

# National Historic Recognition Project 2000-2020



## 2020 National Honors

Recognizing significant contributions  
in the field of intellectual and  
developmental disabilities in the  
United States between 2000 and 2020

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**Essential Change Agent**, 2020 National Honors, the National Historic Recognition Project, for significant contributions in the service of people with of intellectual and developmental disabilities in the U.S. between 2000 and 2020.

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## Frequently Used Abbreviations and Acronyms in this Booklet

AAIDD	American Association on Intellectual and Developmental Disabilities
ADA	Americans with Disabilities Act
ANCOR	American Network of Community Options and Resources
AUCD	Association of University Centers on Disabilities
CEO	Chief Executive Officer
CRPD	Convention on the Rights of Persons with Disabilities
DSP	Direct Support Professional
IASSIDD	International Association for the Scientific Study of Intellectual and Developmental Disabilities
IDD	Intellectual and Developmental Disabilities
LEND	Leadership Education in Neurodevelopmental and other Disabilities
NADSP	National Association of Direct Support Professionals
NASDDDS	National Association of State Directors of Developmental Disabilities Services
NCI	National Core Indicators
NYSARC	The Arc New York
OMRDD	New York State Office of Mental Retardation and Developmental Disabilities, renamed OPWDD
OPWDD	New York State Office for People With Developmental Disabilities
The Arc	The Arc of the United States
UCEDD	University Center for Excellence in Developmental Disabilities
UCP	United Cerebral Palsy



# The National Historic Recognition Project 2000-2020: The Legacy of the Past 20 Years in Our Field

Margaret J. Gould | The VISIONS Center for Creative Management

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## The 20th Century Historic Recognition Project

In 1999, the *20th Century Historic Recognition Project* recognized 35 individuals and groups for their significant contributions over the 20th century within the U.S. Additionally, seven brief essays highlighted key trends over this period.

The organizations involved in the 20th Century project were ANCOR, AAIDD, The Arc, ANCOR, NASDDDS, AUCD, UCP, NYSARC, ADAPT Community Network, IAC NYC, New York Alliance for Inclusion and Innovation, and Cerebral Palsy Association of New York State.

## National Historic Recognition Project: 2000-2020

The *National Historic Recognition Project: 2000-2020* continues the project in recognizing the key people that transformed the field of IDD within the U.S. over the past 20 years and highlights important trends in the field during this period with eight brief essays.

The intent of both the *20th Century Historic Recognition Project* and this *National Historic Recognition Project: 2000-2020* are to contribute to the historical record of the field. While major trends and influences in the field of IDD are chronicled in the professional literature, it remains important to document and reflect on the personal contributions and events in our most recent history continues to shape the field.

The 2020 recognition committee represents the following organizations: AAIDD, ANCOR, AUCD, NASDDDS, The Arc, UCP, ADAPT Community Network, Cerebral Palsy Association of New York, New York Interagency Council of Developmental Disabilities Agencies, New York Alliance for Inclusion and Innovation, NYSARC, and the VISIONS Center for Creative Management.

## Recognition of Individuals and Groups

A total of 87 individuals and groups are recognized for contributions to the field of IDD in the U.S. as the nation transitions toward supporting people with IDD in having a high quality of life in the community.

## Essays that Highlight Key Trends in the Field

The essays contained in this document reflect on the significant events that contributed to the transformation the field of IDD during the past two decades. Notably, as the field moved toward personalized supports, the role of individuals with IDD as advocates and the value of the contributions of direct support professionals were embraced. During this period, professional, family, and self-advocate leadership in the field transitioned as the field evolved and as individuals aged.

The past 20 years have seen a significant shift toward individualized and inclusive supports, an increase in employment options, and a greater emphasis on small, community-integrated residential settings.

Human service organizations are changing. The advent of managed care, changes in funding, and the mergers have strongly influenced organizational approaches to service. Individuals in long-term leadership roles are retiring and the next generation of leadership are entering these positions. The Boards of Directors of nonprofit providers, previously heavily populated by family members, have become more diverse in their members and perspectives.

## Final Thoughts

It is important to know your history. With this project, we considered and reflected on the legacy of the transformation of the past 20 years on the field and people with IDD. It is our hope that others will continue to collect and record historically significant contributions, and we trust that the process begun with *20th Century Historic Recognition Project* will continue.

The history in our field will be told through the lives of people supported, their families, and the professionals who have come before us and those who will follow.

## The Growth & Evolution of a Community System of Supports

Edward R. Matthews | ADAPT Community Network

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### Evolution in Education as a Model

In 1954, the US Supreme Court, in a landmark decision, unanimously ruled in *Brown v. Board of Education* that state laws enforcing racial segregation in public schools were unconstitutional, stating that “separate educational facilities are inherently unequal” and violated the Equal Protection Clause of the 14th Amendment of the US Constitution. In 1975, the Education of All Handicapped Children Act—later renamed Individuals with Disabilities Education Act (IDEA)—was signed into law, establishing the right of children with disabilities to free and appropriate education in the least restrictive setting.

### Evolution and Growth of Community Supports and Services

After services for returning Korean and Vietnam war veterans with disabilities were established, advocates were able to work with states and local governments to include adults with IDD in vocational training activities, and the 1965 amendments to the Vocational Rehabilitation Act formally extended evaluation and employment services to people with a broad range of disabilities.

Public policy began to address the needs of people with IDD. In 1961, President John F. Kennedy established the President’s Panel on Mental Retardation and in 1966, President Lyndon Johnson established the President’s Committee on Mental Retardation—now known as the President’s Committee for People with Intellectual Disabilities to insure a “decent, dignified place in society” for people with IDD.

While public policy was evolving, the intuitional approach to was often lagging. In 1965 the Willowbrook State School on Staten Island was

severely overcrowded and engaged in questionable medical practices and experimentation when Senator Robert F. Kennedy called it a “snake pit,” with its residents “living in filth and dirt, their clothing in rags, in rooms less comfortable and cheerful than the cages in which we put animals in a zoo.”

