

## Presidential Address, 2014—Embracing Complexity: Community Inclusion, Participation, and Citizenship

Amy Hewitt, President, 2014-2015

### Introduction and Background

A couple of years ago, Mike Wehmeyer set a new precedent by issuing the presidential address at the beginning of his term, rather than at the end. So, thank you Mike for establishing this tradition—I am sure that I will like it more in about 30 minutes—and thanks to all of you, who stayed to the end of the conference, for the opportunity to speak to you this afternoon to deliver my presidential address, *Embracing Complexity: Community Inclusion, Participation, and Citizenship*, and to serve your organization in a leadership role. It is such an honor to be here today among so many people that I consider esteemed colleagues and dear friends. I am certainly humbled by this opportunity and, frankly, a little intimidated to be speaking to a group of such distinguished leaders in the field of intellectual and developmental disabilities (IDD).

My path to the American Association on Intellectual and Developmental Disabilities (AAIDD) was pretty simple. I was working for a provider organization and one of my colleagues came back from an AAIDD Minnesota meeting and mentioned planning the upcoming state conference. I told her that sounded interesting, and she invited me to the next meeting. I have been involved since that time and have always found AAIDD to be my professional home because of its multidisciplinary focus on IDD. My path to this organization should be a reminder to all of you that all it takes is a simple invitation and people respond and become engaged. I urge each of you to invite at least one of your colleagues or friends to join AAIDD.

As a good steward of the role of incoming president of this organization and this task of putting together these thoughts, I did my homework. Thanks to Maggie Nygren's help, I was able to read presidential speeches in every decade since this organization began. I started with 1894 and ended by reading every speech that I have listened to in the 20+ years I have been a member. My

purpose for this task was to understand a bit of AAIDD history and to look for trends and themes that relate to the topic of my address, *Embracing Complexity: Community Inclusion, Participation, and Citizenship*.

I can unequivocally report to you that this organization has been wrestling with these issues since its beginning; certainly in different time periods and contexts but, at the root, very similar issues. In preparing, I also consulted with living past presidents of the association to learn from them what they perceived as the most complex issues we face in the contemporary field. Now, I have to admit, part of this exercise was to validate that I was not way off base in the complexities I thought existed and planned to include in my address. To my surprise, nearly all of the living past presidents who responded to my request had remarkably similar ideas about the complexities we face, and, luckily for me, I was not way off base.

Most importantly, as I prepared, I reflected on and consulted with the people with whom I have worked and learned from throughout my career who live with disabilities. Their voices and our shared experiences will certainly be heard throughout my remarks.

Lastly, I consulted with the *Merriam-Webster* dictionary to ensure that I had a clear understanding of the words I selected for the conference theme. I was initially a bit overwhelmed and stunned at the amount of advertising that was occurring as I was consulting the online dictionary, and I was simultaneously fascinated by how this advertising changed depending on the word I was searching for. It is truly fascinating. This complex marketing was a lesson for me in the remarkable changes that have occurred in our culture since I have been a member of this association and a lesson in the power of marketing and advertising. However, as a quick reminder, or perhaps as a mini-lesson to you, here's what *Merriam-Webster* had to say about the conference theme.

## Conference Theme Defined

According to *Merriam-Webster*, complexity is really the state of not being simple or, conversely, the state of being complex, which is something that is complicated or hard to understand. I asked myself if I really thought that what has evolved to be the community living services and support system for people with IDD in the United States is complex, complicated, and hard to understand. Without question, the answer to this is, YES, through my lens and the lenses of the people with disabilities and their families that I know.

Inclusion is the act of including or to be included. However, this definition also discusses the relationship between two classes, where all members of both are included. I was surprised to discover that in the dictionary I consulted, the definition of inclusion also defines this word as the practice of students with disabilities being included in regular school classes. To me, this is evidence of how we use words in this field and how, over time, these words result in changed meanings or definitions of the original word.

Participation is about being involved in and being related to a larger whole, as defined in *Merriam-Webster*. In the context of community living, participation is about participating in communities in ways that others do.

Lastly, citizenship is about being a citizen, having membership in a community, and the quality of a person's response to that membership (as defined in *Merriam-Webster*). In selecting the conference theme, I knew that there needed to be a colon (because there is always a colon in such titles), but I struggled with the words that would follow the colon. In this field, we often use the words inclusion, participation, and citizenship interchangeably. We also use them collectively when referring to people with IDD having full, rich lives of their choice in the community. Separately they do have different meanings. Collectively, I think they represent an overarching and often-promised goal of quality community living.

## Complexities in the Field of Intellectual and Developmental Disabilities

There is limited time to address all of the complexities that have evolved in this field; the issues are simply too complex. As a researcher, mentor, and family member, I often find myself responding to questions asked of me by saying

things like, “it’s complicated,” “the system is complex,” or “the answer is too complex for the time we have.” Even simple questions, such as where people live, where they work, and how much money we spend on services, have an incredibly complex answer. I want to share a few complexities in areas of importance to me that relate to community living, and I am hopeful that they are of interest to you as well.

As you are reviewing these complexities, please contemplate with me how we should handle them moving forward: Should we embrace them, navigate through them, or bypass them and move on to something new?

## Community Living

Everything about services and supports to people with IDD is about community living. Community living has become a complex and evolving construct in this field. What once simply meant “not living in an institution” or “living in the community” now has different meaning and new contexts. We know more; we have learned and evolved our thinking. Community living is now viewed as people: 1) living where and with whom they choose; 2) working in real jobs of their choice and earning real wages; 3) practicing faiths of their choice; 4) being connected to an array of friends and family with whom they have deep personal and intimate relationships; 5) growing and developing personally through opportunities for education and life-long learning; 6) exploring areas of personal interest; 7) having membership in community organizations; 8) making choices, taking risks, and determining the course of their own lives; and 9) accepting the responsibilities of citizenship (such as paying taxes and voting).

The desire for community living is virtually the same for all citizens. However, the complexity of community living comes from the reality that each person lives differently in the community. We all live and participate in different contexts and we view life through a variety of cultural and linguistic lenses. Community living and participation for people with IDD is influenced by many factors: first and foremost by whom they are as a human being and by whom they define as their family and close circle of friends.

It is also influenced by the availability and competence of those individuals who provide the

services and supports necessary for people to participate in their communities and by the policies and service delivery systems that pay for and offer these supports. These factors of the quality of staff and the policies that drive the availability and type of funding seem to determine life in the community for far too many people with disabilities.

### Services

The policies and services that have evolved over the past 30 years have resulted in a complex service maze, one that is increasingly difficult, if not impossible, for individuals and families to navigate. Table 1 provides a sampling, by no means a complete list, of terms that are used in our field. These terms often represent services or the language used within services and supports. These systems are so complex that many states have or are developing new services called “systems navigation.” These services are designed to provide skilled people, whose sole purpose is to help people navigate the complex maze we’ve created.

### Language

The developmental disabilities system we’ve created is so complex that it even has its own language. How many of you provide the individuals and families you support, students you teach, or workers you employ with a list of acronyms or a list of terms with their definitions? These lists are growing, not shrinking.

As we expand service types, change rules, and expand our repertoire of interventions, our unique vocabulary grows and morphs into new words. Additionally, states are moving toward what I call “Big D” systems, in which policy decisions and service development for long-term services and supports are managed in cross-sector environments for all people with all types of disabilities. This makes it necessary for people who work in the field and people who receive services to understand even more words and their nuanced meanings. I know that, in Minnesota, I have spent countless hours trying to negotiate new words or new definitions for concepts like positive behavior support and person-centered

Table 1  
*Complex Maze: A Sample of Many Services to Navigate*

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Case Management	Adult Care Home Penalties
Service Navigation	Nursing Home Relocation
Elderly Waiver	Assistive Technology
Shared Living	Brain Injury Waiver
Sheltered Work	At-Risk Case Management
Habilitation Training	Alternative Care
Support Coordination	Special Education
Respite Care	Early Intensive Behavior Intervention
Alternative Care Waiver	Community Mental Health
Supported Living	Client Assistance Program
Waiver Services	Relay Services
Foster Care	Occupational Therapy
Community Alternatives Waiver	Community Alternative Care Waiver
Intermediate Care Facility	Consumer-Directed Supports
Adapted Recreation	Day Training and Habilitation
Positive Behavior Supports	Vocational Training
Crisis Intervention	Counseling Services
Financial Support	Social Skills Training
Peer Counseling	Physical Therapy
Person-Centered Planning	Independent Living
Communication Skills	Home and Community-Based Services
Information and Referral	Individual Advocacy
Personal Assistance	Home Health
Housing Access Services	

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planning, so they can be embraced by and used in mental health and aging services.

I sometimes wonder: Is creating new words and definitions that expand our already complicated and separate language really helpful? Does it bring us any closer to supporting people by helping them get what they really want out of life? Nonetheless, this complex language exists today (see Figure 1 for examples) and the related complex services also exist and provide services to a lot of people.

### Geography

One of the most significant contributors to the complexity of the service system in the United States is that we have 50 states, the District of Columbia, and five territories. We also have 3,069 counties (National Association of Counties, 2014; see Figure 2).

Time and again, in studies we've done at the Research and Training Center on Community Living, University of Minnesota, the single biggest predictor of availability, access, and outcomes of services or interventions is geography. The state, county, and city in which a person lives have a significant influence on the type and quality of services they receive.

