing a broad range of expertise and perspectives. This committee was representative of many of the perspectives in the disability community. As such, different, even conflicting perspectives were represented in the work of the committee. Second, as I indicated, the final report and recommendations represent the consensus of the committee. All of the recommendations represent the consensus of the entire committee and were issued without objection. Third, the work of the committee was time limited. That is, as created by WIOA, the committee was tasked with developing and agreeing on recommendations in less than a 2-year time period.

The committee's report emphasizes the need to build the capacity, in communities and states across the country to deliver competitive integrated employment to individuals with intellectual or developmental disabilities and other individuals with significant disabilities.

I will draw your attention in particular to 6 key aspects of the committee's report focused specifically on what the Federal Government and Congress can do to increase the number of real jobs in integrated settings for people with disabilities.

*1. Align funding of employment services with competitive integrated employment outcomes.*

This includes making adjustments in the ways employment services are funded to create incentives for employment outcomes. This can include changes in the Medicaid Waiver program, to increase the federal match for employment as well as creating milestone and outcome payment structures. There already exist, in CMS, methodologies (such as Money Follows the Person (MFP)), which focus on priorities and outcomes. And, CMS has already begun investigating payment based on employment milestones and outcomes.

*2. Create incentives to states to make CIE a priority and build capacity to deliver CIE.*

This means creating state grants as incentives and to develop the capacity in local communities to develop and support organizations that assist people with disabilities to get and keep competitive and integrated jobs. This will need to include training and technical assistance to local organizations as well as investment in the infrastructure in states that provides employment services. This includes personnel preparation and development as well as assistance to organizations to transform from sheltered workshops and day programs to organizations that deliver CIE outcomes to people with significant disabilities. Examples already exist, that can be extended and replicated, of states working to develop increased capacity to deliver CIE. The Federal Government and Congress should invest in this capacity building in states across the country to deliver CIE outcomes.

*3. Address the issue of the payment of sub-minimum wages.*

After considerable investigation and discussion, the committee crafted a recommendation specific to the issue of sub-minimum wages.

Congress should amend Section 14(c) of the FLSA to allow for a "well-designed, multi-year phase-out" that results in people with disabilities entering CIE. Along

with this legislative change, there should be oversight of the phase-out through increased data collection. In addition, there should be the appointment of a federal interagency taskforce to develop and oversee a plan for phaseout that considers the mandates of WIOA regarding 14(c), resources for technical assistance, measures to mitigate unintended consequences of phaseout, and safeguards to ensure people currently under 14(c) certificates are engaged and equipped with information and the opportunities necessary for understanding options and making informed choices. The U.S. Department of Labor should also engage in stronger enforcement of sub-minimum wage certificates.

*4. Establish an interagency commission or working group to establish guidance and technical assistance to states to deliver CIE.*

Federal agencies should convene a cross-agency working group to develop policy guidance and technical assistance on integrated day services and other wraparound supports, with the goal of:

- Clarifying that integrated day and wraparound services are intended to maximize and not displace CIE
- Identify best practices in integrated day and funding strategies
- Clarifying that integrated day services should not be in a facility or require a program schedule
- Clarifying how federal funds can be used to promote CIE and natural supports in integrated workplaces.

This means establishing a working group to turn the recommendations of the committee into an implementation plan of national scope that includes specific tasks, roles, responsibilities, timelines and resources needed to expand CIE on a national scale. This can also include attention to aging citizens with disabilities and the need for integrated supports and services for older citizens with disabilities, or retired individuals to participate in community life in the same ways and in the same community spaces as other older or tired citizens.

*5. Provide assistance and incentives to the business community to employ people with significant disabilities.*

This means creating a national campaign about the ability of people with significant disabilities to work productively in CIE and about the benefits of a diverse workforce and of hiring people with disabilities. In addition, the Federal Government and Congress should update and amend tax credits and other incentives to employers who hire and employ people with significant disabilities.

*6. Make changes in the AbilityOne® Program so it aligns with modern disability and employment policy.*

AbilityOne® is a federal set-aside program that requires all federal agencies to purchase certain supplies and services from agencies that employ people with disabilities. In Fiscal Year 2014, AbilityOne® awarded approximately \$2.8 billion in contracts. Agencies who are awarded AbilityOne® contracts must ensure that at least 75 percent of the labor hours necessary to complete the contracts are completed by people with disabilities, and they may pay subminimum wages to people working on these contracts.

The committee found that although the AbilityOne® program could be powerful in creating opportunities for CIE for people with significant disabilities, the design of the current program actually inhibits increasing those opportunities. The barriers include: (1) potential conflicts of interest in determining who is eligible to participate in AbilityOne® contracts because the agencies function as both the employer and service provider; (2) the 75 percent contract hour requirement in practice ends up segregating people with disabilities from the mainstream workforce; (3) the lack of a requirement or expectation that AbilityOne® contract work offers a path to CIE with mainstream employers; and (4) that the AbilityOne® Commission, which oversees the program, was not designed to ensure the program aligns with the goals of CIE in federal law.

To address these findings the committee recommended that Congress amend the statute authorizing the AbilityOne® Program, the Javits-Wagner-O'Day Act (JWOD), to align with modern disability laws by requiring CIE be a goal of participation in the AbilityOne® program. This needs to include significant research and development of new and innovative strategies to align AbilityOne® with the ADA and other modern disability policy, and doing so in ways that does not create unintended consequences.

The over-arching theme of our report is building the capacity to deliver competitive and integrated jobs to people with disabilities in communities, large and small, across the United States.

In order to deliver CIE in communities nationwide, we need organizations, and a skilled workforce fully capable of providing employment services that result in CIE outcomes. And, in the same way competitive integrated employment for people with disabilities mirrors typical employment for any citizen, other services and supports should also represent what is typical for others in any community. This is also true for those returning to work. Older people with disabilities nearing retirement will need supports to participate in community life in the same ways and in the same places as their same age peers. These supports must also be provided in fully integrated settings.

I will end my testimony where I began. We know that people with disabilities want good jobs, in integrated settings, and with good wages. We know that people with disabilities want to pursue careers. We know that people with significant disabilities are fully capable of working productively in CIE when provided with supports individualized to each person's talents and needs. We know that when people with disabilities leave day programs and sheltered work settings, they earn more money, are more fully integrated in communities, work in a greater variety of jobs, pay more taxes, and receive more employer sponsored benefits.

Thank you for this opportunity to testify today.

**Service and Support Needs of Adults Aging with Intellectual/Developmental Disabilities**

**Testimony to the U.S. Senate Committee on Aging**

**Working and Aging with Disabilities: From School to Retirement**

**October 25, 2017**

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Given the demographic imperatives of the longer life expectancy of adults with intellectual and developmental disabilities (IDD) and the aging of the baby boomers, a growing challenge exists to address this population's later life needs. People with IDD are aging at unprecedented rates and have unique health and service and support needs. They have a higher risk of developing chronic health conditions at younger ages than other adults, due to the confluence of biological factors related to syndromes and associated disabilities. Also, they may face poor access to adequate health care, as well as lifestyle and environmental issues. Furthermore, people with IDD are less likely to be employed and those that are employed or retired may need additional services and support as they reach middle and older ages. This testimony addresses the needs of people aging with IDD, including implications for employment and retirement.

These unique service needs of this population pose new challenges for existing service networks. Traditionally the aging and developmental disabilities service systems have run on parallel tracks. Large-scale legislative changes that target long-term services and supports require greater communication and coordination between the two systems. In this time of great transformation, it is critical for the two systems to work together as their populations face similar needs including managed long-term, integrated care for people who are dually eligible for Medicaid and Medicare, and rebalancing initiatives that promote community living (Factor, Heller, & Janicki, 2012).

The population of adults age 60 and older with IDD is growing dramatically and is estimated to increase from 850, 600 in the community based on the 2010 U.S. census to an estimated 1.4 million by 2030, due to increasing life expectancy and the aging of the baby boomer generation (Factor et al., 2012). Older adults with IDD are often more vulnerable to conditions that make their old age potentially more difficult with poorer health, needs for more supports, and fewer resources than other older adults. They also have fewer opportunities to exercise their self-determination in order to have a meaningful and fulfilling life.

To understand strategies for addressing the service and support need of adults aging with IDD one needs to examine the unique aspect of aging with IDD, particularly in regard to such life transitions that accompany their aging such as development of chronic health conditions, changes in family caregiving and supports, changing needs for supports in employment, and retirement from employment (Hahn et al., 2016).

#### **Life Transitions and Aging**

*Age-related changes in health.* While the life expectancy of individuals aging with IDD is increasing, it is still lower than for the general population, particularly for those individuals with more severe intellectual and physical disabilities and certain genetic syndromes (Bittles et al., 2002; Haveman et al., 2009). For example, Down syndrome has been linked to premature aging, Alzheimer's disease, and certain organ dysfunctions (Janicki, Henderson, & Rubin, 2008). In addition to genetic disorders, specific health problems related to the older age trajectories of several common neurodevelopmental conditions such as cerebral palsy (e.g., osteoporosis and degenerative joint disease), autism (e.g., digestive system disorders and neuropsychiatric factors) and spina bifida (e.g., neuromotor and other organ system consequences) are of concern (Janicki et al., 2008). People with IDD are likely to be in poorer health and experience earlier age-related chronic health conditions, including dementia, osteoporosis, oral disease, and diabetes (Haveman et al., 2009; Acharya, Schindler, & Heller, 2016). They are also more likely to be obese and overweight (Hsieh, Rimmer, & Heller, 2013) and experience a high rate of falls (Hsieh, Rimmer, & Heller, 2012). Sedentary behaviors and unhealthy diets contribute to greater cardiovascular disease for adults with IDD (Hsieh et al., 2016)

Health care access is often poor for adults with IDD resulting in more morbidity and earlier mortality (Haveman et al., 2010; Krahn & Drum, 2007; Perkins & Moran, 2010). For

example, diagnosis of cancer occurs at a later stage and deaths from conditions that could have been amenable to health care interventions are more common among individual with IDD than in the general population (Hosking et al., 2016). They also are less likely to receive organ transplants or dialysis often due to criteria such as years of life expectancy, ability to keep a regimen, and amount of support available (Stratling & Louw, 2011). Furthermore they may have undiagnosed conditions due to communication barriers.

Their health concerns and lifestyle differences point to the need for health promotion interventions, exercise and nutrition programs, health behavior education, and health screenings. Also a need exists for education of health professionals, direct support professionals, and families and other caregivers in addressing the health issues of adults aging with IDD.