Subsequent exposés in print and on TV shone a light on institutions throughout the country. In New York, a class action lawsuit resulted in a 1975 Consent Decree that committed the state to improve its capacity for community residential supports and to close the facility. The Willowbrook case forced all states to look closely at their institutions and create service and financial models for community-based services. In 1977, New York received approval from the Health Care Financing Administration (HCFA), now known as the Centers for Medicare and Medicaid Services (CMS) to modify nursing home regulations to create Intermediate Care Facilities for the Mentally Retarded (ICF-MRs)—now known as ICF-IDDs—to allow Medicaid reimbursement for residential services. Medically-based day activities or day treatment programs were subsequently created to fulfill requirements for active treatment.

By the early 1980s advocates and some providers were starting to become dissatisfied with the ICF model, believing that residents were being prevented from reaching their potential, obtaining high school diplomas, securing employment, and most importantly, exercising choice about who to live with or where. ICF program services were medically-based and focused on addressing the deficits of residents. In addition, while many states had established ICFs, few had built community capacity for community living.

In 1983, the amendments to Section 1915 of the Social Security Act authorized CMS to consider



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Home and Community-Based (HCBS) waivers to allow states relief from the stricter of ICF regulations as long as provided services were community based, person centered, and did not cost more than ICFs. For a variety of reasons, this opportunity took years for states and providers to recognize to its advantages. Between 1988 and 1995, states used the waiver to support deinstitutionalization and build capacity in family and individualized settings, as well as group homes, and in underserved communities. In addition, employment supports, were developed under the HCBS waivers that resulted in the employment of people with IDD in record, but still dismal, numbers.

As 2020 approaches, we stand at the precipice of another seismic shift in where, how, and when people with IDD access long term supports and services (LTSS). LTSS make up a significant portion of the Medicaid budget in some states, and the shift toward Medicaid managed care for the IDD population has resulted in mixed outcomes. As the dust settles in the new decade, we can expect that more people will be supported by fewer providers. At the same time, we expect supports to be provided in far more individualized settings, with service plans and relationships of chosen by recipients, and that these services will be better and at a lower cost per person. We shall see what the future holds.

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## The Importance of Defining Quality of Life Through Personal Outcomes

Carli Friedman, PhD, CQL | The Council on Quality and Leadership

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Historically, quality of life measures concerning people with disabilities were developed for medical contexts and often had a negative spin, focusing on the ‘burden’ of different impairments; however, the concept has shifted in recognition that supports available to the person, their family, community, and society can all positively impact the individual’s quality of life. Not only has the concept of quality of life expanded to contain notions such as security, relationships, self-determination and choice, community integration, and rights, there has also been a recognition that quality of life should be defined specifically through personal outcomes.

Unlike measures that define quality as mere compliance with organizational or regulatory standards, personal outcomes focus on an individualized, person-centered definition of quality. Personal outcomes are non-prescriptive, and the meaning and definition of personal outcomes (for example, how one defines health, friendship, or respect). differs among people. Not only do individual’s perspectives on, and prioritization of, outcomes differ depending on their current and past life experiences, they also have different priorities. For example, some people with intellectual and developmental disabilities may favor interdependence, and thus place less emphasis on independence. As what constitutes ‘quality’ differs from person to person, and as such is not transferable between people, systems and organizations concerned with quality of life must pay attention to personal outcomes. In fact, both person-centered planning and self-determination are based in the idea that quality of life is dependent on personal outcomes.

Choice and self-determination are foundational aspects of personal outcomes. According to self-advocates, “making choices and decisions for ourselves is an important part of who we are. It is fundamental to having control over our own lives and important for securing all other rights: if we are not allowed to make our own decisions, how can we have a voice in anything else that is important to us?”

Personal outcomes are important because they emphasize what really matters in people’s lives and help promote quality in service provision. In the past, a human service organization might have only provided limited opportunities or choices ignored and/or outcome areas not directly related to its mission. However, organizations that focus on personal outcomes find that the relevance and quality of their services improve as they become directly responsive to the goals and desires of the person.

Attention to personal outcomes also results in a different perspective on organizational processes; “when organizations realize that supports are methods, not ends in themselves, they become more thoughtful in connecting services with priority outcomes. They start to question whether they should continue services and supports that may have a strong constituency but are unconnected to personal outcomes.”<sup>1</sup>

Furthermore, by focusing on personal outcomes, organizations often find they can provide increased flexibility in the roles that direct support professionals play in delivering individualized supports. As organizations “examine the alignment between people’s priority outcomes, services that connect to those outcomes, and resources allocated to supporting those outcomes... it is not uncommon for

## Essays That Highlight Key Trends in the Field

organizations to implement changes to better align their practices and resources with what is important to the individuals they support.”<sup>ii</sup>

To ensure people with intellectual and developmental disabilities have a high quality of life, quality must be defined through personal outcomes. Not only do personal outcomes recognize each person’s unique individuality, when systems and organizations incorporate peoples’ personal outcomes into their provision of services, they promote dignity and respect.

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<sup>i</sup>The Council on Quality and Leadership. (2017). *Personal Outcome Measures<sup>®</sup>: Measuring personal quality of life* (3rd Ed.).

<sup>ii</sup>Ibid.

## Advocacy in Action: Power in Working Together

Marty Ford, JD & Kristen McKiernan | The Arc of the United States

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### The Power of Advocacy Movements

Over the last 20–30 years, there have been significant new developments in practice and public policy that emphasize human and civil rights and promote greater independence, self-determination, and community inclusion for people with IDD.

Self-advocates have taken their places in decision making in many arenas, and their desires and concerns are heard at the local, state, and national levels in organizations, government, public agencies, and provider agencies. Self-advocates are defining what they want in terms of their personal quality of life, the supports they need, and from whom they want to receive those supports.

Family advocates have continued to create expanded options and opportunities for their family members of all ages and to support their engagement in a fully inclusive community life.