### Employment

We know that people with IDD want jobs; they want to earn money.

What I want most out of life is to be able to have a good paying job. (Nathan Perry, Self-Advocate)

We have built quite a system of support to people with disabilities who want jobs. We have transition programs in schools that focus on job training; we have vocational rehabilitation programs; we have supported employment, customized employment, individualized employment, microenterprises, and employment first. But do people with IDD have jobs? The answer to this question is that the overwhelming majority of people with IDD **DO NOT** have jobs. As you can see by the data in Figure 3, tremendous growth has occurred since 1990 in the number of people who receive employment and day services. In 2012, roughly 600,000 people with IDD received day or employment services funded through a state developmental disabilities (DD) agency. However, of these, only a little over 100,000 actually had jobs in integrated employment (Butterworth et al., 2014).

Furthermore, as shown in Figure 4, the growth and state investment over time, related to employment and day services, continues to emphasize facility-based and nonwork services, rather than integrated employment services. There is tremendous variation in participation in integrated services based on the state in which a person lives (see Figure 5), with one state serving well over 80% of people in integrated employment and others well under 10% (Butterworth et al., 2014).

There also seems to be a disconnection between what people want and what they are getting (see Figure 6). Using National Core Indicators (NCI) outcome data collected across states, you can clearly see that, of the people who say they want a real job, only 26% of them actually had a goal in their individual support plan to achieve integrated employment (Human Services Research Institute [HSRI], 2014).

Lastly, even people who do work do not earn livable wages, as suggested by the mean weekly wage for people being a little over \$100 in both competitive and individual supported employment (HSRI, 2014). This results in most people with IDD living in poverty. It is clear that although more people are being served over time, the overwhelming majority of people who want real jobs for which they earn real wages are not realizing this aspect of community living.



Figure 1. Sample of acronyms that add to complexity in the service system.

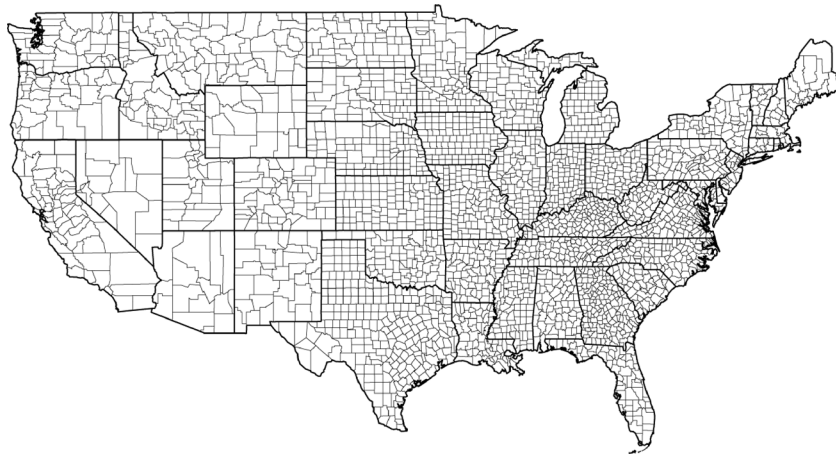


Figure 2. Counties in the United States.

### Home

What do we know about where and with whom people with IDD live? First, we know that the majority of people with IDD DO NOT receive Medicaid-funded long-term services and supports; they live at home with their families and are not

necessarily even known to state DD agencies. Of the estimated 3.5 million people with IDD in the United States, ONLY about 24% of these individuals are served in state DD systems. Certainly a portion of these individuals are children who are in special education but, even excluding those children in

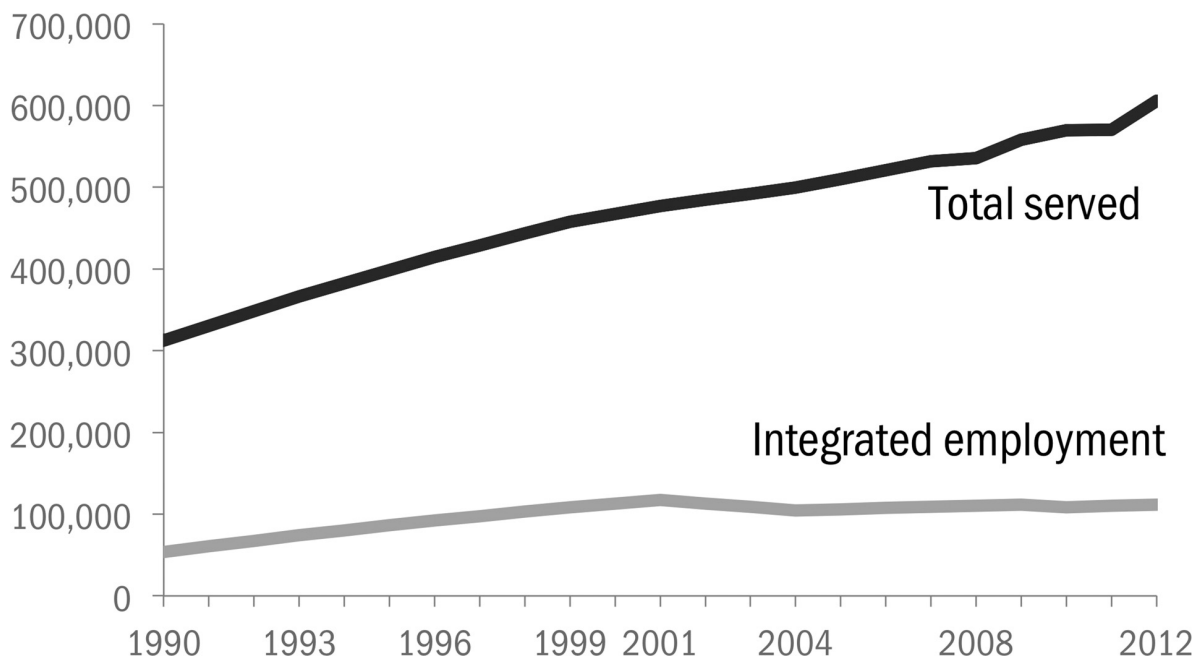


Figure 3. Employment and day supports in the United States, 1990-2012. Data from ICI National Survey of State IDD Agencies FY 2011, University of Massachusetts Boston, in *StateData: The National Report on Employment Services and Outcomes*, by J. Butterworth, F. A. Smith, A. C. Hall, A. Migliore, J. Winsor, and D. Domin, 2014, Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.



Figure 4. Growth in nonwork services, 1999–2009. Data from ICI National Survey of State IDD Agencies FY 2011, University of Massachusetts Boston, in *StateData: The National Report on Employment Services and Outcomes*, by J. Butterworth, F. A. Smith, A. C. Hall, A. Migliore, J. Winsor, and D. Domin, 2014, Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.

school, well over half of the people with IDD in this country are at home with few, if any, services.

Secondly, we know there are just over a million people with IDD that do receive at least one type of

long-term service and support through state DD agencies (Larson, et. al. 2014). Of these people, roughly one third are getting one long-term service or support (often just case management) but are not

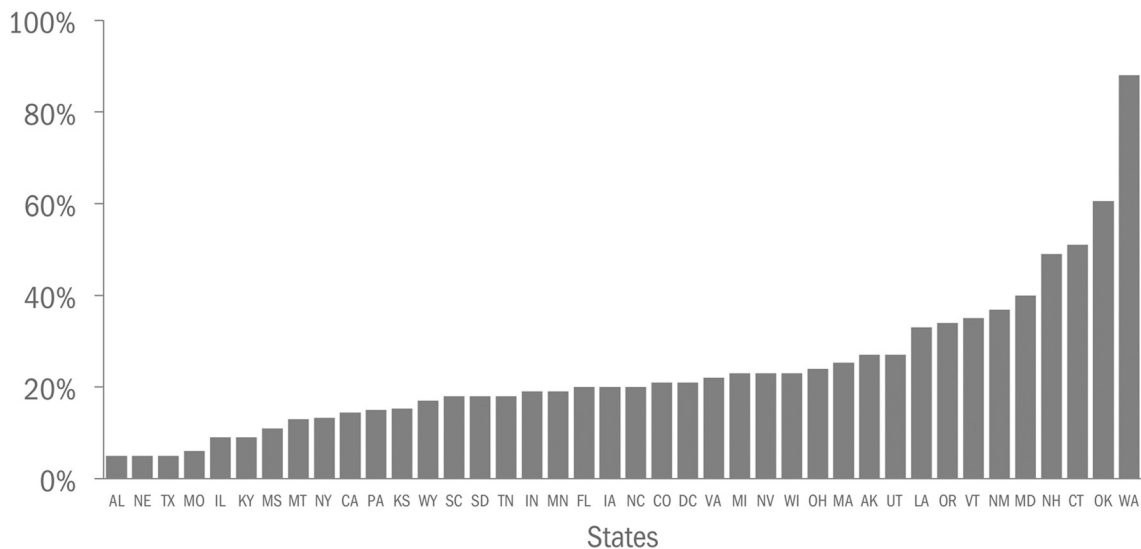


Figure 5. Integrated employment services 2011 across states. Data from ICI National Survey of State IDD Agencies FY 2011, University of Massachusetts Boston, in *StateData: The National Report on Employment Services and Outcomes*, by J. Butterworth, F. A. Smith, A. C. Hall, A. Migliore, J. Winsor, and D. Domin, 2014, Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.