To address multiple chronic diseases that often occur in older ages, geriatric assessments and chronic disease self-management programs play a central role in diagnosing and treating such conditions. An in-home health risk and geriatric assessment adapted for people with IDD (Aronow & Hahn, 2005; Hahn & Aronow, 2005) resulted in identification of health conditions and in follow-up checks. Wilson and Goodman (2011) adapted a chronic disease self-management program for individuals with IDD and found that it was a promising practice for individuals with at least a moderate level of intellectual functioning. Given the higher prevalence of dementia in adults with Down syndrome at earlier ages (Janicki & Dalton, 2000), myriad interventions target dementia care in this population drawing on the extensive research on dementia care interventions in the general population. These include practices that increase safety, make environmental accommodations, and ensure a more positive quality of life (Jokinen et al., 2013). Other health related adaptations include falls prevention programs, such as the modified Otago program that shows promise as a method of prevention falls for adults with IDD (Renfro, Bainbridge, & Smith, 2016). An evidenced based health promotion program that has been shown to improve fitness and health of adults aging with IDD is *Health Matters: The exercise and nutrition health education curriculum for people with developmental disabilities* program which is being implemented state-wide in several states (Marks, Sisirak, & Heller, 2010).

*Long-term supports and services.* Adults aging with IDD are more likely than adults in the general population to have received life-long services and supports. Based on 2015 data, an estimated 71% of individuals with IDD live with their family caregiver. Of those living with their family caregiver, 24% are with caregivers aged 60+ and another 35% are with caregivers aged 41 to 59 years. Only 13% of adults with IDD live in supervised residential settings (Braddock et al., 2017). As of 2014, nationally, there were nearly 100,000 individuals on waiting lists for residential out-of-home services and over 216,000 estimated to be waiting for any type of long-term services and supports (Larson et al., 2017).

Parents, who often provide life-long care for their offspring with IDD, experience both their own aging and the aging of the adult with IDD. The impact of caregiving, particularly on

mothers include fewer opportunities for employment and a restricted social network (Seltzer, Floyd, Song, Greenberg, & Hong, 2011). Many adults with IDD continue to live with aging parents until their parents are no longer able to care for them or pass away (Braddock et al., 2017). Life expectancy gains indicate there will be growing numbers of two-generation elderly households of people with disabilities living with their parents. These families remain intact out of choice or due to the shortage of alternative residential options. Both generations will require supports to age in place. Often when parents can no longer provide care, siblings may be called upon to take over that role with little formal support provided to them (Heller & Arnold, 2010). Hence, future planning for the time when parents are no longer able to take care becomes an important task for families and persons with IDD.

Although all states now fund family support in the form of cash subsidies and/or direct services, in 2015, national family support expenditures of \$5.8 billion accounted for only 9% of total national developmental disabilities expenditures. Only 15% of families caring for a relative with a disability at home received family support (Braddock et al., 2017). The gap between need and available public resources is expected to increase with the looming demographic challenges.

These families often first come to the attention of the aging network through referrals from hospital discharge planners, friends, and neighbors, especially when the older parents need support due to age-related changes in health and function. In some households, the person with a disability may care for an aging parent. These families need to make informed decisions about their own support needs, as well as help the person with a disability plan for his or her future. Many older parents and their adult offspring with a disability lack plans regarding what may in store in the future for the adult with a disability. Without adequate plans in place these adults could lose eligibility for benefits, lose protections and supports, and face inappropriate admission to emergency residential settings. Evidence-based interventions exist to assist these families in planning for the future that are based on peer support, person-centered planning, and inclusion of siblings, and the individuals with IDD and other families members (Factor et al., 2010). However, currently there is no national infrastructure available to assist these families with future planning. Future planning must include such issues as financial, legal, advocacy, residential, vocational, and community participation.

The Research and Training Center on Family Support at the University of Illinois at Chicago (<http://fsrtc.ahslabs.uic.edu/>) is an example of a national center that bridges research in aging and in disability, including interventions with older caregivers of adults with IDD in future planning as well as studies of self-directed supports for older adults and for adults with IDD and their families. An innovative project administered through an aging agency and titled “Caring for the Caregiver” was a training and support program for adults with IDD who were caring for their parents (Carbine, Buri-Kurtz, & Varick, 2010).

*Employment.* While there have been many advances in knowledge about ways to support adults with IDD in employment, only 16% of people receiving services (as of 2015 National

Core Indicators Data) from state IDD agencies work in integrated employment, including both individual and group supported employment. (Heirsteiner, Bershadsky, Bonardi & Butterworth, 2016). According to the American Community Survey (2015) 24.8% of individuals of working age (age 24 to 64) with a cognitive disability were employed, in comparison with 34.3% of individuals with any disability, and 73.6% of people without a disability. Only an estimated 12.5 percent of the individuals with a cognitive disability were employed full-time/full-year.

The majority of persons who receive IDD services are still in facility based and non-work settings. However, the percentage of people served in facility based settings vary significantly by states with some states not funding facility based programs (e.g., Vermont, District of Columbia, Maine, New Hampshire, and Massachusetts). Among adults with competitive employment, many work part-time, have low income, and few benefits (Winsor et al., 2017). There is little data available on employment of people with IDD by age. For general disability in 2016, the labor force participation rate for people with disabilities aged 65 and older was 7.6% and the unemployment rate was 6.4%, compared to the general population aged 65 and older who had a labor force participation rate of 24.2% and an unemployment rate of 3.5%.

While facility based work has declined for people with IDD, the percentage of people served in non-work settings has increased with the number of states reporting that option increasing from 18 states in 1996 to 34 in 2015. In 2015, 43% of individuals with IDD receiving day services received them in non-work settings (Winsor et al., 2017). Some of these programs have developed options that help persons with IDD engage in the community, including retirement options, such as volunteering, recreational and health promotion activities, senior center participation, and continuing education for older individuals (Sulweski et al., 2017).

Many middle age and older adults with IDD in integrated and competitive work environments may want to continue working as in the general older population. With age-related health and functioning changes they may need additional or different accommodations. This could include cognitive and assistive technology to help them remain on the job, or more customized employment (e.g., changing the type of job or task demands). It may also include more supports with transportation, as there could be changes in residential settings and family or other caregiver supports.

There are many examples of middle age and older adults with IDD who with proper supports are continuing in integrated employment settings. For example, in our University Center of Excellence at the University of Illinois at Chicago we employed a self-advocacy specialist, Tia Nelis. With help in writing grants, managing fiscal issues, and other supports, she has been able to serve as a leader nationally in speaking up for the rights of people with disabilities. She has been one of the founders of the national Self-Advocates Becoming Empowered (SABE) and is now working for TASH, a national disability advocacy organization. She also provides leadership training to emerging self-advocacy leaders.

*Retirement.* Given that adults with IDD have very low employment rates and usually rely on government benefits, retirement may take on different meanings than for other individuals who are aging as it likely results in less financial implications. Hence, the focus of retirement becomes more of the transition from employment or IDD day program activities to socialization, health promotion, and leisure activities. For people with IDD transitioning to retirement may also mean participating in generic senior centers. Often the person with IDD has little choice in the type of activities and does not want to retire given that their social life and activities have centered around their day programs or employment which as noted above often includes segregated programs (Hahn et al., 2016).

Several programs have focused on retirement and later life activities using individualized approaches that respect the self-determination of people with IDD through education, support, and opportunities to participate in activities that are meaningful to them and desired by them. The *Person-Centered Planning for Later Life for Adults with Mental Retardation* found improvements in knowledge, leisure activities, and self-determination among older adults with IDD who participated (Heller et al., 1996). More recently the *Transitions to Retirement* (Stancliffe et al., 2013) curriculum is using a mentored approach in which older adults volunteer to mentor adults with IDD in leisure retirement activities, which has resulted in greater social participation of the participants with IDD.

#### **Models of Services and Supports for Adults Aging with IDD**

*Historical approaches.* Models of services and supports for adults aging with IDD over the last four decades reflect the transformative changes in philosophies of care both in the aging and disability fields. These models include: (1) segregated services, (2) services in senior network, (3) person-centered services and supports, and (4) rights based supports for full community inclusion. The segregated services, common in the 1980s included such examples as the senior activity center within a sheltered workshop, state institutions, or other large facilities. These senior activity centers often included programs developed primarily for senior centers and nursing homes, such as reminiscence therapy (Stuart, 1998).

As principles of normalization began to take hold in the late 1980s and in the 1990s, there was an emphasis on “age appropriate” services in “generic”, that is not IDD specific settings. Hence, when adults with IDD reached a chronological age deemed as “senior” then a preferred setting was a senior setting or a nursing home. The innovative aspect was figuring out how to enhance acceptance of people with IDD into these settings by other older persons. One example was a project headed up by Ruth Roberts that provided an individualized peer mentor approach as opposed to busing a van load of people with IDD to a senior center. She paired up an elderly person with similar interests to be a peer mentor to the person with IDD who would then accompany the person to the senior center (Sutton, Factor, Hawkins, Heller, & Seltzer, 1993).

In the 1990s the notion of individualized supports and person-centered planning began to take shape. Principles of person centered planning centered on the self-determination of adults

with disabilities and the community of supports around them. One example of person-centered planning for older adults with IDD was the curriculum titled “*Person-Centered Planning for Later Life for Adults with Mental Retardation*” that provided training for the adult with disabilities in making choices, experiencing different activities in the communities, goal-setting in various domains of their lives, planning for the future, and obtaining and engaging their supports. At the same time training also occurred for the persons who the person with a disability designated as their desired circle of support (Heller et al., 1996).

With the United Nations Convention on the Rights of People with Disabilities (CRPD) (United Nations, 2006) in the twenty first century there is an increasing emphasis on the human rights of people with disabilities. This includes the rights to full inclusion in the community, universal design, and supported decision-making. While each era brings new models and approaches, the older ones continue to exist in many places. For example, there are still segregated settings being built for people with IDD and dementia (Janicki, 2011). As new models evolve we need to make sure to examine best and promising practices and their outcomes to inform policies and practices that bridge aging and disabilities (Sutton et al., 1993).

*Bridging aging and disability policies.* In the U.S. there are now many opportunities for common ground between the aging and the disability service networks. At the national level the Administration for Community Living (ACL) now includes both the developmental disabilities and the aging networks under its umbrella. It also has several initiatives that encompass both aging and disability, including the Aging and Disability Resource Centers, Lifespan Respite Care, the National Family Caregiving Support Program and the National Alzheimer’s Project Act (NAPA). The National Task Group on Intellectual Disabilities and Dementia Practices (NTG) has been successful in promoting the inclusion of people with IDD in the NAPA initiatives so that now four states have funding from the ACL to provide training and support to people with IDD who develop dementia (<http://aadmd.org/NTG>).