Organizations and professional advocates have also participated in remarkable changes. National organizations have seen their memberships evolve to include families, self-advocates, and professionals and to see self-advocates take leadership roles. In addition, strong national self-advocacy organizations have emerged to influence practices and public policy.

### Self-Advocates Take the Mic

Today, leaders with IDD advocate for their own best possible life and can provide a voice for others who don't have the opportunity to advocate for themselves. Recently, self-advocates at a conference in Washington, DC took the mic and shared what's important for them to live a meaningful life:

*"People with disabilities, they belong in the community, just like anyone else, truly, because we all get a voice, and we all get a life to live."*

– Melody from Indiana

*"I'm working and I'm out in the community. People*

*know who I am."*

– Jason from Washington

*"My big story is I moved down to my own apartment in October of this year, and that was one big milestone."*

– Julian from Colorado

*"If you don't advocate, nobody is gonna know what really matters to you."*

– Joe from New York

*"As someone with intellectual and developmental disabilities, including autism and multiple other disabilities, I am really proud of the steps we are taking to enhance higher education. As a college student myself, I see us growing towards full inclusion."*

– Savannah from Colorado

### Working Together to Advance Public Policy

Working together, self-advocates, family advocates, and organizations supporting people with IDD and their families worked to advance the rights of people with disabilities to be fully included in their home communities, to leave or avoid institutions and other large settings, and to exercise basic rights to vote, marry, have families, and other rights under the US Constitution. The combined efforts of self-advocates, family advocates, and national organizations resulted in the following:

***Americans with Disabilities Act (ADA)***, enacted in 1990 to prohibit discrimination in public facilities and by public entities. The ADA also served as the basis of the U.S. Supreme Court's decision in the *Olmstead v. LC* case in 1999 which led to more states serving people in their home communities rather than in large institutions. Holding that unjustified segregation of persons with disabilities constitutes discrimination in violation of title II of the Americans with Disabilities Act, the Court's decision helped to open doors for people in profoundly significant new ways.

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**Affordable Care Act (ACA)**, enacted to prohibit discrimination in provision of health care and health insurance and to expand health coverage to previously non-covered people. The ACA's significant improvements to access to health care and home and community based services included the Community First Choice program which gave states the option of adding comprehensive community based services to the Medicaid state plan as an alternative to nursing home and other institutional settings.

**Medicaid long-term supports and services programs** reoriented to spending more funds in the community on significantly more people with IDD than in the past. Further, dedication of the **Medicaid Home and Community Based Services (HCBS)** programs to community-based services only, with significant support to states for transitioning their programs, was intended to ensure focus of those funds in actual community settings.

**Employment policies** developed and implemented to downsize segregated workshops and eliminate sub-minimum wage programs while providing appropriate employment and other supports to people affected by the changes. Passage of the **Workforce Innovation and Opportunity Act (WIOA)** which ensures that Vocational Rehabilitation funds are used to support individuals in competitive, integrated employment, with a focus on transition-aged youth and those with the most significant disabilities.

**Achieving a Better Life Experience (ABLE) Act**, enacted to allow eligible people with disabilities to save money in a special account. The funds are protected from being counted for eligibility purposes for federal means-tested programs like Supplemental Security Income (SSI), Medicaid, housing programs, and the Supplemental Nutrition Assistance Program (SNAP).

**Prohibition of the execution of people with intellectual disability** by the U.S. Supreme Court in *Atkins v. Virginia* (2002), where the Court held that the execution of people with ID was cruel and unusual punishment under the Eighth Amendment of the Constitution. Later rulings clarified that *Atkins* applied to all people diagnosed with ID using clinical standards, as in *Hall v. Florida* (2014), where the Court rejected statutes that disagree with clinical standards for ID diagnosis and in *Moore v. Texas* (2014 and 2019), where the Court again emphasized the need to rely on well-established clinical standards—rather than

stereotypes—in making intellectual disability determinations in death penalty cases.

**Alternatives to full guardianship and conservatorship** developed, including supported decision-making, resulting from recognition of the rights of individuals to make decisions for themselves as well as the limitations of existing guardianship and conservatorship systems and approaches. In 2017, the Uniform Law Commission<sup>1</sup> completed, for state legislatures' consideration, The Uniform Guardianship, Conservatorship, and Other Protective Arrangements Act (UGCOPAA), a comprehensive statute which promotes person-centered planning to incorporate an individual's preferences and values into a guardianship order and requires courts to order the least-restrictive means necessary, including consideration of supported-decision making, for people who need some support.

**Rosa's Law** enacted, to eliminate the "r" word from certain federal laws, with other federal programs and state laws following suit; the initiatives were led by self-advocates and family members.

**Matthew Shepard and James Byrd, Jr. Hate Crimes Prevention Act** enacted, which added "disability" to the list of bias-motivated violent crimes that the Justice Department is authorized to investigate and prosecute.

**Disability Integration Act (DIA)** introduced, a bill written by people with disabilities to secure the right of all individuals with disabilities to live in the community.

**Waiting lists for services** reduced or eliminated in a few places gives hope to advocates at the state and national levels to continue working toward the goal of the total elimination of waiting lists.

**Wages and career opportunities** improved for direct support workers in several states with continued advocacy to achieve nation-wide gains in these areas.

In addition to the significant accomplishments above, there have also been many hard-fought battles to protect vital programs such as Medicaid, SSI, and Social Security Disability Insurance (SSDI).

### Power Into The Future

Local and national organizations worked in coalitions

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together and with others to ensure enactment and implementation of the above and many other policies. Work continues with the recognition that much more remains to be done to fully secure the rights of people with disabilities and full inclusion in their communities.

Moving forward, the perspectives of people with IDD must continue to be front and center in federal policy.