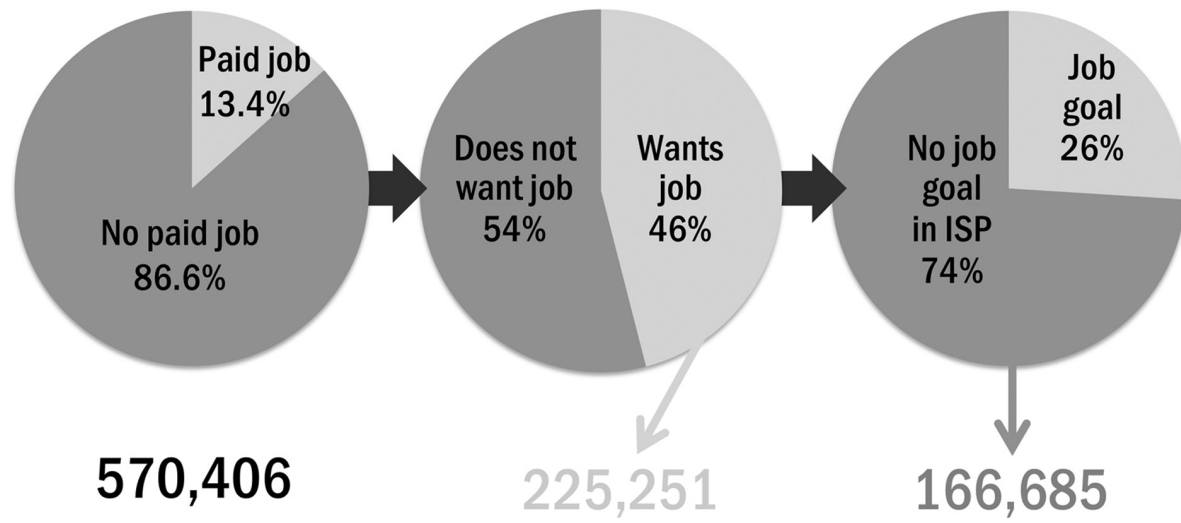


Figure 6. People who want jobs and have a goal, 2011–2012. Data from National Core Indicators Data Brief 2012, in *StateData: The National Report on Employment Services and Outcomes*, by J. Butterworth, F. A. Smith, A. C. Hall, A. Migliore, J. Winsor, and D. Domin, 2014, Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.

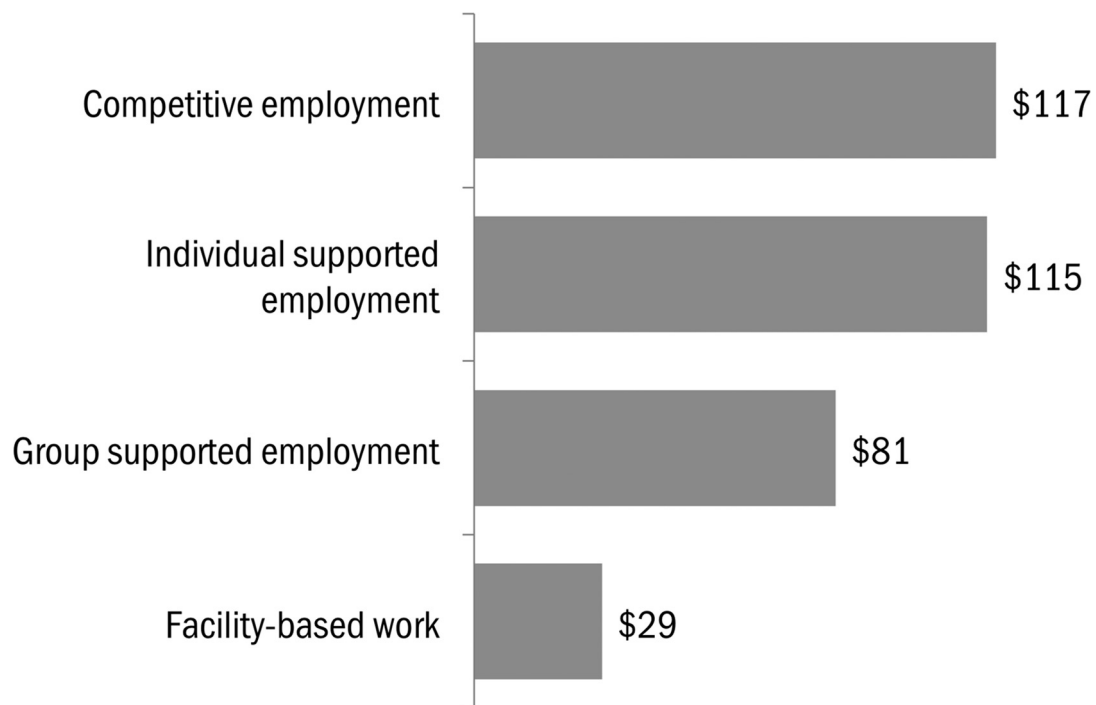


Figure 7. Mean weekly wage, 2011–2012. Data from National Core Indicators Project 2011–2012, in *StateData: The National Report on Employment Services and Outcomes*, by J. Butterworth, F. A. Smith, A. C. Hall, A. Migliore, J. Winsor, and D. Domin, 2014, Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.

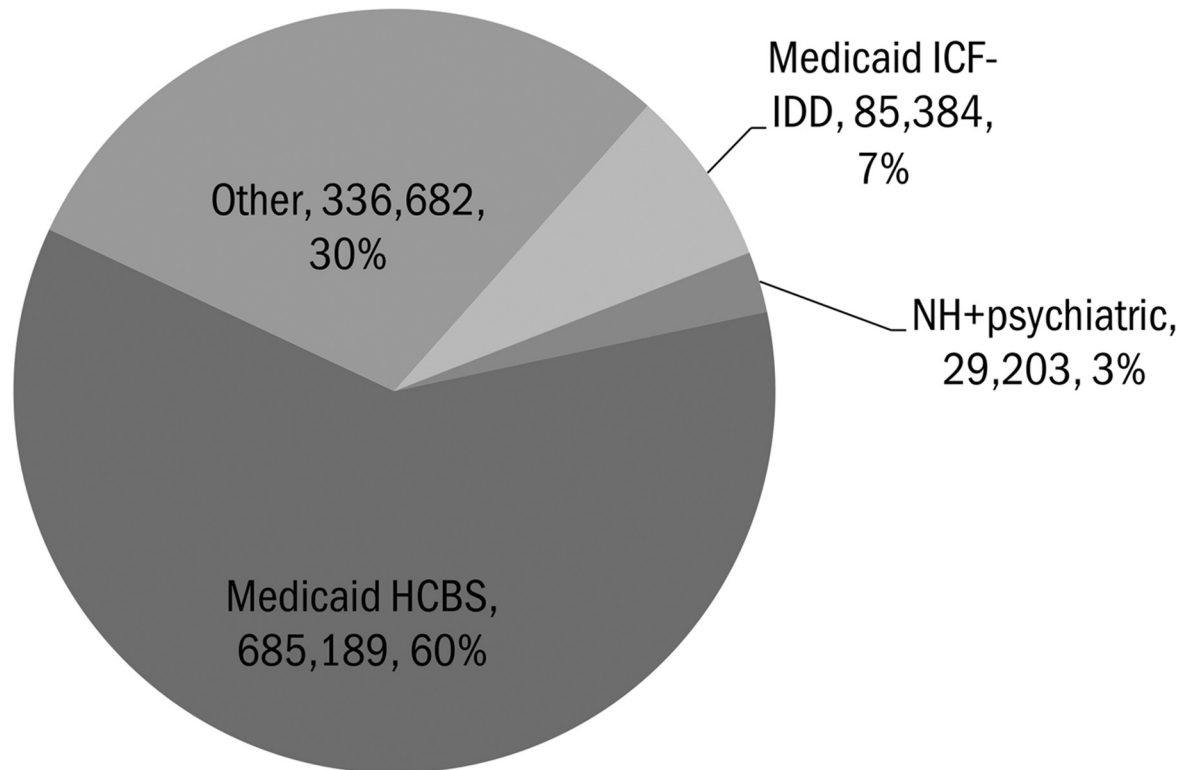


Figure 8. Funding sources for residential supports for people with IDD: FY 2012 estimated. Adapted from *In-Home and Residential Long-Term Supports and Services for Persons With Intellectual or Developmental Disabilities: Status and Trends Through 2012*, by S. A. Larson, L. Hallas-Muchow, F. Aiken, A. Hewitt, S. Pettingell, L. L. Anderson, C. Moseley, M. Sowers, M. L. Fay, D. Smith, and Y. Kardell, 2014, Minneapolis, MN: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

served by the dominant Medicaid programs such as Home and Community-Based Services (HCBS). For these individuals, we do not know if they are getting state plan Medicaid services (such as Personal Care Assistance [PCA]) or if they are on a waiting list for waiver or intermediate care facility (ICF) residential services. Although waiting lists have their inherent inaccuracies, for reasons many of you understand, state DD agencies do report knowing there were over 150,000 people on waiting lists for services as of June 30, 2012 (Larson et al., 2014).

As shown in Figure 9, since 2001, the majority of people that do get Medicaid-funded long-term services and supports receive those services while living at home with a family member.