### **Conclusion and Recommendations**

As people with IDD reach middle age and older age, there is an increasing need for supports in order for them to have fulfilling lives. Addressing age related health needs, family support, and community participation interacts with the ability of people with IDD to lead productive lives which could include employment and retirement as they age. With changes in health, it is critical that greater efforts are made to increase preventive care and health promotion activities. Employee health promotion programs and attention to prevention and health promotion by managed care organizations can help address the health care needs of people with IDD. Increased supports for families are integral to helping the many adults with IDD who are living at home with family members. For adults aging with IDD as well as for other aging adults, assistive and cognitive technology and universal design increase in importance. Similarly, inclusive transportation assistance is needed to help individuals participate in the community, including employment, access health care services, paratransit, and other community based

supports. Challenges will occur as there is more pressure on community based systems to supply a work force that can support people aging with and into disability. There is a growing recognition of supportive decision-making and interdependence between people across generations. Finally a need exists for research on better ways to bridge aging and disability.

### References

- Acharya, K., Schindler, A., & Heller, T. (2016). Aging: Demographics, trajectories, and health system issues (pp. 1423-1432). In L. Rubin & A. Crocker, *Health care for people with intellectual and developmental disabilities across the lifespan, 3<sup>rd</sup> edition*. L. Rubin, J. Merrick, D. Greydanus & D. Patel (Eds). Switzerland: Springer Publishing.
- Aronow, H., & Hahn, J. (2005). Stay Well and Healthy! Pilot Study Findings from an Inhome Preventive Healthcare Programme for Persons Ageing with Intellectual and/or Developmental Disabilities. *Journal of Applied Research in Intellectual Disabilities, 18*, 163-173.
- Bittles, A., Petterson, B., Sullivan, S., Hussain, R., Glasson, E. & Montgomery, P. (2002). The influence of intellectual disability on life expectancy. *The Journals of Gerontology Series A: Biological Science and Medical Science, 57*, 470-472.
- Braddock, D., Hemp, R., Tanis, E.S., Wu, J. & Haffer, L. (2017). *The State of the States in Intellectual and Developmental Disabilities: 2017*. Washington, DC: American Association on Intellectual and Developmental.
- Carbine, P., Buri-Kurtz, D., & Varick, T. (2010). In T. Heller, P. Stafford, L.A. Davis, L.A., L. Sedlezky, & V. Gaylord. (Eds.). *Impact: Feature Issue on Aging and People with Intellectual and Developmental Disabilities, 23*(1), 22-23. Minneapolis: University of Minnesota, Institute on Community Integration.  
<https://ici.umn.edu/products/impact/231/231.pdf>
- Factor, A., DeBrine, E.J., Caldwell, J., Arnold, K., Kramer, J, Nelis, T. & Heller, T. (2010). *The future is now: A future planning curriculum for families and their adult relative with developmental disabilities* (3<sup>rd</sup> Edition). Chicago, IL: Rehabilitation Research and Training Center on Aging with Developmental Disabilities, University of Illinois at Chicago.
- Factor, A., Heller, T. & Janicki, M. (2012). *Bridging the aging and developmental disabilities service networks: Challenges and best practices*. Chicago: Rehabilitation Research and Training Center on Aging with Developmental Disabilities, Lifespan Health and Function, University of Illinois at Chicago. Retrieved from:  
[http://www.acf.hhs.gov/sites/default/files/aidd/bridgingreport\\_3\\_15\\_2012.pdf](http://www.acf.hhs.gov/sites/default/files/aidd/bridgingreport_3_15_2012.pdf)

- Hahn, J.E., & Aronow, H.U. (2005). A pilot of a gerontological advanced practice nurse preventive intervention. *Journal of Applied Research in Intellectual Disabilities*, 18, 131-142.
- Hahn, J. E., Gray, J., McCallion, P., Ronneberg, C., Stancliff, R., Heller, T., . . . Janicki, M. (2016). Transitions in Aging: Health, Retirement and Later Life: Review of Research, Practice and Policy. *Critical Issues in Intellectual and Developmental Disabilities: Contemporary Research, Practice, and Policy*. Washington, DC: AAIDD.
- Haveman, M., Heller, T., Lee, L. A., Maaskant, M. A., Shoostari, S., & Strydom, A. (2009). *Report on the State of Science on Health Risks and Ageing in People with Intellectual Disabilities*: IASSID Special Interest Research Group on Ageing and Intellectual Disabilities/Faculty Rehabilitation Sciences, University of Dortmund.
- Heirsteiner, D., Bershady, J., Bonardi, A., & Butterworth, J. *Working in the community: The status and outcomes of people with intellectual and developmental disabilities in integrated employment-Update2-NCIData Brief*, April, 2016 Cambridge, Ma. Human Services Research Institute.
- Heller, T., & Arnold, C. K. (2010). Siblings of adults with developmental disabilities: Psychosocial outcomes, relationships, and future planning. *Journal of Policy and Practice in Intellectual Disabilities*, 7(1), 16-25. doi: <http://dx.doi.org/10.1111/j.1741-1130.2010.00243.x>
- Heller, T., Sterns, H., Sutton, E., & Factor, A. (1996). Impact of person-centered later life planning training program for older adults with mental retardation. *Journal of rehabilitation*, 62(1), 77-83.
- Hosking, F.J., Carey, I.M., Shah, S.M., Harris, T., DeWild, S., Brighton, C., & Cook, D. G. (2016), Mortality among adults with intellectual disability in England: Comparisons with the general population. *American Journal of Public Health*, 106(8), 1483–1490. doi: [10.2105/AJPH.2016.303240](https://doi.org/10.2105/AJPH.2016.303240)
- Hsieh, K., Rimmer, J. & Heller, T. (2012). Prevalence of falls and risk factors in adults with intellectual disabilities. *American Journal on Intellectual and Developmental Disabilities*, 117(6), 442-454.
- Hsieh, K., Rimmer, J. & Heller, T. (2013). Obesity and associated factors in adults with intellectual disability. *Journal of Intellectual Disability Research*, 58(3), doi: 10.1111/jir.12100
- Janicki, M. P. (2011). Quality outcomes in group home dementia care for adults with intellectual disabilities. *Journal of Intellectual Disability Research*, 48, 426.
- Janicki, M. P. & Dalton, A. J. (2000). Prevalence of dementia and impact on intellectual disability services. *Mental Retardation*, 38, 277-289.

- Janicki, M.P., Henderson, M.C. & Rubin, I.L. (2008). Neurodevelopmental conditions and aging: Report on the Atlanta Study Group Charrette on Neurodevelopmental Conditions and Aging. *Disability and Health Journal*, 1(2), 116-124.
- Jokinen, N. Janicki, M.P., Keller, S.M., McCallion, P., Force, L.T., & the National Task Group on Intellectual Disabilities and Dementia Practices. (2013). Guidelines for structuring community care and supports for people with intellectual disabilities affected by dementia. *Journal of Policy and Practice in Intellectual Disabilities*, 10, 1-28.
- Krahn, G. L., & Drum, C. E. (2007). Translating policy principles into practice to improve health care access for adults with intellectual disabilities: a research review of the past decade. *Mental Retardation and Developmental Disabilities Research Reviews*, 13(2), 160-168. <https://doi.org/10.1002/mrdd.20149>
- Larson, S.A., Eschenbacher, H.J., Anderson, L.L., Taylor, B., Pettingell, S., Hewitt, A., Sowers, M., & Fay, M.L. (2017). *In-home and residential long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2014*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. Access at <https://risp.umn.edu/publications>
- Marks, B., Sisirak, J., & Heller, T. (2010). *Health matters: Health education curriculum for individuals with intellectual and developmental disabilities*. Baltimore: Brookes Publishing.
- Perkins, E. A., & Moran, J. A. (2010). Aging adults with intellectual disabilities. *JAMA*, 304(1), 91-92.
- Renfro, M.O., Bainbridge, D., & Smith, M.L., (2016). Validation of evidence-based fall prevention programs for adults with intellectual and/or developmental disorders: A modified Otago exercise program. *Frontiers in Public Health* 4(7), 261 doi: 10.3389/fpubh.2016.00261
- Seltzer, M.M., Floyd, F., Song, J., Greenberg, J., Hong, J. (2011). Midlife and aging parents of adults with intellectual and developmental disabilities: Impacts of lifelong parenting. *American Journal on Intellectual and Developmental Disabilities*. 116(6), 479-99.
- Stancliffe, R. J., Wilson, N. J., Gambin, N., Bigby, C., & Balandin, S. (2013). *Transition to retirement: A guide to inclusive practice*. Sydney, Australia: Sydney University Press.
- Stuart, M. (1998). *Looking back, looking forward: Reminiscence with people with learning disability*. Brighton: Pavilion Publishing.
- Stratling, M.W.M. & Louw, S. (2011). Disability-ethical issues: as complex and under-recognized challenge in clinical ethics consultation. *Clinical Ethics* 6(1), 2-4.

- Sutton, E. Factor, A. R., Hawkins. B., Heller, T. & Seltzer, G.B. (Eds.), (1993). *Older adults with developmental disabilities: Optimizing choices and change*. Baltimore, MD: Brookes.
- Sulweski, J.S., Timmons, J.C., Lyons, O., Lucas, J., Vogt, T., & Bachmeyer, K. (2017). Organizational transformation to integrated employment and community life engagement. *Journal of Vocational Rehabilitation*, 46(3), 313-320.
- Wilson, P & Goodman , C. (2011) Evaluation of a modified chronic disease self-management programme for people with intellectual disabilities, *Journal of Nursing and Healthcare of Chronic Illness* , vol. 3 , no. 3 , pp. 310-318. doi: 10.1111/j.1752-9824.2011.01105.x
- Winsor, J. Timmons, J., Butterworth, J., Landa, C., Smith, F., Domin, D., Migliore, A., Bose, JH., & Landin, L. (2017). *State Data: The national report on employment services and outcomes*. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.

# Caregiving and Intellectual and Developmental Disabilities and Dementia: Report of the Pre-Summit Workgroup on Caregiving and Intellectual and Developmental Disabilities

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on Caregiving and Intellectual/Developmental Disabilities\*

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Submitted on behalf of the National Task Group on Intellectual Disabilities and Dementia Practices, the Rehabilitation Research and Training Center on Developmental Disabilities and Health, University of Illinois at Chicago, and the Alzheimer's Association, to the National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers.



Additional information can be found at the Summit website (<https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers>) or the National Alzheimer's Project Act website (<https://aspe.hhs.gov/national-alzheimers-project-act>). The opinions and views expressed in this report are those of the authors. They do not necessarily reflect the views of HHS, the contractor or any other funding organization.

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**Notation**

This report was prepared at the request of the National Task Group on Intellectual Disabilities and Dementia Practices for submission to the National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers.