*“If I could say one thing to the President and the Congress, it would be my community has worked much too hard to move away from institutions. I will not let us go backward. It is bad for me, and it is bad for my country.”*

– Bryan from North Carolina

*“The only way to make a difference and a change is to speak up, making others aware of what our needs and desires are, just like any average person.”*

– Steve from Virginia

*“It’s not going to come to you, you have to get your voices heard out there.”*

– Barbara from New Jersey

*“We have power to continue our advocacy work and to make our lives so much greater!”*

– Martha from Georgia

As the disability rights movement has evolved and grown, so has the advocacy role of people with IDD. Advocacy today will benefit generations to come, and it is invigorating to think about what we can achieve in the future, as self-advocates continue to advance the field.

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<sup>i</sup>“The Uniform Law Commission (ULC, also known as the National Conference of Commissioners on Uniform State Laws), established in 1892, provides states with non-partisan, well-conceived and well-drafted legislation that brings clarity and stability to critical areas of state statutory law.” <https://www.uniformlaws.org/aboutulc/overview>

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## Workforce: Recruiting and Retaining Talent in the Field

Bonnie-Jean Brooks | OHI & Robert S. Budd | Family Residences and Essential Enterprises, Inc.

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The demographics of the direct support workforce have shifted over the last 20 years, influenced by the ebb and flow of the economy, unemployment, and the demographics of the country.

Today, we are on the precipice of a workforce crisis: the number of people entering the direct support workforce are no longer adequate to meet the demand of those who need them. Literally, soon there will not be enough people to recruit for these roles. This is an unprecedented circumstance requiring unprecedented solutions.

The direct support workforce crisis has long been foreseen. Over the last decade, leading national organizations have documented the causes of this crisis and explored how support needs might be met in the future. Over the last few years, a consensus has emerged on the need for a multi-pronged approach.

In a 2017 report from ANCOR, *Addressing the Disability Services Workforce Crisis of the 21st Century*,<sup>i</sup> identified higher wages, improving professional recognition, more effective use of technology, and the creation of career ladders for workers as possible solutions.

The 2017 report of the President's Committee for People with Intellectual Disabilities, *America's Direct Support Workforce Crisis: Effects on People with Intellectual Disabilities, Families, Communities and the U.S. Economy*,<sup>ii</sup> also identified improving professional recognition, expanding recruitment strategies, improving training and wages, and using technology to enhance supports as possible solutions.

The winter/spring 2018 issue of *Impact*,<sup>iii</sup> a quarterly publication of the University of Minnesota, Institute on Community Integration, was dedicated to the

direct support workforce crisis. Recommendations from this feature issue included improving professional recognition, expanding recruitment strategies, funding competency-based training for the workforce, increasing the use of technology-enhanced supports, creating an occupational title recognized by the Bureau of Labor Statistics, and gathering comprehensive direct support workforce employment data across states.

In these, and many other sources, the voices people receiving supports, their families, and direct support professionals can be found. In the face of the workforce crisis, there is still hope, resilience, determination, stories of inspiration, and calls for more creativity, innovation, technology applications, and new ways of thinking.

One constant is the creativity of those in our field—from all walks of life—that see opportunity where others see challenge. It is inspiring to see millennials and generation Z team members coming up with solutions using off-the-shelf technology. Another constant is the passion for making a difference in the lives of people with disabilities.

While the landscape of support provision has changed the first two decades of this century, our core values have remained the same. Ultimately, we need to take the steps necessary to support the recruitment and retention of the talent that is necessary to meet the needs of people with disabilities.

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<sup>i</sup>ANCOR (2017). *Addressing the Disability Services Workforce Crisis of the 21st Century*, [https://cqrcengage.com/ancor/file/ZuL1zlyZ3mE/Workforce\\_20White\\_20Paper\\_20-20Final\\_20-20hyperlinked\\_20version.pdf](https://cqrcengage.com/ancor/file/ZuL1zlyZ3mE/Workforce_20White_20Paper_20-20Final_20-20hyperlinked_20version.pdf)

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<sup>ii</sup>President's Committee for People with Intellectual Disabilities (2017). *America's Direct Support Workforce Crisis: Effects on People with Intellectual Disabilities, Families, Communities and the U.S. Economy*, [https://acl.gov/sites/default/files/programs/2018-02/2017\\_20PCPID\\_20Full\\_20Report\\_0.PDF](https://acl.gov/sites/default/files/programs/2018-02/2017_20PCPID_20Full_20Report_0.PDF)

<sup>iii</sup>Feature Issue: The Direct Support Workforce and People with Intellectual and Developmental Disabilities (Winter/Spring 2018). *Impact*, 31, 1. Research & Training Center on Community Living, Institute on Community Integration, University of Minnesota, <https://ici.umn.edu/products/impact/311/#Cover>

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## Changing Service, Changing Workforce

Regis Obijiski & Joseph Macbeth | National Association of Direct Service Professionals

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### Changing Roles

While the world of services for people with IDD has been changing dramatically from program-based to individualized supports, there can be no further service transformation without a transformation of the workforce. In particular, the role of direct support professionals (DSPs) who are at the frontline of a system of paid services and supports for people with IDD, must be transformed.

Unlike families (who still provide the majority of supports), the DSP workforce has evolved from its roots of providing care to delivering professional, individualized supports. This evolution emphasizes the vital role of the DSP in assisting the person with IDD achieve their personal outcomes.

The emerging role of the DSP requires knowledge, skills, and ethics to support people with IDD live a life they value, engage in informed decision-making, develop enriching friendships, engage in work, be involved in the community, and be valued by others. To deliver high quality, professional support valued by the individuals they work with, DSPs must have substantial knowledge, independent judgement, and firm ethics.

### Knowledge and Skills

Several projects that have examined and validated the knowledge and skills needed by DSPs to be effective in today's workforce, agree that to be effective, DSP preparation must be competency-based. Rather than providing an academic curriculum with hopes for practical application, this research tells us that DSP preparation should focus on "core" competencies for the work to be done. Recent examples of core competency standards are:

### Community Support Skill Standards (CSSS) for the Direct Support Workforce<sup>i</sup>

These 1996 standards were developed and nationally validated by Human Services Research Institute under a joint grant from the US Departments of Labor and Education.