For people who do not live at home with families, since the mid-1960s, when well over 220,000 people with IDD lived in large state-run institutions, we have seen remarkable progress in

people moving out of these institutions (see Figure 10). Since 1962, 220 institutions have closed their doors and 14 plan closures in the next few years (Larson et al., 2014). This is quite an accomplishment, and certainly something for which we should be proud. Although there is much to celebrate in these closures, our goal of deinstitutionalization has certainly not been achieved. Today, nearly 27,000 people still live in large institutions (Larson et al., 2014).

Additionally, nearly a quarter of a million people with IDD live in group settings (Larson et al., 2014). Does this mean they live and participate in the community? The answer to this question is particularly complex. The word “institution” is one of those words that has changed and morphed in its meaning within this field over time. In the 1960s through the 1990s I think most in this room would have defined this word as a large, state-run facility where 50, 100, or more people lived. Today, I think many of us



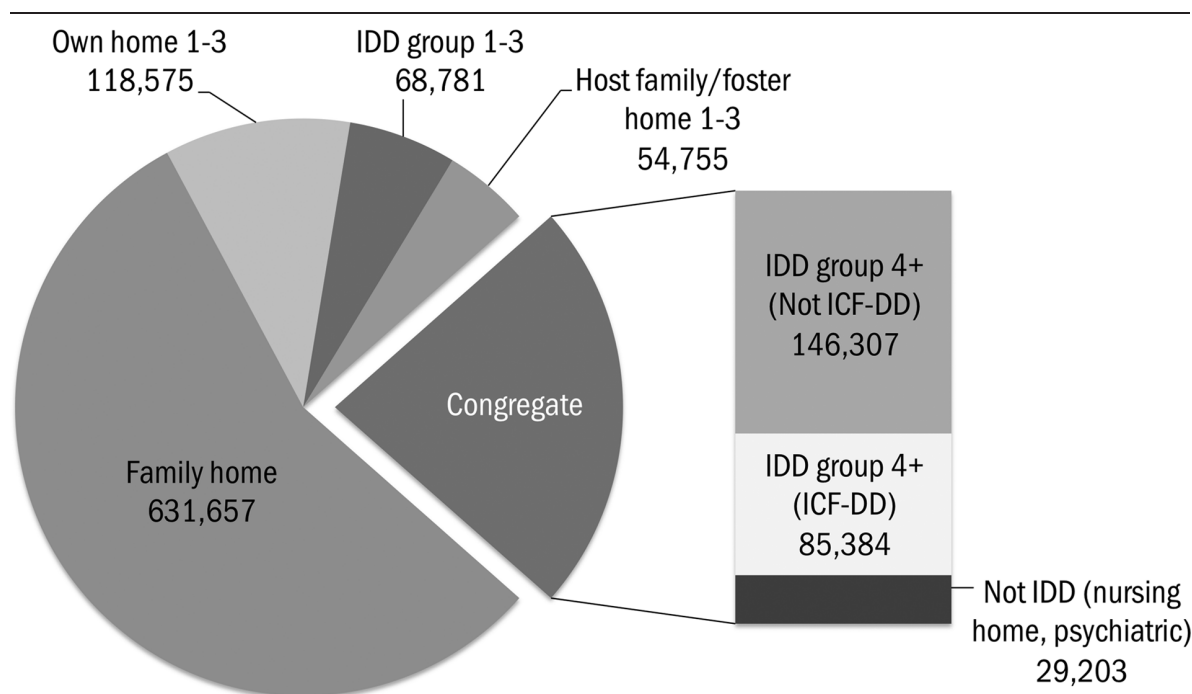


Figure 9. Types of residential settings, FY 2012. Adapted from *In-Home and Residential Long-Term Supports and Services for Persons With Intellectual or Developmental Disabilities: Status and Trends Through 2012*, by S. A. Larson, L. Hallas-Muchow, F. Aiken, A. Hewitt, S. Pettingell, L. L. Anderson, C. Moseley, M. Sowers, M. L. Fay, D. Smith, and Y. Kardell, 2014, Minneapolis, MN: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

would agree that “institution” is not just about the size of the place and the number of people who live there. It is about attitude, it is about control, it is about lack of choice, it is about lack of respect, it is about lack of opportunity, and it is about lack of relationships and being IN the community but NOT a part OF the community.

I believe that many people who live in community group homes today, do live in “institutions.” I am hopeful that the new Centers for Medicare and Medicaid Services’s (CMS) definition of community that requires HCBS to support people to 1) be fully included in their communities, 2) provide choice and self-determination about where and with whom they live, and 3) determine from whom they receive services, will be enforced. The very fact that this new definition exists, is an indication that many of the services we have been calling community-based are really more like institutions where people have limited to no real choice about the big and small decisions in their lives.

As suggested in Figure 12, and as was true in employment services, the type and size of residential

supports for people with IDD varies tremendously by the state in which a person lives. In some states, nearly everyone who does not live at home with their family lives in a small, more individualized place; yet in others nearly no one does (Larson et al., 2014).

As Self Advocates Becoming Empowered (SABE) has reminded us, time and time again, we have a long way to go before our goal of deinstitutionalization is realized. Their position on this is EXTREMELY clear:

We believe that all institutions, both private and public should be closed. All people regardless of the severity of their disabilities should live in the community with the support they need. (Self Advocates Becoming Empowered, 2014)

This is such a simple call to action adopted by SABE in 1995 nearly 20 years ago, yet the complexity of the services we have built makes it challenging to realize.

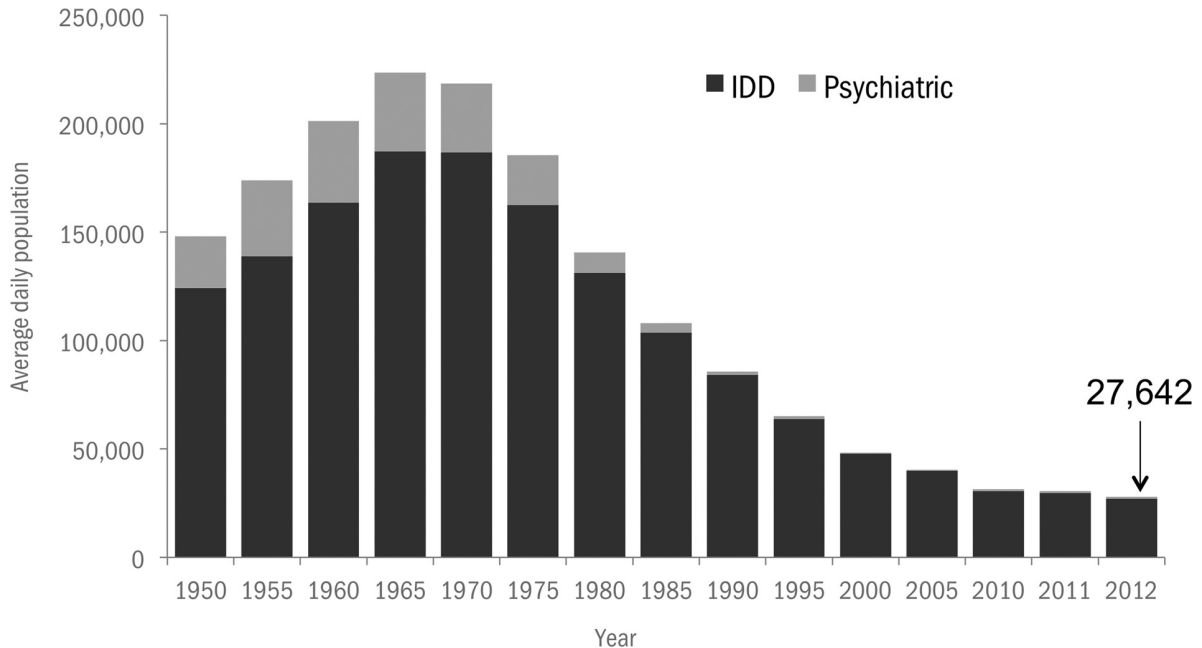


Figure 10. People with IDD in large public facilities. Adapted from *In-Home and Residential Long-Term Supports and Services for Persons With Intellectual or Developmental Disabilities: Status and Trends Through 2012*, by S. A. Larson, L. Hallas-Muchow, F. Aiken, A. Hewitt, S. Pettingell, L. L. Anderson, C. Moseley, M. Sowers, M. L. Fay, D. Smith, and Y. Kardell, 2014, Minneapolis, MN: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

I look at the growing list of HCBS and state plan services, identified in Table 2, that are designed to support people living in the community, and I see clearly why it is so hard to realize SABE's call to action. We are good at building complexity. We seem to have a knack for adding new services, BUT we are slow to, or hardly ever, retire the old ones. The result is our very own version of Medicaid alphabet soup and a maze of services for which individuals and families now need navigators. Clearly, service and funding mechanisms to support people with IDD must become broader or radically different if we plan to reach all individuals who have needs.

I was at a meeting a few weeks ago and was given a copy of a new resource developed for individuals and families. Its purpose is to assist people in finding housing. Although this tool does richly describe the steps needed to find housing in this state, the tool is so complex and complicated that even the tool leaves one feeling overwhelmed. I can only assume how overwhelming these complex processes must feel to individuals and

families. I consider myself pretty well informed and savvy with regard to the complex maze of long-term services and supports, but I can honestly tell you that, each and every year, my family needs help from an advocate or our case manager to "fix a glitch" or figure out a "work around."