### Summary

This report summarizes the findings and recommendations from a pre-summit activity for the National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers. The report was developed by a working group of experts in caregiving, dementia, and intellectual and developmental disabilities (IDD) and organized by the National Task Group on Intellectual Disabilities and Dementia Practices (NTG) in partnership with the Rehabilitation Research and Training Center in Developmental Disabilities and Health at the University of Illinois at Chicago and the Alzheimer's Association. The purpose was threefold: (1) to assess the current state of research, policy, and practice, and develop recommendations related to caregiving supports for older adults with intellectual and developmental disabilities; (2) to translate the contributions of these findings to the greater dementia care agenda; and (3) to promote inclusion of issues particularly relevant to intellectual disability and dementia concerns as part of the Summit platform. The Report examined the foundational similarities and differences in focal areas affecting people with dementia, both with and absent IDD. Considered were five major areas related to care and caregiving: (1) family caregiving interventions; (2) supportive care settings; (3) effects of diversity; (4) screening and early detection; and (5) bridging service networks. Recommendations are offered in each of these areas, including how funding and actions might be undertaken and by which federal or non-federal organizations.

### Background

The Family Caregiver Alliance estimates 65 million people in the U.S. serve as caregivers to older family members or family members with a disability (Alliance, 2016). Among these is an important and often overlooked group, caregivers of older adults with intellectual and developmental disabilities (IDD) and dementia. With an estimated 46.2 million adults ages 65 and older in the U.S. (U.S. Administration on Aging, 2016), there are at least 180,000 older adults with IDD and, at minimum, 11,000 of these adults will be affected by dementia (Janicki & Dalton, 2000). As the population of older adults in the United States continues to rapidly increase this group will likely need additional services and supports. Caregivers of adults with IDD and dementia have many of the same challenges and stressors as caregivers of older adults with dementia. However, they may have different patterns of caregiving experience, additional challenges and stressors, and access different forms of support and education.

This report summarizes the findings and recommendations from the *Pre-Summit on Caregiving and Intellectual/Developmental Disabilities* for the *National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers*. It was developed from findings and recommendations of a working group of experts in caregiving, dementia, and IDD organized by the National Task Group on Intellectual Disabilities and Dementia Practices (NTG) in partnership with the Rehabilitation Research and Training Center in Developmental Disabilities and Health at the University of Illinois at Chicago and the Alzheimer's Association.<sup>1</sup>

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<sup>1</sup>The Workgroup worked first *in absentia* and then met on-site on March 22, 2017 at the Headquarters of the Alzheimer's Association in Chicago, Illinois.

The purpose was threefold:

- 1) To assess the current state of research, policy, and practice, and develop recommendations related to caregiving supports for older adults with intellectual and developmental disabilities;
- 2) Translate the contributions of these findings to the greater dementia care agenda; and
- 3) Promote inclusion of issues particularly relevant to intellectual disability and dementia concerns as part of the Summit platform.

#### **Commentary on Issues Relevant to the NIH Summit**

##### ***Similarities and Differences in Needs and Supports***

While people with IDD and their caregivers have similar needs for dementia care supports as other adults with dementia and their caregivers, there are also unique aspects for the IDD population. These differences include differences in the trajectory of dementia, often with earlier onset of dementia, a shorter duration of dementia, and greater difficulties in diagnosing dementia given the life-long cognitive limitations. Secondly, individuals with IDD often require life-long services and supports, including family caregiving or supported living outside the family home. An estimated 71% of all individuals with intellectual and developmental disabilities (IDD) live with their family caregiver (Braddock et al., 2015). Of those living with their family caregiver, 24% are with caregivers aged 60+ (Braddock et al., 2015). A body of research has examined the nature of extended, often life-long caregiving among these caregivers, as well as the different challenges and adaptations experienced by lifelong caregivers when contrasted to late-life caregivers, and the nature of adaptations to caregiving when adults with IDD begin to experience dementia, and then progress through the course of Alzheimer's disease or related dementias. Thirdly, other kin—primarily siblings—play a significant role for adults with IDD when parents are no longer able to provide care (Heller & Kramer, 2009).

Lifelong caregivers experience differences from later life caregivers with respect to adaptation, ascendance to caregiver roles, and via experience, mobilizing and drawing upon networks of support. Financially, many of these caregivers are also more readily able to access public support for extended caregiving and receive assistance with respite, when the adults with IDD are enrolled in community day programs or home-based support services. As many formal providers and governmental agencies exist to aid people with IDD, some educational and support resources have been made available to help orient caregivers to age-related caregiving (e.g., NDSS, 2012), including raising awareness of the symptoms of dementia and being oriented to care practices tailored to caring for someone with dementia (NDSS, 2017).

A critical distinction among caregivers of adults with IDD is that they are often 'career' caregivers, with extensive experience with providing supports and adapting to the ups and downs related to extended caregiving. Many also have extensive experience with social and health care services and advocating on behalf of their relative with IDD. With the onset of dementia many of these caregivers are adapting to new challenges and bring to fore their experience and capacity to continue caregiving. *This rich literature on 'career' caregivers can be of benefit to the Summit—as the findings can translate to increasing our capacity to understand and sustain caregiving among late-life conditions, in particular dementia.*

***Findings from Aging and IDD Research on Family Caregiving Interventions***

Family caregivers of older adults and adults with IDD (including dementia) face many challenges including stress, depression, poor health, and financial hardship. However, research on the long-term impact of caregiving on caregivers of individuals with IDD is mixed depending on the characteristic of the adult with disability, the health of the caregiver, life events, the context of care, and the informal and formal supports available. Much research is needed to better understand the impact of caregiving on families and how they are managing the new challenges presented by dementia (Jokinen, 2016; 2017).

Programs and services are available to help families cope with these challenges, but they usually focus on either caregivers for older adults or caregivers for adults with IDD, but not both. A recent scoping review of nearly 70 empirical intervention studies (Heller, Gibbons, & Fisher, 2015) looked at some of the differences and similarities between these programs and what the aging and IDD fields can learn from each other as they develop new interventions to support family caregivers.

The review found several important differences between these two fields. In reviewing the research, there was a difference in semantics, that is, the way each community talked about providing care for a family member. While the aging field referred to providing care as “caregiving,” the IDD field more often referred to it as “family support.” Caregiving programs tended to focus on the person providing care, while family support programs were often directed to the entire family. For both groups, most support programs fell into two broad categories: government programs and small-group interventions that addressed psychological and social issues. Government programs tend to focus on either care coordination and support services or financial and home supports. These include, but are not limited to, case management programs, respite care, consumer-directed services, and in-home medical supports. The psychosocial programs tend to focus on either support and counseling or education and training for the caregivers. Examples of these interventions included future planning programs, support groups, disease-specific education, and counseling sessions, among others.

Both caregiving and family support programs benefited those who participated. Government care coordination and respite programs gave caregivers more access to services and satisfaction with the caregiving role, while psychosocial support programs improved participants’ mental health and attempted to reduce “caregiver burden”. Aging studies focused on ‘self-care’ as caregiving was generally assumed in later age, while disability studies often considered caregiving as lifelong. Some programs also benefitted participants’ physical health, employment, productivity, future planning, and access to supports, and resulted in delayed institutional placement for the care recipient. Few studies in both the aging and disability fields examined the cost of family supports.

However, there was little or no cross-over discussion between the fields of aging and IDD. Only a few articles in the family support literature recognized the intersection of aging and IDD, and no articles in the caregiving literature included people aging with lifelong disabilities like IDD (Heller et al., 2015). This is an important gap to bridge for both groups. The IDD family support literature, while not as developed as the gerontology research, has a greater emphasis

on future planning, self-direction and person-centered planning. These types of interventions were assumed to also be useful to older adults and their caregivers, as these interventions were found to empower the person receiving care and often had positive impacts on the caregivers as well. Additionally, among older adults, the IDD interventions featured family peer support and peer leaders as another way to empower and support the independence of people with disabilities. Among older adults the focus was more on adapting to new care capacities and demands as it was assumed the aging caregivers might also benefit from group interaction when the groups are led by their peers with similar lived experience. While both fields were concerned with reducing negative outcomes of caring for a family member, the IDD family support research was more likely to also examine positive outcomes such as evaluating future planning or caregivers' abilities to maintain employment. Researchers in caregiving may want to seek a similar balance when evaluating the outcomes of their interventions.

As more people are aging with and into disability, collaboration among the aging, dementia care and IDD sectors will be increasingly important. As new programs are developed, these three fields may benefit from each other's efforts. Researchers working on family support interventions for people with IDD may want to incorporate ideas from the aging and dementia care literature, with its broader history and variety of well-researched interventions. Researchers developing programs in caregiving for aging individuals may want to incorporate concepts from the field of IDD on person-centered planning for families and broaden their focus to include both negative and positive aspects in caring for a family member with a disability.

Research dedicated to understanding the course of dementia and the impact of caregiving has mostly excluded people with IDD in their samples. Inclusion of people with IDD and their caregivers into research will increase the breadth and applicability of studies as well as promote full community inclusion. In a similar vein, community organizations that provide education and services to older adults and their caregivers should make a concentrated effort to reach people with IDD and dementia.

***Recommendation 1: Better integrate community education, outreach, research, and supports for caregivers of older adults and caregivers of adults with IDD and dementia to capitalize on the strengths of both programs and promote inclusive practices.***

- a) Include people with IDD and their supporters in both generic aging and dementia studies.
- b) Document the cost of family support programs and how they benefit society and reduce the overall cost of non-family care.
- c) Acknowledge positive aspects of caregiving.
- d) Incorporate concepts such as future planning, person-centered planning, and supported decision-making in research and practice.

***Residential Services and Supports***

One housing model extant in both dementia services (van Zadelhoff et al., 2011) and those for persons with IDD (Janicki, 2011) is the use of small group homes. While most states are moving away from using this model for younger adults with IDD, some states are returning to its use for aged-care and, more prevalently, for dementia capable care. This model offers one option for alternative care in the community for persons with IDD affected by dementia,

who otherwise may be forced to seek institutional admission. As most adults in group homes for dementia may remain in the homes for up to 10 years (Janicki et al. 2005), there is a greater need for more IDD and dementia-capable group homes and research to determine best practice applications.

Existing research has compared dementia special care units (SCUs) to group homes and found that group homes tend to provide higher quality care (because they provided a home-like environment and they operated according to a therapeutic philosophy of care). In addition, costs for caregiving are more economical in group homes (Chaput, 2002; Janicki et al. 2005). As quality of life and personalization are the underlying foundations for this type of dementia care, such settings can help promote dignity, maintain reasonable levels of autonomy, and continue a relationship with the community, while providing safety and supports for physical and psychological functions.

While the use of small, neighborhood-based group homes is a complement to at-home care and an alternative to institutional care, there still remain some unknowns, which to make this a universal model applicable to all sectors, need resolution. For example, administrators often complain that funders generally did not increase the reimbursement or contract rates for the care provision of people affected by dementia, even when their decline requires more staff-intensive care. While some agencies may be able to absorb this cost differential on the short term, with an increase in the number of older adults with IDD affected by dementia, this may become a significant issue in determining whether aging-in-place and in-place- progression dementia care supports can be viable in the long term.