### US Department of Labor (DOL) Competency-Based Standards for Direct Support Professionals<sup>ii</sup>

These 2010 standards were developed by the US DOL, NADSP, and ANCOR, and based on the CSSS, the NADSP direct support professional credential (2007), and the US DOL time-based Direct Support Specialist Apprenticeship (2001).

### Centers for Medicare and Medicaid Services (CMS) Direct Service Workforce Core Competencies<sup>iii</sup>

The 2014 final competency set was developed by the University of Minnesota Research and Training Center on Community Living, in partnership with others. The competency set was validated with stakeholder consensus process<sup>iv</sup> in 2013 and with survey and focus groups<sup>v</sup> in 2014.

### National Frontline Supervisor Competencies<sup>vi</sup>

This 2013 competency set for supervisors of direct support professionals was developed by the University of Minnesota Research and Training Center on Community Living, in partnership with others.

### Codes of Ethics and Conduct

Codes of ethics and codes conduct share a common goal of self-regulating behavior in different ways. A code of ethics governs the decision-making process and guides judgment on wide- ranging topics. A code of ethics is values-based framework exercising good judgment in varied situations. The NADSP Code of Ethics<sup>vii</sup> is one such example.

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A code of conduct, on the other hand, applies ethics to specific situations and stipulates certain behaviors that are required or prohibited. A code of conduct requires clear and specific obedience and compliance, leaving little need for judgment.

### Credential

The purpose of credentialing is to establish a standard for professional knowledge and performance. Typically, credentials are gained through the successful completion of education or training and demonstrated proficiency in standards of practice and maintained through continuing education relevant to the profession.

Credentialing solidifies the expectations of professionals, and often provides them with career lattices. Additionally, services are improved because the workforce who provides the services must all meet the standards of the credential. Two examples of credentials currently open to DSPs in New York use an apprenticeship model, with one requiring time-based work experience using the CSSS,<sup>viii</sup> the other requiring the attainment of demonstrated, observable and measurable competencies in lieu of meeting time-based work experience and on-the-job learning requirements.<sup>ix</sup>

### Stabilizing the Workforce

Professionalizing the DSP role is no easy matter, but it is precisely what is needed to stabilize this workforce and achieve the personal outcomes of people with IDD.

The largest influence on the DSP profession is not adherence to mission but rather, accountability for how that mission is practiced (its perceived quality). Pay for performance in any business creates a powerful incentive to understand, measure, and meet the defined notion of quality. Viewing quality as achieving an individual's desired personal outcomes answers the fundamental question: "What difference does your service mean to me?"

An organization that determines its success rests on personal outcomes will require DSPs with a very sophisticated combination of knowledge, skills, and ethics. DSPs of this dimension do not exist in the

general job market. To stabilize this essential workforce, their skills must be developed, their performance expectations codified with a credential, and they must be compensated with a living wage.

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<sup>i</sup>Community Support Skill Standards (CSSS) for the Direct Support Workforce (1996), <https://nadsp.org/15-competency-areas>

<sup>ii</sup>DOL Competency-Based Standards for Direct Support Professionals (2010), [https://www.doleta.gov/oa/bul10/Bulletin\\_2010\\_31\\_NADSP\\_ANCOR.pdf](https://www.doleta.gov/oa/bul10/Bulletin_2010_31_NADSP_ANCOR.pdf)

<sup>iii</sup>CMS Direct Service Workforce Core Competencies (2014), <https://www.medicaid.gov/medicaid/ltss/downloads/workforce/dsw-core-competencies-final-set-2014.pdf>

<sup>iv</sup>Phase III-A: Road Map of Core Competencies for the Direct Service Workforce Stakeholder Consensus (2013), <https://www.medicaid.gov/medicaid/ltss/downloads/workforce/dsw-core-competency.pdf>

<sup>v</sup>Phase III-B: Road Map of Core Competencies for the Direct Service Workforce Project Validation (2014), <https://www.medicaid.gov/medicaid/ltss/downloads/workforce/dsw-core-competencies-phase-iii-december-2014.pdf>

<sup>vi</sup>Frontline Supervisor Core Competency Set (2013), [http://rtc.umn.edu/docs/National\\_Frontline\\_Supervisor\\_comp\\_7-2-13.pdf](http://rtc.umn.edu/docs/National_Frontline_Supervisor_comp_7-2-13.pdf)

<sup>vii</sup>NADSP Code of Ethics (2016), <https://www.nadsp.org/code-of-ethics-text>

<sup>viii</sup>New York State DSP Apprenticeship, Time-Based (2006), <https://labor.ny.gov/apprenticeship/pdfs/ActiveTrades/89-547.pdf>

<sup>ix</sup>New York State DSP Apprenticeship, Competency-Based (2013), <https://labor.ny.gov/>

# National Honorees

Recipients of this honor are recognized for their significant national contributions to or impact in the field of IDD in the U.S. between 2000 and 2020. These individuals or groups were often engaged in nationally significant research, practice, public policy, and advocacy initiatives that enhanced quality of life for people with IDD.



## 2020 National Honorees



**Alison Barkoff, JD**

Center for Public Representation  
*Having made an overall contribution  
through public policy*

Ms. Barkoff is a disability advocate who works to advance the rights and inclusion of people with disabilities. As the Director of Advocacy at the Center for Public Representation, Ms. Barkoff leads disability policy and litigation about community integration, access to healthcare, employment, housing, and inclusive education. She has testified before Congress and the U.S. Commission on Civil Rights and was appointed to a federal advisory committee on disability employment. She is a co-chair of the Consortium for Citizens with Disabilities and leads several other disability coalitions.