### Education and Learning

We do not often talk about education as being a long-term service and support. But it is; 21 years is a long-term service in my opinion. School is a place of learning and socializing. It is a lifeline for individuals and families. It predicates the transition cliff we all know about, talk about, and understand to be a foundation that is critical to successful community living as an adult. Once school is over, individuals and families often find themselves left with no service and support. All too often, young adults with IDD often lose the structure of the school day and their connections to peers.

We know that when children with IDD are included in classrooms with children without disabilities they have better outcomes as adults.

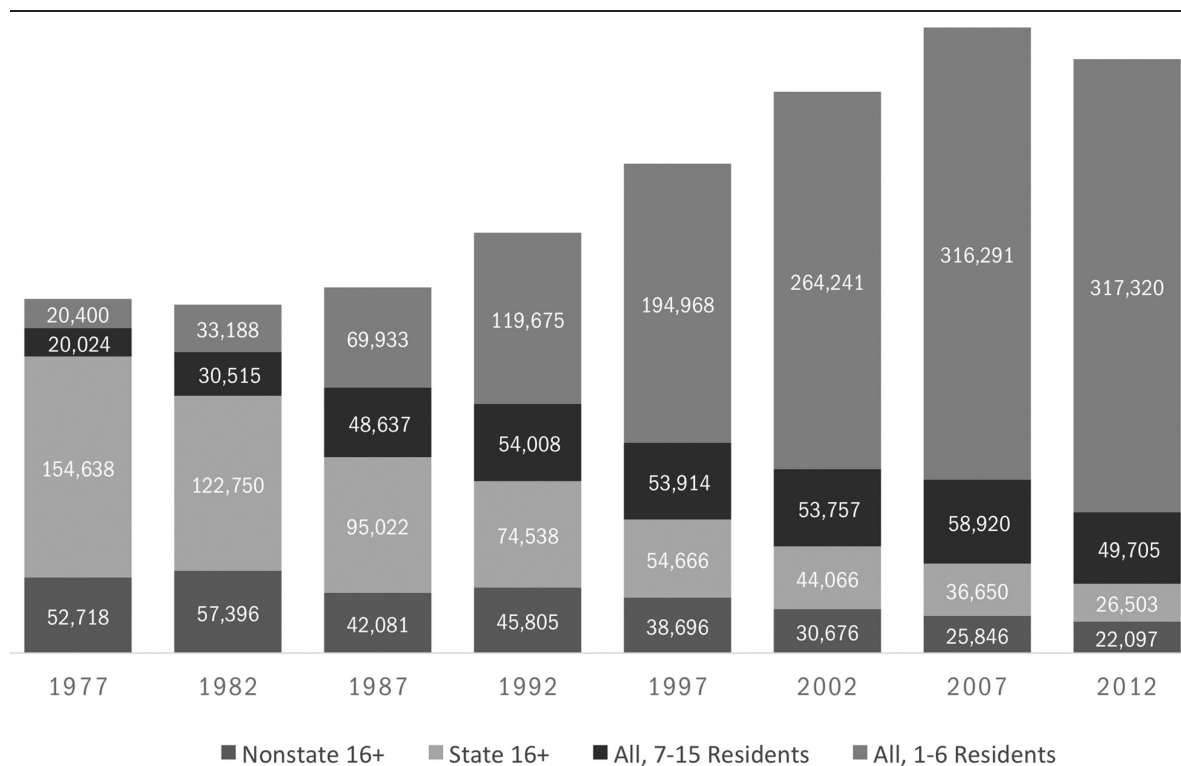


Figure 11. Changes in congregate settings. Adapted from *In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends Through 2012*, by S. A. Larson, L. Hallas-Muchow, F. Aiken, A. Hewitt, S. Pettingell, L. L. Anderson, C. Moseley, M. Sowers, M. L. Fay, D. Smith, and Y. Kardell, 2014, Minneapolis, MN: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

Yet, of the over a million children with IDD in special education in the United States, less than half spend over 50% of their time included in regular education classrooms (National Center for Educational Statistics, 2014).

I know one of my most solid litmus tests about how we are doing with regard to inclusion of children with disabilities in school is to ask my sons periodically about their experiences in school and to make observations when I am at their school activities. On the one hand, I feel very good about what I hear from them and what I observe. On the other hand, it is clear that we have similar issues in schools with regard to inclusion and participation. Children with disabilities are in classrooms with other children, but they are not a part of the classroom. This reality is understood by their peers.

People with disabilities, they're in our classes, but I don't think that enough is being done to really incorporate them and make them feel a

part of the class. They're brought in for shorter periods of time and they don't really work with us. They're off with their aide a lot and I think that people that don't have disabilities could be educated a lot better as to, like, what a disability is and just what people who have disabilities have to go through. (Amos Hewitt-Perry, high school student)

Less is known about the opportunities for young adults and adults to continue their educational experiences. In school year 2011–2012, there were 43 transition postsecondary programs for students with IDD that served about 800 individuals (Think College, 2014). We know there are other similar programs in the United States that offer postsecondary opportunities to additional people. Although we know very little about the outcomes of these programs, we know they do not begin to be available for all who want access to opportunities for continued education.

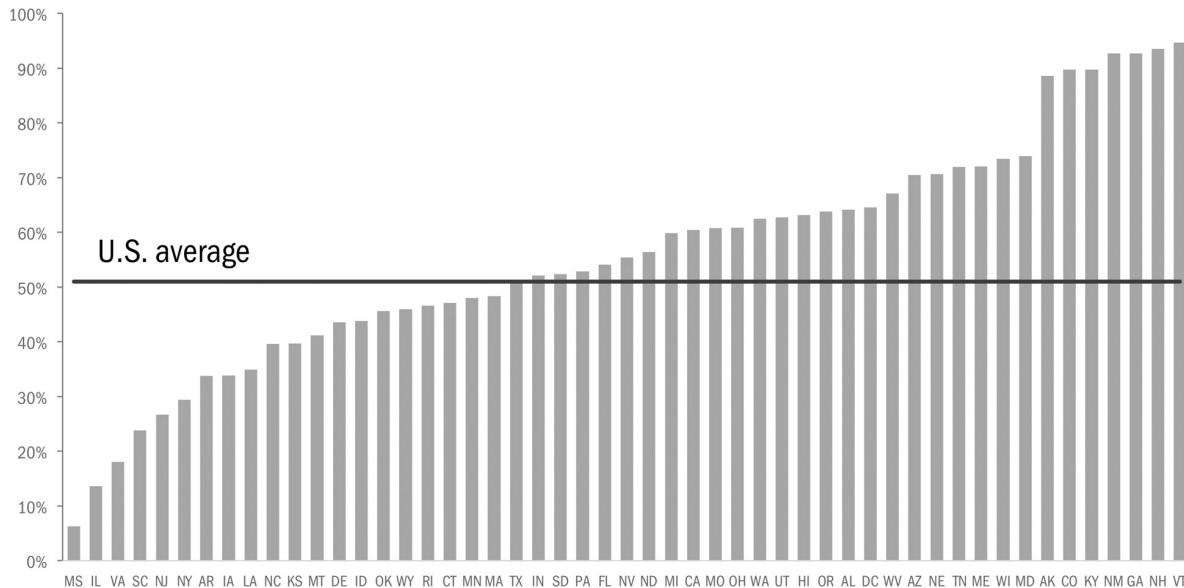


Figure 12. People with IDD in settings of 1-3 (excluding people living in family home). Adapted from *In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends Through 2012*, by S. A. Larson, L. Hallas-Muchow, F. Aiken, A. Hewitt, S. Pettingell, L. L. Anderson, C. Moseley, M. Sowers, M. L. Fay, D. Smith, and Y. Kardell, 2014, Minneapolis, MN: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

### Investments/Expenditures

So, I have discussed three primary service systems—work, home, and school—that support people to have full lives in the community. What are our investments in these services, and is funding at the root of their complexities? In all of life, money has strings attached. That is no different in long-term services and support systems. It is the strings attached to funding of services that, more often than not, add layers upon layers of complexity and hoops. First and foremost, there are processes for eligibility determination—who gets the service or support and who does not. Second, there are processes for determining what and how much a person gets of the service. Lastly there are processes to appeal decisions and offer due process. Managing these processes costs a lot of money and the actual provision of services and supports costs even more money.

As indicated in Figure 13, the total nonschool public spending for IDD services and income maintenance in the United States for FY 2011 was nearly 57 billion dollars. Nearly half of these expenditures were for HCBS, also known as the “waiver” (Braddock et al., 2013).

Over time, as we have increased options and served more people, we have certainly simultaneously increased overall spending. Overall spending has increased from \$14 billion in 1977 to \$57 billion in 2011, yet growth rates have slowed from 4.5% between 1977-07 to 1% between 2008-11 (Braddock et al., 2013).

I think it is important to note that the largest overall investments are being made on the most individualized supports, though we still spend the most money per person served on institutional and congregate care services (see Figure 15).

Again, as I have shown a few times thus far, there is wide variation on spending for IDD services and supports depending on the state in which you live. This variation creates significant disparities in the availability and access to community services and supports.

We also invest a lot in special education services. The overall special education expenditures, especially when you add the state and local dollars that are the overwhelming majority of dollars that flow into special education services, are comparable to the total of all other spending on long-term services and supports discussed (U.S. Department of Education, 2011).