The research also suggests that care requirement issues arising during early stage dementia are not as problematic from a staff management perspective, but that staff involvement and staff time requirements become more important issues in the mid-stage of dementia when losses of capability and the presence of behavioral and psychological symptoms of dementia (BPSD) become more significant care issues. Understanding how the course of dementia may impact care and continued residence in a group home setting will be important to understand so that policy makers and providers can plan for how to best support people and caregivers in these situations.

**Recommendation 2: Increase research and community programming to support people with IDD and dementia living in group home settings.**

- a) Examine the benefits of dementia capable communities “Dementia friendly America” with respect to aiding families caring at home for adults with IDD.
- b) Develop and test models of residential supports that are dementia capable for both an adult with IDD and other older adults with dementia.
- c) Provide sufficient training and financial supports for dementia capable homes.
- d) Examine the degree of family caregiver supports associated with living out-of-home dementia care of adults with IDD.

***Diversity in Population***

People with IDD and dementia and their caregivers are far from a homogeneous group, and this diversity impacts caregiving and service access. The issue of caregiving in older age for people with IDD impacts all people of all ethnicities, languages, and socioeconomic classes, as

well as people living in a variety of geographic locations with vastly different resources. For example, research indicates that the majority of adults with IDD live at home with their families (Braddock, et al., 2015). For racial/ethnic/linguistic minority groups this may be even more common (Heller, Markwardt, Rowitz, & Farber, 1994; Magaña & Smith, 2006a). As a result, caregivers within minority groups are more likely to experience both the positive and negative effects of continual caregiving, especially when faced with the progression of dementia. Some research has found that Latino mothers experience less caregiver burden and stress than European-heritage mothers; however, mothers who were unable to care for their son or daughter at home experienced high levels of depressive symptoms (Magaña & Smith, 2006a; Magaña & Ghosh, 2010). Culturally in the United States, the push is for independence for adults with IDD. However, this may not fit with the cultural norms of certain minority groups, or even be feasible for some members of minority groups. Further, there is a dearth of research exploring cultural perceptions of dementia among adults with IDD and what norms exist for extended caregiving.

Most studies that examine minority caregivers have found poor health when compared to European-heritage caregivers (Blacher et al., 1997; Magaña, Seltzer, & Krauss, 2004; Miltiades & Pruchno, 2002). This includes more chronic health conditions, limitations due to health conditions, and lack of appropriate health care (Magaña & Smith 2006b; Magaña & Smith 2008). Part of the explanation for these findings may lie with the theory of *cumulative adversity* (Zarit & Pearlin, 2005). Cumulative adversity refers to any combination of three processes: 1) a chain of hardships over the life course; 2) a layering or buildup of hardship effects; and 3) a single hardship that persists over the life course. For many racial/ethnic minority families, the additional strain of providing lifelong care may be an add-on to hardships such as poverty, low education, and discrimination, creating a life-long pattern that may contribute to poor outcomes.

Diversity in geography is also an important fact to consider, as caregivers living in a rural area may experience different supports, stressors, and care aid options. A systematic review of family caregiving for older adults in rural and remote settings across the globe found low use of formal supports, gaps in services, and unmet service needs (Innes, Morgan, & Kostineuk, 2011). Other findings in this area have generally shown that rural caregivers are more likely than those in urban areas to rely on informal supports (Bedard, Koivuranta, & Stuckey, 2004; Montoro-Rodriguez, Kosloski, & Montgomery, 2003). Additional research is needed to discern whether these differences are based on cultural norms or a dearth of services in these areas and also to assess the impact of these differences on outcomes. Focus needs also to be given to the issues faced by caregivers in linguistic isolation situations.

Families who live in rural areas or are members of a minority group may have unique experiences in caregiving that are not generally captured by research and policy. To ensure support, education, and positive outcomes for these families, researchers and policy makers need to be sure to acknowledge the differences that may exist for these groups. Research needs to include all variations of extant minorities as well as people living in rural or remote settings and policy makers and service providers should focus on culturally competent, or culturally aware and sensitive, care.

**Recommendation 3: Acknowledge and respect the diversity of family values and caregiving practices.**

- a) Develop linguistic and cultural sensitivity among providers based on ethnic and cultural values and practices.
- b) Consider the special needs of families living in poverty and families not identified by the service system.
- c) Develop methods of reaching families in rural areas and those in linguistic and/or ethnic geographic groupings.

***Screening and Assessment of Dementia***

People with IDD who are aging face many of the same age-related health issues that people without disabilities face. However, they may develop health issues such as dementia at an earlier age and their initial symptom presentation may differ from that of the general population. In particular, adults with Down syndrome are likely to experience dementia at a much younger age and with greater frequency than would be expected. A systematic review over an 11-year span found a higher prevalence of dementia in persons with Down syndrome. Prevalence was 9% in those under 49 years, 5.7–10.3% for 40–49 years, 30.4–40% for 50–59 years, and 41.7–50% for 60–70 years (Strydom et al., 2010).

Additionally, adults with IDD may exhibit early symptoms of dementia which are not as easily identifiable to caregivers. One study of over 200 aging adults with IDD found functional decline such as changes in independence with daily living skills was a common early symptom often missed by caregivers and clinicians (Strydom, Livingston, King, & Hassiotis, 2007). These barriers to early clinical diagnosis; differing symptom presentation, lack of appropriate screening tools, and concerns over accuracy of informant reporting may lead to later diagnoses (Sheehan, et al., 2015). Early diagnosis is essential to ensure timely interventions such as medication for symptom management, establishing advance care plans, and psychosocial interventions for both the older adult and their caregiver. Such earlier onset of dementia and elevated need for early diagnosis may be a differentiating feature among persons with IDD.

To combat these barriers and increase timely and accurate diagnosis a push is needed to increase public awareness and improve clinical competence. Researchers have developed and tested instruments to aid in the identification of dementia symptoms in people with IDD, these include the Wolfenbütteler Dementia Test for Individuals with Intellectual Disabilities (WDTIM; Kuske, Wolff, Gövert, & Müller, 2017), and the Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID; Deb, Hare, Prior, Bhaumik, 2007). While research has shown promising results on screening in general, the level of adoption of specific screening of persons with IDD by professionals is unknown and warrants greater focus on utility and usage. With respect to screening by caregivers, the National Task Group (NTG) has developed an early detection and screening administrative instrument (the NTG-EDSD [National Task Group-Early Detection and Screening for Dementia]) that has been adopted by many agencies and jurisdictions for use by caregivers, both formal and informal (Esralew, Janicki, & Keller, 2017). Increased training for clinicians and widespread dissemination of instruments specifically applicable for people with IDD may aid in making more early diagnoses. As

caregivers and family members are often the first to notice a change in behavior (Jamieson-Craig et al., 2010), increases in public awareness regarding prevalence and early symptomatology may increase referrals for early screenings.

**Recommendation 4: Increase early screening and public awareness of dementia and other aging related issues in people with IDD and their caregivers.**

- a) Increase training for clinicians and widespread dissemination of diagnostic instruments developed specifically for people with IDD.
- b) Help families and other persons who provide support recognize the signs of dementia in people with IDD.
- c) Adopt an early detection and screening instrument for persons with IDD as part of the annual wellness visit under the Affordable Care Act.

***Bridging the Two Service Networks***

While many families and caregivers of people with IDD are familiar with the broader developmental disability service system, accessing and understanding the aging system may present challenges. The need to bridge the fields of aging and disability has been identified and outlined in The Toronto Declaration on Bridging Knowledge, Policy and Practice in Aging and Disability (Bickenbach et al., 2012). Despite many of the differences noted between the fields of aging and disability, the NTG has emphasized that adults with IDD require the same community education, and community based supports for themselves, their caregivers, and the organizations working with them as do other adults affected by dementia. For both groups, families do the majority of caregiving and need support, and both need a quality direct support workforce. Hence, in recognition of the importance of family and staff caregivers to community supports offered person with IDD and dementia, the NTG has drawn upon both on the aging and disability fields to develop practice guidelines (Bishop et al., 2015; Jokinen et al., 2013; Moran et al., 2013) and a national training curriculum (Janicki & Keller, 2014; see <http://aadmd.org/ntg/education-and-training>) to enhance caregiving understanding of dementia and strategies for continued care of people with IDD and dementia.

For both the aging and disability fields there is a growing concern about common issues, such as end of life care, abuse and neglect, residential supports, health declines, financial supports, and assistive technology needs. Hence, there are many benefits to bridging between the networks. One issue that particularly illustrates the need for collaborations across systems is the common situation for families of adults with IDD in which aging-related health issues arise for both the adult with IDD and the family members providing support (Haley & Perkins, 2004). Parents and other family members may develop aging related chronic disease and illness (including dementia) that results in caregivers undertaking multiple caregiving roles.

This scenario has been termed "*compound caregiving*" as this additional caregiving responsibility is in addition to a significant lifelong caregiving role that has lasted for decades (Perkins, 2010; Perkins & Haley, 2010). In Perkins and Haley's (2010) study, 37% of aging caregivers (mean age 61) of co-residing adult children with IDD, were also a compound

caregiver. Sixty-six percent reported they had previously been a compound caregiver, and a further 34% anticipated becoming so in the near future. In the compound caregiving recipient, dementia was the most frequent health condition (21%). Supports (if available) are not assessing the full range of caregiving needs for caregivers of adults with IDD (Williamson & Perkins, 2014).

This is of concern, as compound caregivers reported spending an average of 52 hours per week undertaking their caregiving-related tasks (Perkins & Haley, 2010). Home and Community Based Long-term Services and Supports are based on age eligibility criteria. This may result in the caregiver not having adequate support from either service system (i.e., state developmental disability services for their older child with IDD, or state aging services for their compound caregiving recipient) to fully meet the combined needs.

Some areas of development include finding programmatic solutions that allow for wrap-around supports of both the primary and compound caregiving roles, including effective respite coordination, and programs that are: a) responsive to overall caregiving needs irrespective of caregiver/care recipient age, and b) adaptable to changing caregiver status across the lifespan. For example, the National Family Caregivers Support Program (NFCSP) (OAA Title III-E) provides information and assistance, caregiver training, respite care, and caregiving related supplies to adults caring for a family member age 60 or older or a family member of any age with dementia, as well as for grandparents age 55 and older caring for grandchildren ages 18 and younger. The NFCSP may also need to adapt program offerings and materials for persons aging with lifelong and/or adult-onset of disability who serve as caregivers to aging parents or older adult spouses as well.

More work is needed in bridging aging and disability to help find solutions to this unique issue. Barriers to collaboration are many and include ideological differences that have notably hindered cross-network collaborations (Putnam & Stoeberl, 2007). Some research suggests that professionals in the field of aging do not feel adequately prepared to work with and/or meet the needs of persons aging with lifelong disabilities or individuals with early and mid-adulthood onset of disabilities (Putnam, 2011). Over the years, numerous efforts have been undertaken to develop cross-network professional and organizational capacity to support persons aging with lifelong and early and mid-onset disability (see Ansello & Rose, 1989; LePore & Janicki, 1997). However, such efforts have to be repeatedly undertaken due to constantly changing administrative, clinical, and staff cohorts. However, when implemented they are functional and productive, and greatly enhance collaboration among aging and disability service providers and advocates and help to foster bridge-building across aging, disability, and social welfare sectors (Putnam, 2014).