Ms. Barkoff previously served as Special Counsel for Olmstead Enforcement in the Civil Rights Division of the Department of Justice, where she enforced the rights of people with disabilities to live, work and receive services in the community. She also worked on disability policy at the Centers for Medicare & Medicaid Services and the Department of Labor. Prior to her government service, Ms. Barkoff was an attorney with the Bazelon Center for Mental Health Law and clerked for judges on federal district and appellate courts.

Ms. Barkoff has an adult brother with an intellectual disability and has been involved in disability advocacy most of her life. She has published numerous articles and speaks nationally. She earned a bachelor's degree from Cornell University (New York) and a juris doctor degree with highest honors from Emory University School of Law (Georgia).

State: Washington, DC



**Julia Bascom**

Autistic Self Advocacy Network  
*Having made an overall contribution  
through advocacy*

In her role as the Executive Director of the Autistic Self Advocacy Network (ASAN) since 2017, Ms. Bascom has worked to increase both public acceptance of neurodiversity and the authentic representation of people with autism in public policymaking. Most notably, she gave the keynote address at the United Nations celebration of World Autism Awareness Day on April 2, 2018.

Ms. Bascom works with leaders of other national disability organizations to design and champion scalable public policy solutions, build advocacy coalitions, and develop research partnerships. She has served on the boards of directors of the Consortium for Citizens with Disabilities, Advance CLASS, the Collaboration to Promote Self-Determination, Allies for Independence, the Alliance for Citizen Directed Supports, and No Pity. She has served on advisory boards, leadership councils, or steering committees for the Centene National Disability Advisory Council, the National Disability Leadership Alliance, Felicity House, and the HSC Foundation's Youth Transitions Collaborative.

A person who identifies as autistic, Ms. Bascom is a leading advocate for full community inclusion of people with autism. She has authored several articles in peer-reviewed journals concerning gender differences in autism and *The Obsessive Joy of Autism* (2015, Jessica Kingsley Publishers), a reflection on the lived experience of autism. Ms. Bascom's contributions in the areas of autism inclusion and acceptance have informed and advanced the work of self-advocates and professionals.

State: Washington, DC

## 2020 National Honorees



**Henry (Hank) Bersani, Jr., PhD**  
(1951–2012)

*Having made an overall contribution  
through scholarship, teaching, and service*

Dr. Bersani was a respected leader in the field of special education and disability rights. Over the course of his career, he held positions at Syracuse University, Oregon Health & Science University, and Western Oregon University. His influence extended to collaborations with The Arc Oregon, Oregon Council on Developmental Disabilities, United Cerebral Palsy Oregon, Human Services Research Institute, Portland State University, Lewis & Clark College, and The Arc of Multnomah County.

A Fellow of AAIDD, Dr. Bersani also served as a Joseph P. Kennedy Jr. Public Policy Fellow, assigned to U.S. Senator John H. Chafee (R-RI), and a Mary Switzer Distinguished Research Fellow with the National Institute on Disability and Rehabilitation Research. He was an integral part of the AAIDD's name change from AAMR in 2007.

Dr. Bersani left an extensive body of scholarship, teaching, and service in the areas of education, public health, service quality, and communication. He earned a bachelor's degree at St. Michael's College (Vermont) and both master's and doctoral degrees from Syracuse University (New York).

State: Oregon



**Alexandra (Alix) Bonardi, MS, MHA**

Human Services Research Institute and  
University of Massachusetts Medical School

*Having made an overall contribution  
through research and public policy*

Ms. Bonardi's work concerns person-centered practices, measures of quality, health surveillance, health-service utilization, and program evaluation in both of her current roles: Senior Policy Specialist at the Human Services Research Institute (HSRI) and Clinical Assistant Professor in the Department of Family Medicine and Community Health at the University of Massachusetts Medical School (UMMS).

Ms. Bonardi directs the National Core Indicators (NCI) project—a data-collection effort focused on performance and outcome measures—in addition to other national efforts: the National Center on Advancing Person-Centered Practices and Systems and the Developing HCBS Quality Measures project of NCI.

Ms. Bonardi has authored or co-authored several book chapters and a number of peer-reviewed articles on health disparities, public health surveillance, and the use of data to inform long-term services and supports (LTSS) policies, and she serves as a reviewer for a number of peer-reviewed international journals. In addition, she currently serves on the board of directors of AAIDD and the advisory boards of the National Center for Cultural Competence at Georgetown University (Washington, DC) and the Right Care Now Project.

A Fellow of AAIDD, Ms. Bonardi earned a bachelor's degree from McGill University (Quebec, Canada), a master's degree in occupational therapy from Columbia University (New York), and a master's degree in health administration from Suffolk University (Massachusetts). In 2001, she completed the UMMS Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program.

State: Massachusetts

## 2020 National Honorees



### **David Braddock, PhD**

University of Colorado (Emeritus)  
*Having made an overall contribution  
through research and public policy*

Dr. Braddock is the past Associate Vice President of the University of Colorado, emeritus founding Director of the Coleman Institute, and emeritus Coleman-Turner Endowed Chair in Cognitive Disability. Dr. Braddock previously served the University of Illinois at Chicago in the following capacities: Professor of Human Development and Public Health, founding head of the Department of Disability and Human Development and of its research institute, and Associate Dean.

Dr. Braddock's many publications addressed long-term care, health promotion, public policy, and technology access. He founded the national surveillance project that resulted in many editions of *The State of the States in Intellectual and Developmental Disabilities*, a resource in near-constant use by advocates to improve the quality of life of people with disabilities.

Dr. Braddock founded the Archives and Library on Disability at the University of Colorado, established from his personal collection of books, ephemera, and materials related to disability. The purpose of the collection is to acquire, preserve, and catalogue materials on the history of disability and to make those materials available to scholars.

A Fellow of AAIDD, Dr. Braddock served as President of the AAIDD board of directors from 1993 to 1994 and received many honors and accolades over his career. He earned a bachelor's and a master's degree in government and a doctorate in special education from the University of Texas.