Table 2  
*Growing Number of Options*

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## Waiver funding authorities

- **1115 Demonstration waivers**
  - **1915(a) – Voluntary managed care**
  - **1915(b) – Managed care**
  - **1915(b/c) – Managed care**
  - **1915 (c) Waivers (Total)**
    - **1915(c) Comprehensive waivers**
    - **1915(c) Capped supports waivers**
    - **1915(c) Model waivers (e.g., for children or adults with special healthcare needs )**
    - **1915 (c) Autism waivers**
  - **Other Medicaid waiver authorities**
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## State plan services

- **Intermediate Care Facility for Individuals with Intellectual Disability**
- **1915(i) – State plan HCBS**
- **1915(j) – Self-directed personal assistance services**
- **1915(k) – Community First Choice**
- **Other state plan - long-term services and supports**

## Other state services

- **Many and varied**
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### Spending Realities

As those of you involved in policy advocacy at the state or federal levels know, there are not endless resources available to support people with disabilities. Increases in spending and the development of new programs and funding authorities need legislative authorization. Following what is often referred to as the “Great Recession” of 2009, states faced severe budget deficits and, as a result, cuts and stagnation of expenditures were seen in services and supports to people with IDD while, simultaneously, demand was increasing not only for people with IDD but also for the elderly and people with other types of disabilities. This has resulted in a resurgence of states looking at moving long-term services and supports (LTSS) for people with IDD into managed care. Now nine states have fully moved to managed care systems for at least some of their LTSS for people with IDD, and nine have plans to move in that direction. This should not be surprising to us. The cost per person served in LTSS is extremely high, and the inequities in the expenditures based on who is in the system and who is not are very clear. I am reminded of these inequities daily in my work. There are individuals in our system for which we spend well over a million dollars a year for them to live in the community (and, for some, to live in institutions),

yet most people receive nothing. Another way to say this is that some people have “Lamborghini” services and others have “no means of transportation” services. I think we need to be paying much more attention to these inequities and doing something about them.

We have evolved a system in which the well-informed squeaky wheel gets the best services and those who can best navigate and fight the complex systems we have built fair better, and this is simply not fair (or equitable). Do I think managed care organizations (MCOs) are the best way to find this equity? I am not sure. It’s complex. However, I am not surprised to see state systems of government turning to MCOs as a possible solution, because we have not given them sufficient alternatives. The very system we have created is costly, has created significant disparities and inequities, and does not even come close to serving everyone who needs support.

### Person Centered

What is so hard about what we all are trying so hard to do—support people to have full lives in the communities of their choice where they are included, participate, and are active citizens—is that every person is unique, their context is unique, and their support needs are unique. This

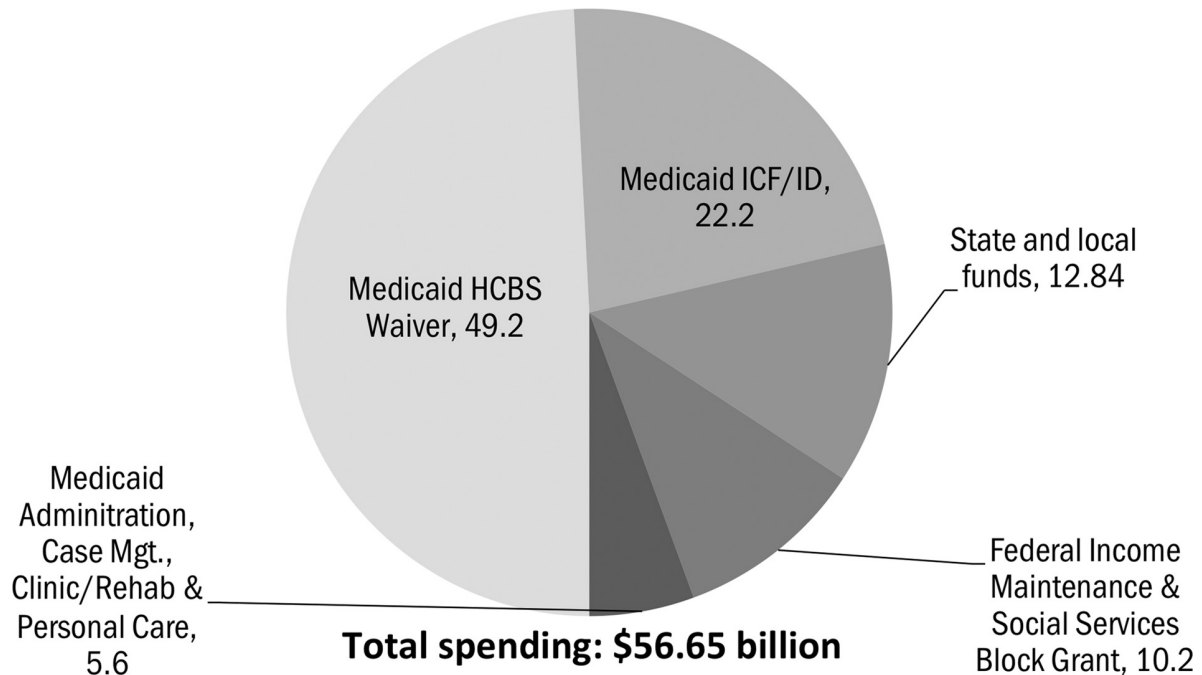


Figure 13. Public spending for ID/DD services and income maintenance in the United States, FY 2011. Adapted from *State of the States in Developmental Disabilities 2013: The Great Recession and Its Aftermath*, by D. L. Braddock, R. E. Hemp, M. K. Rizzolo, E. S. Tanis, L. Haffer, A. Lulinski, and J. Wu, 2013, Washington, DC: American Association on Intellectual and Developmental Disabilities.

requires nimbleness and flexibility on the part of service providers and systems. With 3.5 million unique individuals to serve and finite resources, this is a challenge. Over the past 30 years we have certainly moved in the right direction. Our services are more flexible, there are increased opportunities for self-direction, and we are certainly spending more resources on keeping people in the community in the context of their family home. Many, many people with IDD have vibrant, or as Ann and Rud Turnbull would say, enviable lives in their communities.

But, I think we are on the cusp of a new 21st century deinstitutionalization movement. Recent actions by the Department of Justice requiring states to offer employment opportunities in the most integrated setting, the new HCBS regulations that so clearly define community living, the growing intolerance of the use of aversive and deprivation procedures in schools, and long-term services and supports all point to the need for radical change in how we are supporting citizens with IDD in the United States. It is a time for new action, new thinking, and embracing this next

wave of deinstitutionalization. We must move away from services and supports that are “institutions” defined by attitude, control, and being in the community but not of the community. We must move toward true community living, where people are included, participate, and realize the full potential of their citizenship. This is not going to be easy. It will take courage. It will upset many, it will cause debate and discourse just like the 20th century deinstitutionalization movement did. But if we are truly committed to a long-term services and supports infrastructure that supports people with IDD being included, participating and being full citizens in our communities, we must lead the way in this new movement.

### Facing Difficult Realities

As we think about this next push toward fully included communities, we have to focus on some difficult realities. Like accepting that far too many people who live in group homes or supportive living programs have few opportunities to make choices and, as Jenny Hatch so vividly shared with us in the opening plenary, people with IDD are often

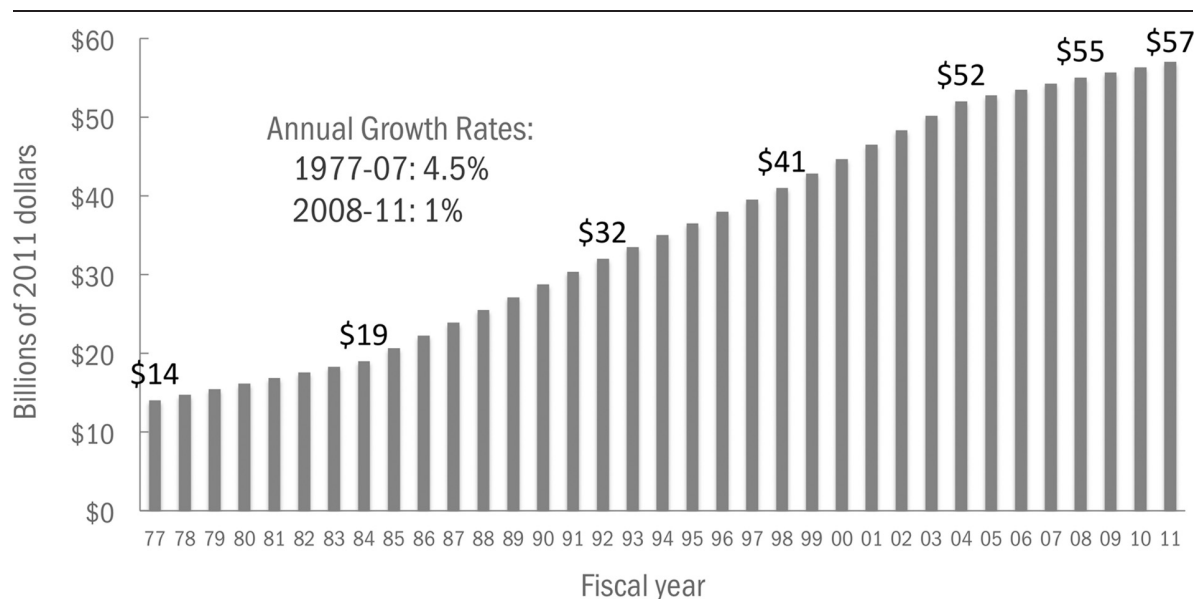


Figure 14. Total public spending for IDD services in the United States: FY 1977-2011. Adapted from *State of the States in Developmental Disabilities 2013: The Great Recession and Its Aftermath*, by D. L. Braddock, R. E. Hemp, M. K. Rizzolo, E. S. Tanis, L. Haffer, A. Lulinski, and J. Wu, 2013, Washington, DC: American Association on Intellectual and Developmental Disabilities.

controlled and prevented from seeing the friends they want to see.