**Recommendation 5: Focus on the integration of the aging and developmental disability networks to provide quality continuous care.**

- a) Examine the impact of the “Perfect Storm”—an aging population, more numbers of persons with dementia, and diminution of numbers of care workers (i.e., via reductions due to changing policies on immigration).
- b) Fund more research on best practices that apply to dementia caregiving including family support models, relationship-based care, and supported decision-making.
- c) Examine how more cross-cutting collaborations can occur among the aging, dementia care, and disability sectors to address the needs of caregivers of persons with IDD and dementia.

**Recommendations**

In summary, the following are the workgroup recommendations to the National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers (See Table 1 for recommendations along with potential implementers):

- 1) Better integrate community education, outreach, research, and supports for caregivers of older adults and caregivers of adults with IDD and dementia to capitalize on the strengths of both programs and promote inclusive practices.**
  - a) Include people with IDD and their supporters in both generic aging and dementia studies.
  - b) Document the cost of family support programs and how they benefit society and reduce the overall cost of non-family care.
  - c) Acknowledge positive aspects of caregiving.
  - d) Incorporate concepts such as future planning, person-centered planning, and supported decision-making in research and practice.
- 2) Increase research and community programming to support people with IDD and dementia living in group home settings.**
  - a) Examine the benefits of dementia capable communities “Dementia friendly America” with respect to aiding families caring at home for adults with IDD.
  - b) Develop and test models of residential supports that are dementia capable for both adult with IDD and other older adults with dementia.
  - c) Provide sufficient training and financial supports for dementia capable homes.
  - d) Examine the degree of family caregiver supports associated with living out-of-home dementia care of adults with IDD.
- 3) Acknowledge and respect the diversity of family values and caregiving practices.**
  - a) Develop linguistic and cultural sensitivity among providers based on ethnic and cultural values and practices.
  - b) Consider the special needs of families living in poverty and families not identified by the service system.
  - c) Develop methods of reaching families in rural areas and those in linguistic and/or ethnic geographic groupings.

- 4) Increase early screening and public awareness of dementia and other aging related issues in people with IDD and their caregivers.**
  - a) Increase training for clinicians and widespread dissemination of diagnostic instruments developed specifically for people with IDD.
  - b) Help families and other persons who provide support recognize the signs of dementia in people with IDD.
  - c) Adopt an early detection and screening instrument for persons with IDD as part of the annual wellness visit under the Affordable Care Act.
  
- 5) Focus on the integration of the aging and developmental disability networks to provide quality continuous care.**
  - a) Examine the impact of the "Perfect Storm" - an aging population, more numbers of persons with dementia, and diminution of numbers of care workers (via reductions due to changing policies on immigration).
  - b) Fund more research on best practices that apply to dementia caregiving including family support models, relationship-based care, and supported decision-making.
  - c) Examine how more cross-cutting collaborations can occur among the aging, dementia care, and disability sectors to address the needs of caregivers of persons with IDD and dementia.

<b>Table 1 Caregiving and Intellectual and Developmental Disabilities (IDD) and Dementia: Recommendations to the NIH Summit on Dementia Care and Services Research</b>	
<b>Recommendation</b>	<b>Who Could Do It?</b>
<b>1. Better integrate community education, outreach, research, and supports for caregivers of older adults and caregivers of adults with IDD and dementia to capitalize on the strengths of both programs and promote inclusive practices.</b>	
a) Include people with IDD and their supporters in both generic aging and dementia studies	Administration on Community Living (ACL); National Institute on Health (NIH); Foundations
b) Document the cost of family support programs and how they benefit society and reduce overall cost of non-family care	ACL; NIH; Foundations
c) Acknowledge positive aspects of caregiving	ACL; Area Agencies on Aging (AAA); National provider groups
d) Incorporate concepts such as future planning, person-centered planning, and supported decision-making in research and practice	ACL; AAA; National provider groups, State developmental disabilities authorities
<b>2. Increase research and community programming to support people with IDD and dementia living in group home settings.</b>	
a) Examine the benefits of dementia capable communities "Dementia friendly America" with respect to aiding families caring at home for adults with IDD	ACL; Assistant Secretary for Planning and Evaluation (ASPE)
b) Develop and test models of residential supports that are dementia capable for both adults with IDD and other older adults with dementia	NIH; ACL; Centers for Medicare and Medicaid Services (CMS)
c) Provide sufficient training and financial supports for dementia capable homes	CMS; AAA; State developmental disabilities authorities
d) Examine the degree of family caregiver supports associated with living out-of-home dementia care of adults with IDD	ACL
<b>3. Acknowledge and respect the diversity of family values and caregiving practices.</b>	
a) Develop linguistic and cultural sensitivity among providers based on ethnic and cultural values and practices	ACL; National provider groups; Professional organizations; Caregiver associations
b) Consider the special needs of families living in poverty and families not identified by the service system	State Units on Aging (SUAs); State developmental disabilities authorities
c) Develop methods of reaching families in rural areas and those in linguistic and/or ethnic geographic groupings	ACL; CMS

Recommendation	Who Could Do It?
<b>4. Increase early screening and public awareness of dementia and other aging related issues in people with IDD and their caregivers.</b>	
a) Increase training for clinicians and widespread dissemination of diagnostic instruments developed specifically for people with IDD	CMS; Health Resources and Services Administration (HRSA); American Psychological Associations; American Association on Intellectual and Developmental Disabilities; Geriatric Workforce Education Programs (GWEPs); National Task Group on Intellectual Disabilities and Dementia
b) Help families and other persons who provide support recognize the signs of dementia in people with IDD	ACL; GWEPs; AAA; SUAs; State developmental disabilities authorities
c) Adopt an early detection and screening instrument for persons with IDD as part of the annual wellness visit under the Affordable Care Act.	CMS
<b>5. Focus on the integration of the aging and developmental disability networks to provide quality continuous care.</b>	
a) Examine the impact of the "Perfect Storm" - an aging population, more numbers of persons with dementia, and diminution of numbers of care workers (via reductions due to changing policies on immigration)	NIH; ACL; Centers for Disease Control and Prevention (CDC)
b) Fund more research on best practices that apply to dementia caregiving including family support models, relationship-based care, and supported decision-making	NIH; ACL; Foundations
c) Examine how more cross-cutting collaborations can occur among the aging, dementia care, and disability sectors to address the needs of caregivers of persons with IDD and dementia	ACL; SUAs; State developmental disabilities authorities

ACL: Administration on Community Living; CDC: Centers for Disease Control and Prevention; CMS: Centers for Medicare and Medicaid Services; GWEPs: Geriatric Workforce Education Programs; NIH: National Institute of Health; SUAs: State Units on Aging

## References

- Alliance, F. C. (2016). Caregiver statistics: Demographics. Retrieved January, 15, 2017.
- Ansello, E.F., & Rose, T. (1987). Aging and lifelong disabilities: Partnership for the twenty-first century (The Wingspread Conference Report). College Park: University of Maryland.
- Bedard, M., Koivuranta, A., & Stuckey, A. (2004). Health impact on caregivers of providing informal care to a cognitively impaired older adult: Rural versus urban settings. *Canadian Journal of Rural Medicine*, 9(1), 15-23.
- Bickenbach, J., Bigby, C., Salvador-Carulla, L., Heller, T., Leonardi, M., LeRoy, B., ... & Spindel, A. (2012). The Toronto declaration on bridging knowledge, policy & practice in aging & disability. *International Journal of Integrated Care*, 12(8).
- Bishop, K. M., Hogan, M., Janicki, M. P., Keller, S. M., Lucchino, R., Mughal, D. T., . . . Wolfson, S. (2015). Guidelines for Dementia-Related Health Advocacy for Adults With Intellectual Disability and Dementia: National Task Group on Intellectual Disabilities and Dementia Practices. *Intellectual and Developmental Disabilities*, 53(1), 2-29.
- Blacher, J., Shapiro, J., Lopez, S., Diaz, L., & Fusco, J. (1997). Depression in Latina mothers of children with mental retardation: A neglected concern. *American Journal on Mental Retardation*, 101, 483-496.
- Braddock, D. Hemp, R., Rizzolo, M., Tanis, E., Haffer, L., ...Wu, J. (2013). State of the States in Developmental Disabilities 2013. American Association on Intellectual and Developmental Disabilities, Washington DC.
- Braddock, D., Hemp, R., Rizzolo, M.C., Tanis, E. S., Haffer, L., & Wu, J. (2015). *The State of the States in Intellectual and Developmental Disabilities: Emerging from the Great Recession*. Washington, DC: American Association on Intellectual and Developmental Disabilities.
- Chaput, J. L. (2002). Adults with Down syndrome and Alzheimer's disease: Comparison of services received in group homes and in special care units. *Journal of Gerontological Social Work*, 38(1/2), 197-211.
- Deb S., Hare M., Prior L. & Bhaumik S. (2007b) Dementia Screening Questionnaire for Individuals with Intellectual Disabilities. *British Journal of Psychiatry*190, 440-444.
- Esralew, L., Janicki, M.P., & Keller, S.M. (2017). National Task Group Early Detection Screen for Dementia (NTG-EDSD). In V. Prasher (Ed.), *Neuropsychological assessments of dementia in Down syndrome and intellectual disabilities*. Basel, Switzerland: Springer.
- Haley, W. E., & Perkins, E. A. (2004). Current status and future directions in family caregiving and aging people with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 1(1), 24-30.
- Heller, T., Gibbons, H. M., & Fisher, D. (2015). Caregiving and family support interventions: Crossing networks of aging and developmental disabilities. *Intellectual and developmental disabilities*, 53(5), 329-345.
- Heller, T. & Kramer, J. (2009). Involvement of adult siblings of persons with developmental disabilities in future planning. *Intellectual and Developmental Disabilities*, 47(3), 208-219.
- Heller, T., Markwardt, R., Rowitz, L., & Farber, B. (1994). Adaptation of Hispanic families to a member with mental retardation. *American Journal of Mental Retardation*, 99, 289-300.
- Innes, A., Morgan, D., & Kostineuk, J. (2011). Dementia care in rural and remote settings: a systematic review of informal/family caregiving. *Maturitas*, 68(1), 34-46.
- Janicki, M.P., (2011). Quality outcomes in group home dementia care for adults with intellectual disabilities. *Journal of Intellectual Disability Research*, 55(8), 763-776.
- Janicki, M. P., & Dalton, A. J. (2000). Prevalence of dementia and impact on intellectual disability services. *Mental Retardation*, 38(3), 276-288.
- Jamieson-Craig, R., Scior, K., Chan, T., Fenton, C. & Strydom, A. (2010). Reliance on carer reports of early symptoms of dementia among adults with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 7(1), 34-41.
- Janicki M. P., Dalton A. J., McCallion P., Davies Baxley D. & Zendell, A. (2005). Group home care for adults with intellectual disabilities and Alzheimer's disease. *Dementia* 4, 361-85.
- Janicki, M.P., & Keller, S.M. (2014). Viability of a dementia advocacy effort for adults with intellectual disability: Using a national task group approach. *Journal of Policy and Practice in Intellectual Disabilities*, 12(3), 176-191.