State: Colorado



### **Valerie J. (Val) Bradley**

Human Services Research Institute (Emerita)  
*Having made an overall contribution  
through research and public policy*

Ms. Bradley led the Human Services Research Institute (HSRI) as President from its inception in 1976 until January 2017, when she became President Emerita. Following her transition in roles, she has continued her work at HSRI as Project Director and Senior Analyst. Prior to founding HSRI, Ms. Bradley held positions at the California State Assembly Office of Research and Arthur Bolton Associates.

Ms. Bradley has been a leader in promoting the use of data and other evidence as the basis for public policies concerning people with IDD and their families. She was instrumental in the founding of the National Core Indicators (NCI) project in 1997 and its continuance in partnership with the National Association of State Directors of Developmental Disabilities Services (NASDDDS), which has grown to become an integral piece of more than half of all states' quality-management systems.

In addition, Ms. Bradley was instrumental (along with NASDDDS and the University of Minnesota) in the founding of the biannual Reinventing Quality Conference. First held in 1991, the conference gathers and disseminates best-practice information on individualized, person-centered supports and related quality-management activities.

A Fellow of AAIDD, Ms. Bradley served as President of the AAIDD board of directors from 2005 to 2006 and earned a master's degree in political science from Rutgers University.

State: Massachusetts

## 2020 National Honorees



**William Bronston, MD**  
*Having made an overall contribution  
through service and advocacy*

Dr. Bronston worked for 3 years as a staff physician at Willowbrook State School in Staten Island, New York, before returning to his home state of California in 1975, where he served for 28 years in senior state positions, retiring as Medical Director of the State Department of Rehabilitation.

While in medical school in 1964, Dr. Bronston founded the Student Health Organization, a nationwide graduate health science student movement dedicated to promoting universal health care as a human right. After completing medical school, Dr. Bronson became a strong advocate for people with disabilities and for deinstitutionalization. He documented in photographs the conditions in Willowbrook, and many of these pictures were used as exhibits in the lawsuit that resulted in Willowbrook's closing, in the Geraldo Rivera expose, and by the Kennedy family in their advocacy.

From 1991 to 1994, Dr. Bronson also led Project Interdependence, a multistate project of national significance to promote youth leadership development through visual media and the arts. Since 1995, he has championed Tower of Youth, a project for youths to use media arts to advocate for social justice and improved economic, educational, and health outcomes. Dr. Bronston earned a medical degree from the University of Southern California School of Medicine.

State: California



**Bonnie-Jean Brooks**  
OHI  
*Having made an overall contribution  
through service*

Ms. Brooks has led OHI located in Bangor, Maine, as President and CEO, from its inception in 1979. Her previous roles have included daycare director, teacher, and recreation director for a state institution. Additionally, she served the President's Committee for People with Intellectual Disabilities as an employee and as a consultant over the course of four years.

Representing the plaintiffs, she chaired the Consumer Advisory Board for the Pineland and Community Consent Decrees for class members who had been committed to Pineland Center. From 1978 through 2010, this Board oversaw rigorous standards for treatment, both at Pineland and for Class Members in the community.

Ms. Brooks currently serves on the board of directors of MACSP and the American Network of Community Options and Resources (ANCOR) Foundation. She is a two-term past President of both ANCOR and the Maine Association for Community Service Providers (MACSP) and served on the boards of AAIDD and Commission on Accreditation of Rehabilitation Facilities (CARF) International. Ms. Brooks earned a bachelor's degree from Sargent College, Boston University (Massachusetts).

State: Maine

## 2020 National Honorees



### **George H.W. Bush**

(1924-2018)

President of the United States of America, 1989–1993

*Having made an overall contribution  
through public policy*

Over the course of his political career, Mr. Bush served in the U.S. House of Representatives, as U.S. Ambassador to the United Nations, as Director of Central Intelligence, and as the 43rd Vice President of the U.S., and was the 41st President of the United States.

During World War II, Mr. Bush served in the U.S. Navy, and earned a bachelor's degree from Yale University (Connecticut). He is the father of President George W. Bush.



### **George W. Bush**

President of the United States of America, 2001–2009

*Having made an overall contribution  
through public policy*

Over the course of his political career, Mr. Bush served as the 46th Governor of Texas from 1995 to 2000 and was the 43rd President of the United States.

Mr. Bush graduated from Yale University (Connecticut) and the Harvard Business School (Massachusetts). Mr. Bush is the eldest son of George H.W. and Barbara Bush and the second person to become a U.S. President after one of their parents.

### **Americans with Disabilities Act**

On July 26th, 1990, President George H.W. Bush, the 41st President of the United States, signed into law the Americans With Disabilities Act (ADA). At the signing event, he said, "With today's signing, every man, woman, and child with a disability can now pass through once-closed doors into a bright new era of equality, independence, and freedom."

Nearly 20 years later, on September 25, 2008, the Americans with Disabilities Amendments Act of 2008 was signed into law by President George W. Bush, the 43rd President of the United States. The amendments to the Act broadened the definition of disability and extended the ADA's protections to a greater number of people.



## 2020 National Honorees



### **Michael Callahan**

Marc Gold & Associates

*Having made an overall contribution  
through service*

Mr. Callahan has worked with Marc Gold & Associates (MG&A) since 1979, serving as its President since 1982. MG&A is a network of consultants who provide technical assistance to systems, organizations, and families in the United States, Canada, and Europe that are interested in the complete community participation of people with severe disabilities.

In addition to his training and consulting work, Mr. Callahan has directed several demonstration, research, and technical-assistance projects designed to improve supported and customized employment for people with severe disabilities. These projects have included a demonstration to increase access of people with severe disabilities to generic one-stop employment centers; a project that examined the feasibility of providing vouchers to people with severe physical disabilities to purchase their own employment services; and a pilot project to test the feasibility of an individualized, competency-based curriculum for staff supporting the employment of people with severe disabilities.

Mr. Callahan has authored, co-authored, or edited a number of chapters, books, manuals, and curricula on supported employment for people with IDD.