We must also accept that far too many people with IDD are lonely. Just this past week, I had the opportunity to hear from a parent who was talking to some of my students; she shared her personal story about her son, who is now in his 30s. As she was sharing his experiences, in the context of their family, the most significant challenge her son faces is that, since he left high school, he has had no friends. He has no social network outside of his family and work. Painfully, I observe this in my own family. My brother-in-law, Nathan, whom many of you know, is a 40-year-old man who lives with autism. He has mostly good days and I think most of the time he'd say he has a good life and we would agree. But Nathan is lonely. Our family loves him, he has co-workers with whom he laughs and for whom he deeply cares about, but they have no relationship outside of work. He has a long-time "friend" who lives in Indiana and with whom he talks to regularly, but my observation is that she has really always been a parent figure to Nathan. Despite having a job and opportunities to participate in his community, Nathan is lonely. He is terribly lonely. Both of these men have far too typical of a story. More than friendships, people

with IDD want and long for close, personal intimate relationships. They want love.

I would just like someone to share my life with, like a girlfriend. (Jeffrey Nurick, Self-Advocate)

As we move forward and embrace this notion of being on the wave of a 21st century deinstitutionalization movement, I ask myself, and all of you, if we should embrace, navigate through, or simply bypass the complex systems we have built to support inclusion, participation, and citizenship of people with IDD? My answer? Well, as you might have guessed, it's complex.

On the one hand, we have made remarkable progress. More people are receiving services and supports in the community; more money is being spent on community residential options than on congregate and institutional services; children are at home with their families; and efforts are underway to increase self-direction options, push for better transition efforts, and ensure real employment opportunities. This suggests that we should embrace the progress we have made and the services and supports that actually do support people to have good lives.

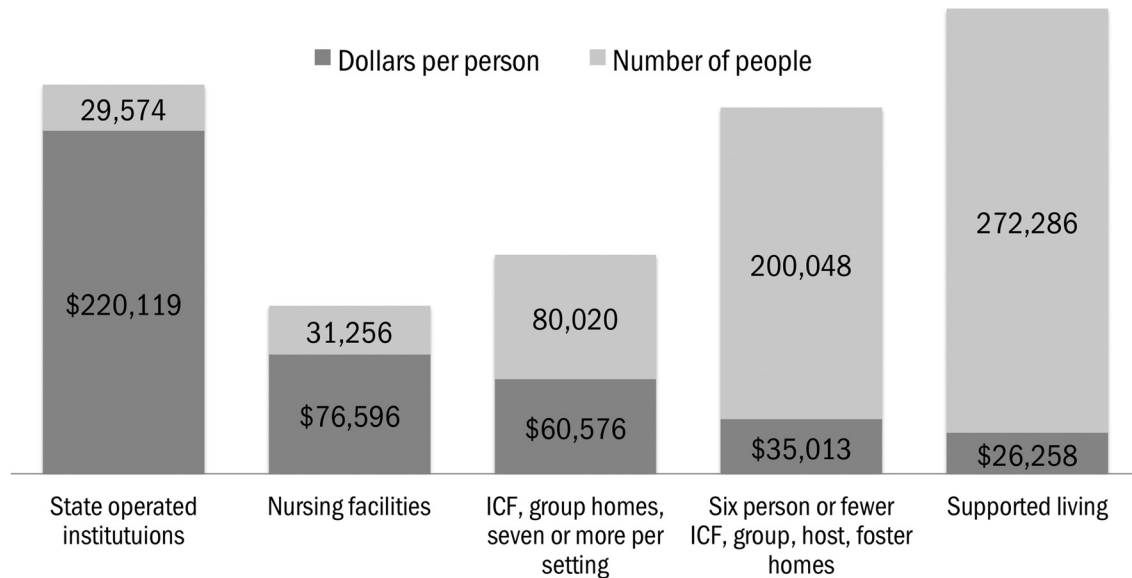


Figure 15. Annual cost per person with IDD by residential setting, FY 2011. Adapted from *State of the States in Developmental Disabilities 2013: The Great Recession and Its Aftermath*, by D. L. Braddock, R. E. Hemp, M. K. Rizzolo, E. S. Tanis, L. Haffer, A. Lulinski, and J. Wu, 2013, Washington, DC: American Association on Intellectual and Developmental Disabilities.

At the same time, we have created systems with so much complexity that appeals, mediation, and litigation are too often the only answer for creating lasting change. As an industry, we work hard to sustain the system. Far too often, legislative agendas in states are about trying to preserve, maintain, grow, and perhaps make tweaks to what we have already evolved. Far too often, litigation is what results in big change. Sometimes this approach can result in lasting positive systemic change. A good example is the recent settlement agreement related to the Jensen class action lawsuit in Minnesota. Terrible, unimaginable things happened to people with IDD in a state-operated program and, as a result, not only did the plaintiffs get a financial settlement, but the state of Minnesota was forced to sunset a rule that allowed for the use of aversive and deprivation procedures and to create an Olmstead Plan. This is an example of a painful process, one that is difficult for policy makers, policy advocates, individuals and families, and for providers to navigate. But by navigating through, I am confident that lives will be improved and new opportunities for community participation, inclusion, and citizenship will be realized.

However, I simply do not see how we can support all people with IDD to be included and

participate in community living if we do not do things different and create some completely new approaches. What we have built does not work for all. It really only serves roughly 25% of people who have IDD; about 75% of people get little or no services. Of those that do receive services and supports, there are tremendous disparities in the quantity and quality of those services. There are just far too many practices and services that we know are not effective and do not result in people being included and participating in their communities, and we need to stop holding on to them. We need to bypass them to create new and better approaches.

### Priorities for the Field

Irrespective of whether we are embracing, navigating through, or bypassing to create new services and supports, I believe we have some priorities. Without attending to these issues and finding new solutions, I do not think we will ever keep our promise of community living.

### Direct Support Workforce

As an industry, we need to reflect and think about what we have created. The direct support workforce that has evolved is one in which the people who



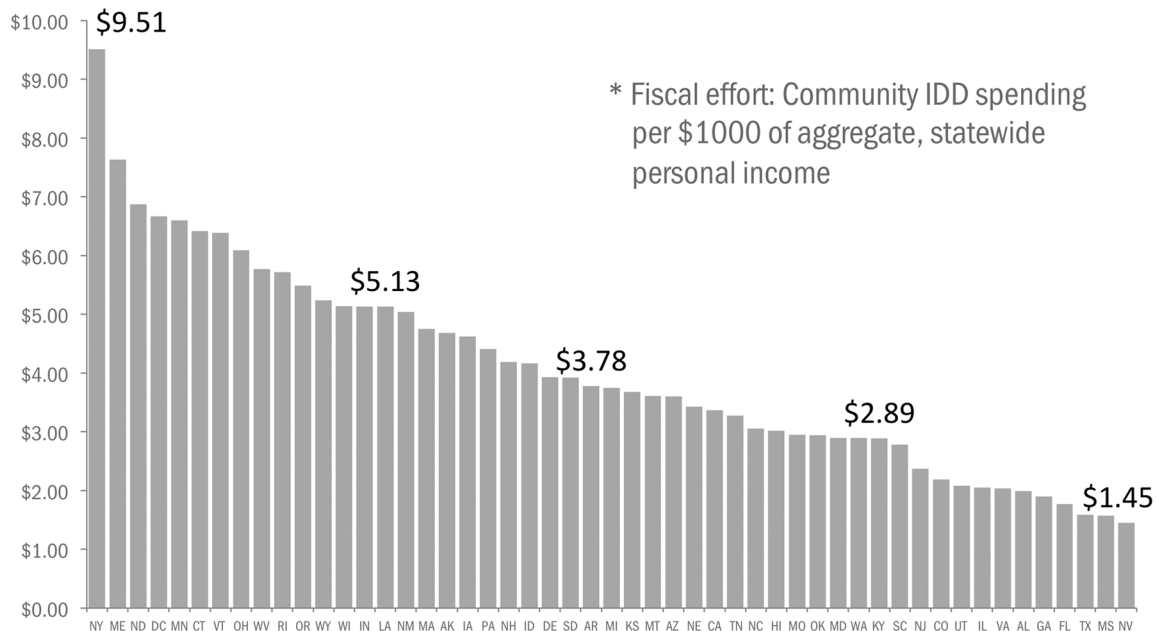


Figure 16. Fiscal effort for IDD community services vary dramatically across the United States: FY 2011. Fiscal effort = Community IDD spending per \$1,000 of aggregate, statewide personal income. Adapted from *State of the States in Developmental Disabilities 2013: The Great Recession and Its Aftermath*, by D. L. Braddock, R. E. Hemp, M. K. Rizzolo, E. S. Tanis, L. Haffer, A. Lulinski, and J. Wu, 2013, Washington, DC: American Association on Intellectual and Developmental Disabilities.

provide the most support to individuals have the fewest qualifications—usually all that is required to be a direct support professional (DSP) is a driver’s license, no felony convictions, and a high school degree. For 25 years, we have known turnover in this workforce is high—hovering between 30 and 50% depending on the economy or study (Bogenshutz, Nord, & Hewitt, in press) with wide variation across organizations from as low as 8% to as high as 300%. The demand is so high for these workers that there are significant vacancies at any given time, and organizations and individuals often find themselves desperate to hire new employees. As a result, the bar has been lowered in terms of the types of people that are hired into direct support positions. Furthermore, once hired, little is done to teach, support, and develop their skills. This workforce has minimal training requirements—and those that do exist are mostly focused on health and safety-related topics.