- Jokinen, N., Janicki, M. P., Keller, S. M., McCallion, P., Force, L. T., & National Task Group on Intellectual Disabilities and Dementia Care Practices. (2013). Guidelines for structuring community care and supports for people with intellectual disabilities affected by dementia. *Journal of Policy and Practice in Intellectual Disabilities, 10*(1), 1-24.
- Jokinen, N. S. (2016). Aging parents. In I. L. Rubin, J. Merrick, D. E. Greydanus & D. R. Patel (Eds.), *Health care for people with intellectual and developmental disabilities across the lifespan* (First ed., pp. 79-84). Switzerland Springer International.
- Jokinen, N., Gomiero, T., Hogan, M., Larsen, L., Beránková, A., Santos, F.H., Watchman, K., Janicki, M.P., & Crowm J. (2017). Perspectives on family caregiving of aging people with intellectual disability affected by dementia: Commentary from the International Summit on Intellectual Disability and Dementia. Stirling, Scotland: University of Stirling.
- Kuske, B., Wolff, C., Gövert, U., & Müller, S. V. (2017). Early detection of dementia in people with an intellectual disability—A German pilot study. *Journal of Applied Research in Intellectual Disabilities.*
- LePore, P., & Janicki, M.P. (1997). *The wit to win: How to integrate older persons with developmental disabilities into community aging programs* (3<sup>rd</sup> Ed.). Albany: New York State Office for the Aging.
- Magaña S. & Ghosh, S. (2010). Latina mothers caring for a son or daughter with autism or schizophrenia: Similarities, differences and the relationship between co-residency and maternal well-being. *Journal of Family and Social Work, 13*, 227-250.
- Magaña, S., Li, H., Miranda, E., & Paradiso, R. (2015) Improving health behaviors of Latina mothers of youths and adults with intellectual and developmental disabilities. *Journal of Intellectual Disability Research, 59*, 397-410.
- Magaña, S., Seltzer, M., & Krauss, W. (2004). The cultural context of caregiving: Differences in well-being between Puerto Rican and non-Latina White mothers of adults with mental retardation. *Mental Retardation, 42*, 1-11.
- Magaña, S., & Smith, M.J. (2006a). Psychological distress and well-being of Latina and non-Latina white mothers of youth and adults with an autism spectrum disorder: Cultural attitudes towards co-residence status. *American Journal of Orthopsychiatry, 76*, 346-357.
- Magaña, S., & Smith, M.J. (2006b). Health outcomes of mid-life and aging Latina and Black American mothers of children with developmental disabilities. *Mental Retardation, 44*, 224-234.
- Magaña, S. & Smith, M. (2008). Health behaviors, service utilization and access to care among older mothers of color who have children with developmental disabilities. *Intellectual and Developmental Disabilities, 46*, 267-280.
- Miltiades, H.B., & Pruchno, R. (2002). The effect of religious coping on caregiving appraisals of mothers of adults with developmental disabilities. *The Gerontologist, 42*, 82-91.
- Montoro-Rodriguez, J., Kosloski, K., & Montgomery, R. (2003). Evaluating a practice-oriented service model to increase the use of respite services among minorities and rural caregivers. *The Gerontologist, 43*(6), 916-924.
- Moran J.A., Rafii, M.S., Keller, S.M., Singh, B.K., & Janicki, M.P. (2013). The National Task Group on Intellectual Disabilities and Dementia Practices consensus recommendations for the evaluation and management of dementia in adults with intellectual disabilities. *Mayo Clinic Proceedings, 88*(8), 831-840.
- NDSS. (2013). *Aging and Down syndrome: A health & well-being guidebook*. Washington, DC: National Down Syndrome Society.
- NDSS. (2017). *Alzheimer's and Down syndrome*. Washington, DC: National Down Syndrome Society.
- Perkins, E. A. (2010). The compound caregiver: a case study in multiple caregiving roles. *Clinical Gerontologist, 33*(3), 248-254.
- Perkins, E. A., & Haley, W. E. (2010). Compound caregiving: When lifelong caregivers undertake additional caregiving roles. *Rehabilitation Psychology, 55*(4), 409-417.
- Putnam, M. (2011). Perceptions of difference between aging and disability service systems consumers: Implications for policy initiatives to rebalance long-term care. *Journal of Gerontological Social Work, 54*(3), 325-342.
- Putnam, M. (2014). Bridging network divides: Building capacity to support aging with disability populations. *Disability and Health Journal, 7*, S51-S59.

- Putnam, M., & Stoeber, A. (2007). Facilitators and barriers to crossing network lines: A Missouri case study. In M. Putnam (Ed.), *Aging and disability: Crossing network lines*. (pp. 19-54). New York, NY: Springer Publishing Company.
- Sheehan, R., Sinal, A., Bass, N., Blatchford, P., Bohnen, I., Bonell, S., ... & Mukherji, K. (2015). Dementia diagnostic criteria in Down syndrome. *International journal of geriatric psychiatry*, 30(8), 857-863.
- Strydom, A., Livingston, G., King, M., & Hassiotis, A. (2007). Prevalence of dementia in intellectual disability using different diagnostic criteria. *The British Journal of Psychiatry*, 191(2), 150-157.
- Strydom, A., Shooshtari, S., Lee, L., Raykar, V., Torr, J., Tsiouris, J. et al. (2010) Dementia in older adults with intellectual disabilities – epidemiology, presentation, and diagnosis. *Journal of Policy and Practice in Intellectual Disabilities* 7, 85–154.
- Rocha, J., & Magaña, S. (2016, January). *Predictors of depression in Latina mothers of youth and adults with intellectual and developmental disabilities: An overview of baseline data for a health promotion intervention*. Paper presented at the Annual Conference of the Society for Social Work Research (SSWR), Washington, DC.
- US Administration on Aging. (2016). *Aging statistics*. Accessed from: [https://aoa.acl.gov/Aging\\_Statistics/index.aspx](https://aoa.acl.gov/Aging_Statistics/index.aspx)
- van Zadelhoff, E., Verbeek, H., Widdershoven, G., van Rossum, E., & Abma, T. (2011). Good care in group home living for people with dementia. Experiences of residents, family and nursing staff. *Journal of Clinical Nursing*, 20 (17/18), 2490-2500.
- Williamson, H. J., & Perkins, E. A. (2014). Family caregivers of adults with intellectual and developmental disabilities: Caregiver outcomes associated with U.S. services and supports. *Intellectual and Developmental Disabilities*, 52(2), 147-159.
- Zarit, S.H., & Pearlin, L.I. (2005) Special issue on health inequalities across the life course. *Journal of Gerontology: Social Sciences*, 60B, 5-14.

**Prepared Statement of Eric Meyer, LCSW, MBA, President and Chief  
Executive Officer, Spurwink Services**

Chairman Collins, Ranking Member Casey, and distinguished members of the Senate Special Committee on Aging. Thank you for the opportunity to testify today. I am Eric Meyer, President and CEO, of Spurwink Services in Portland, Maine.

Long before the closure of Maine's only institution for individuals with intellectual disabilities, Spurwink recognized the importance of connection to community, and began providing integrated services outside the confines of segregated institutions for people with Intellectual and Developmental Disabilities (IDD).

Spurwink began with one house serving eight boys on Riverside Street in Portland in 1960. The developmental needs of the boys could not be met at home or in public school, and the roots of Spurwink were planted. Today Spurwink serves 8,300 people each year through the good work of more than 900 employees throughout the state. Spurwink's mission and vision remain the same: providing exceptional and evidence-based behavioral health and education services for children, adults, and families with disabilities so that they can lead healthy, engaged lives in our communities. Whether it's a preschooler with autism in Saco, a teen with a trauma history in Skowhegan, or an adult with intellectual disabilities in Portland, Spurwink's clients are offered dignity, respect and a chance to build a better future.

We offer special education schools and residential programs in four hubs across the state for children and youth; residential programs for adults with developmental disabilities in southern Maine; and a wide array of outpatient clinical services and supports in homes, public schools, primary care offices, and in the community. At Spurwink our therapeutic model is built on preparing young people with disabilities for a successful transition into adulthood, and for adults with disabilities to live healthy, engaged lives in the community. Our person-centered planning model is driven by the client and their family—creating individualized goals, planning with their team where they'll live, the type of work to pursue—all informing the supports our team will provide to help them meet their goals. It is not about Spurwink doing something to or for our clients—it is about Spurwink supporting clients to meet these goals. People with disabilities can and do work, and we believe it is not only the role of Spurwink, but of our country, to support adults with IDD to live meaningful and productive lives in the community.

How do we do this? Through an array of services that help support people with IDD in the community. We serve many young people who are on the cusp of adulthood. They attend our schools, live in our residences, and see our clinicians. But the reality is that between the ages of 18 and 21, many will age out of the safety and security offered at Spurwink. Resources for adult behavioral health care in Maine have been greatly reduced. We have responded to that gap by working hard to prepare students for a successful transition to adulthood. It involves:

- Education, including a high school diploma, GED or college prep;
- Therapy and supports to address developmental challenges, promoting family, friends and community connections;
- Practical life skills such as budgeting, healthy eating habits, and self-care; and
- Pre-vocational training to prepare to be a productive, independent member of the Maine workforce.

While few of our clients go on to higher education, many benefit from learning a trade or skill. Our small engine repair program based at our Chelsea campus gives students an opportunity to work on tractor motors, small boat engines, and snow blowers for local neighbors and businesses. In this experiential learning setting, students learn not only practical skills in small engine repair, but about responsibility, perseverance, patience, and cooperative work. They build confidence in themselves, and that confidence translates to all parts of their lives.

Riley, one of our former students with autism in Portland, started his career journey at in-house school jobs, moving on to community-based training folding laundry at The Cedar's Nursing Home, shelving and alphabetizing books at the Falmouth Library, and preparing orders for distribution at Planet Dog Warehouse. After graduation he successfully worked in the warehouse at Micucci's Wholesale Foods, Inc. His parents shared, "The Spurwink vocational program exposed our son to a range of work environments and responsibilities with the full support of a job coach, which was not available in our public school. He was able to build work skills and confidence thanks to the Spurwink vocational team's experience."

Spurwink does not receive state or federal funding for these pre-vocational programs, yet we are committed to making them available. We believe that it is absolutely crucial that students leave Spurwink with the skills and experience needed to lead healthy and productive lives.