Having reliable people is what allows you to stay in your own home. (Carol Ely, Self-Advocate)

In nearly every study we have conducted at the Research and Training Center on Community Living at the University of Minnesota, the results are predicted by the influence of the stability, quality, and training of the direct support workers. If you talk to any individual with a disability or their families, you will hear how incredibly important direct support workers are and how hard it is to find and keep good ones.

It is important to understand that this is a very large workforce. By 2020 it will grow to be 5 million strong. There are more DSPs in this country than there are teachers, fast food workers, nurses, and law enforcement (PHI, 2012). But how many of your neighbors and family members know who direct support professionals are? How many plan careers in direct support? My guess is very few. Yet, the quality of services and support to people with IDD are dependent on the competence and ethical decision making of these workers. Everything we care about and are trying to do to support community inclusion and participation is reliant on these workers.

We have got to get to a place where the headlines in our local newspapers are not focused

on the negative and harmful aspects of services and supports to people with IDD and the direct support workforce, but, rather, the headlines are focused on how DSPs have the skills needed to work with people with disabilities, to change communities, to change attitudes, and to support people in having truly connected lives in their communities. The headlines need to focus on the valuable contributions people with IDD make in our communities and the DSPs who provide them support.

### **Community and Family Intervention**

I believe that we have to shift this focus of what we are doing. Our interventions and practices need to shift from being about treating individuals to, instead, treating our communities and supporting families. True and lasting change is not going to happen if we keep doing what we have always done. When we target and work with communities and members of the community, instead of focusing solely on service providers, we see promising results.

Two of my colleagues have recently completed studies where they did not rely solely on the developmental disabilities provider community to implement an intervention, but, instead relied on the community and community members. In a project called “Putting Faith to Work,” strategies were implemented to work within eight congregations to build capacity within those faith communities to include congregation members with disabilities in employment finding and support activities that are available to the full congregation.

During the short project demonstration period, these congregations assisted 30 people with disabilities (including people with IDD) and, of these 30 people, eight obtained full-time employment, six part-time employment, and four were connected to internships (Nord, Timmons, Carter, & Gaventa, 2014). These are remarkable outcomes and they did not involve a single traditional-disability focused provider organization in providing the employment-related services. Instead, they involved capacity building and community building, by having a person who knew a lot about supports needed by people with disabilities working directly with the various faith communities and congregations. A shift from the disability professional focusing on the individual to one in which they focused on congregations.

Similarly, in a randomized controlled study about social inclusion, comparisons were made of the

effectiveness of social inclusion training programs for staff when implemented in a traditional provider organization vs. a model using individual independent community builders. In this study, significant positive outcomes were found in developing friendships, increasing membership in community organizations, and increasing community social roles using both the provider and the community intervention strategy. However, the model of an independent community builder from the local community was the most effective avenue for supporting people to have friends and to be socially included in community organizations (Amado, Stancliffe, McCarron, & McCallion, 2013).

These are two of many studies that have shown the effectiveness of intervening with the community. When you support the community in including people with disabilities, they will. Given that 75% of people with IDD live with their families and do not receive services from state DD agencies, and that over half of the 25% that do receive services receive them within the context of their family home, we MUST figure out ways to support and educate families and communities about the most effective strategies to support their loved one in being included, participating, and exercising full citizenship in their communities.

Not only do we need to change the focus of our services and interventions to include community- and family-focused interventions and services, BUT we also need to FUND these types of community and family services and supports. This may mean we have to look outside of Medicaid for financing. At its core, Medicaid is an individual insurance program—services and supports funded through Medicaid are designed for the individual, not the community and not directly the family. Either we need to navigate through Medicaid, shifting it toward thinking more broadly about supporting and treating communities and families, or we need to bypass Medicaid.

In my mind, there is no hope for ridding our communities of the stigma and disrespect people with IDD experience without shifting the focus of services, supports, and interventions from the individual to the community. Until communities are a part of the solution, people will not be included.

### **Discrimination, Bias, and Stigma**

As I reflect on the system we have built, perhaps the greatest challenge we still face in supporting

community living is the pain of stigma and the resulting discrimination and attitudes toward people with IDD in our communities. I see it in the grocery line with Nathan when he overhears a bagger refer to person as a “retard”—I watch his body stiffen, the deep furrow of his brow appear, and the sweat that builds up on his forehead as we are standing in line—all signs of the hurt and pain he is experiencing. I see it in the ongoing bullying that occurs in schools targeted toward children with disabilities. I hear it in the words people say. I see it from a historical perspective when it seems that no matter the words we choose to describe or define the characteristics of people with IDD, over time, these words become hurtful and stigmatizing. I see it on the news media and in newspaper articles. I see it in meetings I attend in which, every once in a while, representatives from other categorical disability groups are there and make comments that so clearly indicate that, although they or the people for whom they are allies and advocates have a disability, they are NOT like people with IDD. I see it in a community meeting where we were discussing the results of an autism prevalence study we conducted in Minneapolis that had a finding that 100% of the children with autism from the Somali community had a co-occurring IDD—having autism in the community was loaded with stigma and difficult for the community members but adding IDD as a co-occurring disability heightened this stigma and lack of acceptance. If you look, you cannot help but see the overt and subtle ways that stigma, bias, and discrimination exist in our communities. We must make ridding our communities of this stigma and bias a priority. People with disabilities want respect.

I want to be treated with respect and not to be, you know, not for people to call me names and not for people teasing me. (Richard Grimm, Self-Advocate)

They also want opportunity to be challenged.

I've never wanted an easy life. I want a challenging life. I want a full life. I want love. I want professional success. I want to be the guy on the top of the mountain who got there because he worked his ass off. (John Smith, Self-Advocate)

This stigma and disrespect is also seen in the ways in which policies are made and services are

developed without people with IDD REALLY being consulted and REALLY being listened to. In so many ways, we have simply ignored the call “Nothing About Us Without Us.” We need to support and evolve leaders who have IDD. They need to be working in all of the same organizations in which you work. We need to TRULY fund self-advocacy so that, in each and every state and community, people with IDD have access to leadership training and support. When I think of the tens of billions that are spent on services and supports to people with IDD and then look at what of that is spent on fostering self-advocacy leadership, I am literally sickened. It simply is not right. In my opinion, there is no single better quality assurance or enhancement system than effective, enlightened self-advocates!

### Concluding Thoughts

We have made progress since the beginning of the 20th century deinstitutionalization movement—there is much to celebrate and many of you in this audience deserve applause and gratitude for moving us so much farther along the journey of creating inclusive communities in which people with IDD participate as full citizens. This journey is not over. Those positive stories we see and hear, the vibrant lives experienced by the people that you know, need to become the reality for all citizens with IDD.

We need bold leaders. AAIDD and its members need to be at the forefront of this 21st century deinstitutionalization movement. We need to publically embrace and support legislation and policies that promote true inclusion, participation, and citizenship—such as the recent Department of Justice rulings on most integration settings related to employment and the Centers for Medicaid and Medicare Services’s new definition of community. We need to boldly tackle issues such as closing places like the Judge Rotenberg Center, where we know horrific abusive procedures are used that hurt and cause pain for people who live there, and we need to uncover and find similar places and shut them down. We need to continue our quest to stop people with IDD on death row from being executed. We need to listen to what self-advocates have so clearly been saying for the past 2 decades and push for institutional closures, keeping in mind that institutions are not just big places, they are small places too. We also need to be at the forefront of creating new interventions that have as their

focus community organizing and community change as well as family support. We need to ensure that DSPs are supported in their careers and have the knowledge, skills, and ethical foundation to do their jobs well.

We need to have new conversations about how we can do and fund things differently. We need to use the tools at our fingertips—social media and other media, marketing and advertising solutions—to show the world the vibrant and rich lives people with IDD live and the valuable contributions and social capital they bring to our communities.

As we move forward on this journey, we must simultaneously embrace, navigate, and bypass this system that together we have created.

Thank you again for the opportunity to speak to you this afternoon and for the honor of serving this organization in a leadership role. Also, thank you to the most wonderful group of colleagues on the planet who supported me and helped me as I prepared this presentation—it takes a village and I am certainly surrounded and supported by wonderful and extremely talented village members.

I will leave you this afternoon with the heartfelt opinions of one of the happiest, kindest, and most empathetic 10-year-olds I know, whose words of wisdom, if shared by all citizens of the world, could change our communities so that people with IDD are fully included and have opportunities to participate as full citizens:

Treat everybody the same. We're all human beings. (Jack Hewitt-Perry)

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