We also believe that makes good economic sense for the State of Maine. It's no secret that recruitment and retention of employees is a major priority area for Maine businesses, Spurwink included. We are the oldest state in the nation and need to ensure our businesses grow. We do this by preparing our young people to join the workforce and offering them appropriate training, which is crucial to economic development in our State. Young people who are employed in appropriate work are more stable financially and less likely to require additional economic supports in adulthood.

Our adult programs support the principle of "aging in place", ensuring that adults with disabilities age in the community safely, comfortably, and as independently as possible. As mentioned earlier, this is particularly poignant given that a sizable portion of the older adult population we serve were at one time residents of the Pineland Center, where people with disabilities were institutionalized in Maine until the early 1990's. We in Maine are proud to now have community options for adults with intellectual disabilities, and Spurwink and other agencies in the state continue to focus on supporting individual needs and desires so that the pendulum of care never swings back to large institutional settings, like Maine's Pineland Center, once housing 1,700 people.

For our adult population, ages 18 to 84, Spurwink provides residential and community supports. Key to our services is solid social support, a home to live in, and having meaningful activities and work. We believe in the importance of self-determination, individual choice, and the dignity of work. Our aim is to increase or maintain an individual's ability to be a successful, contributing, and accepted member of the community. This includes access to continuing education and/or meaningful employment, a place to call home, robust community involvement, and other components of a meaningful life. Without this, there is no community integration. Our services include:

- Community case management providing advocacy and support to help individuals achieve their goals.
- Residential services where caring and committed staff provide support services within a home, helping individuals engage in their communities, develop social relationships, learn daily living and personal care skills such as shopping, doing laundry, cooking and planning menus.
- Community supports that develop life skills and increase opportunities for community involvement.
- And, where employment is the goal, partnering with local agencies and businesses to provide employment supports that help people find and maintain work to move them toward greater independence.

Employment should be an option for all who want to, and can work, and it is never too late to open this door. Robert, 57, has a mild intellectual disability and mental health challenges. He spent many years in a group home setting, and had dabbled in employment, but intrusive thoughts and lack of focus always led to dismissal. Many thought his unrealistic expectations would get in the way of his workforce success. Robert made the decision to move into a Spurwink shared living home. In this new home he began to thrive and developed a stronger sense of self-advocacy. He decided to try employment again, and for months now, he has been working several hours a week, stocking coolers at a small store. He has done his job well, often offering customers anecdotal comments about the additives of certain carbonated beverages. Despite unsuccessful attempts at employment in the past, he is now considered a valued employee, connected to his community, and a boon to his self-esteem. Let's work together to make community integration, and employment, for people with disabilities the norm in the United States; for people with disabilities, for the strength of our economy, and for the vitality of our communities.

Thank you again for this opportunity to testify. I look forward to your questions.

**Prepared Statement of Jeff Smith, Senior Mail Clerk, Arkema, King of Prussia, Pennsylvania**

Good afternoon. My name is Jeff Smith, I am 63 years old and live in the Philadelphia suburbs. I am excited to be here today to tell you about me. Thank you to Chairman Collins, Ranking Member Casey, and the Special Committee on Aging for inviting me.

My mother is 94 years old and she couldn't come with me today to Washington, but I know she is watching me on TV! I have a brother named Tat who lives in Toronto and a sister named Carol who lives in New Mexico and they also could not come. I have a fiance in Philadelphia named Phyllis. She is here with me today, and so are Stacy Levitan and Dave Mytych from JCHAI, Judith Creed Horizons for Achieving Independence, which helps over 130 people with disabilities like me to live independently.

I have worked at Arkema for 39—almost 40—years delivering the mail as a Senior Mail Clerk. I have my own apartment where I live by myself and I do not need help from my mother or my family.

I get help once a week from Dave Mytych, my social worker, who works at JCHAI. JCHAI helps me to be independent and has changed my life. JCHAI helps me feel more positive about life because they help me have more friends and I see how happy everyone else is. Everyone I know has changed because of the help they get from JCHAI. JCHAI helps me with shopping, keeping my apartment clean, and cooking. Dave was a cook before and he helped me cook fish. We are going to try a new recipe next time that he says will make the fish taste even better!

Because of JCHAI, it's a whole new way of life. I am treated better by everyone at work and in my life and it's because I am so happy.

I am very proud that I have been able to work at Arkema for all of these years. Working at Arkema is great because I love delivering the mail. I go to a lot of different places, all over our campus which is one square mile. I get to do a lot of walking, which clears my mind and I can think of different ways that I can help the world. I like to meet different people at work and from all over the world, like from Japan, Korea, Vietnam, and China. I also have a lot of friends since I have been working there so long. I even have some friends who have been there almost as long as I have.

I like that I have my own salary that lets me go to the laundromat, the market, and I can take Phyllis on dates or trips with JCHAI. Sometimes, we even go out of state on some of the trips, like to New Hampshire, Connecticut, and Massachusetts. All over the eastern seaboard!

One of the things I like to do in my free time is work on my rock collection, which I have gotten rocks for in Colorado, Pennsylvania, Texas, and Arizona. I especially like quartz. The rocks give me a neat feeling when I look at them. I also collect coins from all over the world. I get them from change that I get when I buy things and sometimes I go to coin shops in Philadelphia and get coins there. Even the Natural Science Museum helps me. I can afford to do all these things because I have my own money that I earn from my job.

Having my own job and support from JCHAI means that my mother doesn't have to worry about me anymore. She knows that I do great on my own! And if I need help, I don't have to get it from her—I know who to call, which is Dave and the people at JCHAI.

Getting older is really just part of life—it's an interesting facet of life. When I was 30, I thought, "I have so many more years of my life!" Now I can look back and say that's gone, but I'm still working hard, making a living, I still have friends, I have help with everything I need, and it's really a tribute to how good life is.

In the future, I will retire when I'm 66 because I will have a full pension and I will be able to live on that. When I retire, Phyllis and I will be able to spend a lot of time together and we'll live our own life. We'll do a lot of things with each other—we'll go on trips and go around together. We like to go to the movies, out to dinner, lunch, and breakfast. We go all over Philadelphia. I am looking forward to the next part of my life.

Thank you for letting me talk to you today.



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**Additional Statements for the Record**

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### Statement of Sara Weir, President, National Down Syndrome Society

Chairwoman Collins, Ranking Member Casey and Members of the Committee, on behalf of the National Down Syndrome Society (NDSS), the leading human rights organization for all individuals with Down syndrome, I appreciate the opportunity to submit this written Statement on barriers that limit opportunities for individuals with Down syndrome to work in meaningful and competitive employment settings.

First, I want to commend Senators Casey and Burr for their leadership in bringing about enactment of the Stephen Beck Jr. Achieving a Better Life Experience (ABLE) Act of 2014 (Public Law 113–295). This was the most significant legislation since the Americans with Disabilities Act was signed into law over 27 years ago to reduce barriers to opportunity, participation, independent living and economic self-sufficiency for people with disabilities. It does so by allowing individuals with disabilities to save money in tax-free savings accounts without it counting toward the assets limitations required to remain eligible for critical government supports. Today, 28 states and the District of Columbia have launched ABLE programs, and 49 states have enacted implementing legislation.

The ABLE Act created a solid foundation for our community to build on as we work to eliminate additional legal and non-legal barriers to the hiring, placement and advancement of individuals with Down syndrome in the workforce. Those barriers include the asset limitations of Medicaid and SSI, a Section 14(c) subminimum wage program that lacks transparency and doesn't facilitate a transition to competitive integrated employment (CIE), home and community based services that vary widely by State, and an employer community that lacks information about the value, productivity and workplace engagement benefits of employing people with disabilities.

NDSS is also doing its part to break down barriers to employment for people with disabilities. In March 2016, we launched a new employment campaign for people with Down syndrome—#DSWORKS™—which is focused on developing employment resources for employers, families, self-advocates and local Down syndrome organizations; advancing a comprehensive federal and state legislative agenda that breaks down barriers to employment and creates incentives to hire individuals with Down syndrome; and launching a NDSS corporate roundtable of corporations committed to hiring individuals with Down syndrome.

Earlier this month, NDSS launched a campaign entitled “Law Syndrome,”<sup>1</sup> which seeks to address outdated laws that discourage all people with Down syndrome from fulfilling their potential. As part of the campaign, we call on Congress to advance a legislative agenda that focuses on the following key employment principles:

1. *Right to Real Jobs for Real Wages*—Individuals with Down syndrome have the right to pursue the full range of employment options that align with their talents, skills and interests and to earn at least the minimum wage for their work.

2. *Presume Competence*—Individuals with Down syndrome can be competitively employed or self-employed, and should be given access to services and supports necessary to succeed in the workplace.

3. *Presume Full Integration*—Employees with Down syndrome should be fully integrated physically, functionally and socially in the workplace, and given the necessary supports for success.

4. *Empower Informed Choice*—Individuals with Down syndrome should be given accurate, up-to-date information regarding their options related to employment and about the potential impact of employment on their quality of life.

5. *Engage Employers*—Employers should recognize the value of employees with Down syndrome as an integral part of their workforce and include all people within recruitment and hiring efforts.

We are excited to be able to work with a new bipartisan working group<sup>2</sup> in the House of Representatives that is focused on developing bipartisan legislation to help tackle archaic, outdated laws that continue to prevent individuals with disabilities from seeking out meaningful, competitive employment opportunities while maintaining and improving access to high quality benefits like Medicaid. The working group is being led by Representatives Cathy McMorris Rodgers (R-WA), Jim Clyburn (D-SC), Joe Crowley (D-NY), Gregg Harper (R-MS) and Tony Cardenas (D-CA).

Finally, we urge all Senators to support the ABLE to Work Act (S. 818), sponsored by Senators Richard Burr and Bob Casey. This legislation promotes employment for people with disabilities by allowing ABLE beneficiaries who work and earn income, but do not participate in an employer's retirement plan, to save additional amounts

<sup>1</sup> See [www.lawsyndrome.org](http://www.lawsyndrome.org).

<sup>2</sup> See <https://www.gop.gov/working-group-employing-people-with-disabilities/>.

in their ABLE accounts up to the federal poverty level (currently \$12,060) in addition to the \$14,000 annual maximum contribution. Beneficiaries would also be eligible for the Saver's Credit, an existing federal tax credit that low and middle-income individuals can currently claim when they make contributions to a retirement account. The legislation is needed because the ABLE Act's current \$14,000 annual contribution cap does not sufficiently incentivize employment since it is the aggregate of all contributions to the ABLE account (including earned income), and employed beneficiaries are still unable to contribute to employer-provided retirement accounts, such as 401(k) plans.

Thank you for the committee's leadership in studying this important issue. NDSS welcomes the opportunity to work with you to advance meaningful employment policies for people with disabilities.