State: Mississippi



### **Bob Casey**

United States Senator from Pennsylvania, 2006–present

*Having made an overall contribution  
through public policy*

Mr. Casey was elected to his senate seat in 2006. His previous roles included service as the Pennsylvania Auditor General and as Pennsylvania Treasurer. As a member of the Senate Committee on Health, Education, Labor and Pensions and the Committee on Finance, he advocates for people with disabilities.

Mr. Casey is a longtime supporter of full funding for the Individuals with Disabilities Education Act (IDEA). He drafted and championed the Achieving a Better Life Experience (ABLE) Act, signed into law by President Obama in 2014, which provides the opportunity for people with disabilities to save for important expenses while retaining eligibility for Medicaid. In 2015, Mr. Casey introduced the Empowering Parents and Students Through Information Act, which was enacted as part of the reauthorization of the Elementary and Secondary Education Act, which clarifies state guidelines and enables parents to make more informed decisions about which educational track is best for their child with a disability.

In 2018, Mr. Casey convened a Disability Employment Summit to highlight the efforts of Pennsylvania employers who are aggressively recruiting and hiring people with disabilities and the work of many nonprofit organizations that are working to increase competitive, integrated employment for people with disabilities.

State: Pennsylvania

## 2020 National Honorees



### **Tony Coelho**

United States Representative from California, 1979–1989  
*Having made an overall contribution  
through public policy*

Mr. Coelho served six consecutive terms as a U.S. Representative from California. He served on the Agriculture, Interior, Veterans Affairs, and Administration Committees during his tenure, but he specialized in rights of people with disabilities. Mr. Coelho was diagnosed with epilepsy as an adult; when the diagnosis was reported to the state of California, he lost both his driver's license and his health insurance.

Mr. Coelho was a primary sponsor of the Americans with Disabilities Act (ADA) in the House, which was introduced in 1988 and signed into law in 1990. The ADA provided protection against discrimination for people with disabilities similar to the protections afforded by the Civil Rights Act of 1964, and in addition required the accessibility of public accommodations and required employers to provide reasonable accommodations to employees with disabilities.

Following his Congressional service, and among other roles, Mr. Coelho served as Chairman of the President's Committee on Employment of People with Disabilities (1994–2001). He is a former Chairman and current member of the board of directors of the American Association of People with Disabilities and serves on the board of directors of the Epilepsy Foundation and the advisory board of the George Washington University Graduate School of Political Management. Among his many accolades, in 2015 he was named the inaugural inductee to the Susan M. Daniels Disability Mentoring Hall of Fame for his commitment to mentoring and improving the lives of people with disabilities.

State: California



### **Al Condeluci, PhD**

Community Living and Support Services (Emeritus)  
and University of Pittsburgh  
*Having made an overall contribution  
through teaching and service*

Dr. Condeluci served as the CEO of Community Living and Support Services (CLASS), affiliated with United Cerebral Palsy (UCP), from 1991 until his retirement in 2018. In this role he directed and administered services and supports for people with intellectual disabilities in western Pennsylvania. Since 1995, Dr. Condeluci has taught courses in the School of Social Work and the School of Health and Rehabilitation Science at the University of Pittsburgh.

In 2008, Dr. Condeluci co-founded the Interdependence Network, an international community of practice committed to shifting rehabilitation toward an interdependence model designed to build and foster social capital and social inclusion within communities to support the full inclusion of people with disabilities.

Dr. Condeluci has authored or co-authored a number of books, curricula, and manuals that address social capital, interdependence, and systems change, and he has served on the boards of directors of several nonprofit organizations in Pennsylvania. He earned a bachelor's degree in psychology at Youngstown State University (Ohio) and both master's (social work) and doctoral (education) degrees from the University of Pittsburgh (Pennsylvania).

State: New York

## 2020 National Honorees



### **James W. (Jim) Conroy, PhD**

Center for Outcome Analysis  
*Having made an overall contribution  
through research*

Dr. Conroy has been the President and CEO of the Center for Outcome Analysis since 1985. His previous roles have included positions at Quality Management Associates and the Institute on Disabilities at Temple University (Pennsylvania).

Dr. Conroy has been a leader in the movement to assess the empirical outcomes of social programs. He was the Principal Investigator of the Pennhurst Longitudinal Study concerning the closing of Pennhurst Center in Pennsylvania. This study demonstrated that people with IDD who moved from the institution to the community realized increases in their adaptive skills, opportunities for integration, general happiness, and longevity. The study, and later replications in other states, helped support the national move from institutions to community.

Using the same empirical approach, Dr. Conroy has demonstrated that the implementation of self-determination strategies results in positive outcomes for people with IDD, notably in increased senses of personal control, satisfaction, and qualities of life.

Dr. Conroy has authored or co-authored a number of books, research reports, and peer-reviewed articles. A Fellow of AAIDD, Dr. Conroy earned a master's degree in sociology and a doctorate in medical sociology from Temple University (Pennsylvania).

State: Pennsylvania



### **Bob Dole**

United States Senator from Kansas, 1969–1996  
*Having made an overall contribution  
through public policy*

Mr. Dole represented Kansas in the U.S. House of Representatives from 1961 to 1969 and in the U.S. Senate from 1969 to 1996. During his service in the U.S. Army during World War II, he was seriously wounded in his back and right arm, resulting in a permanent limitation to his arm's mobility.

During his tenure in the House of Representatives, Mr. Dole voted for the Civil Rights Acts of 1964 and 1968 and the Voting Rights Act of 1965. During his tenure in the Senate, he supported every major disability initiative before Congress.

Mr. Dole played key roles in passing the 1973 Rehabilitation Act, the 1975 Developmental Disabilities Assistance and Bill of Rights Act, the 1975 Education for All Handicapped Children Act (now known as IDEA), the 1986 Protection and Advocacy for the Mentally Ill Act, the 1986 Air Carriers Access Act, the 1986 Education of the Deaf Act, the 1988 Technology-Related Assistance for Individuals with Disabilities Act, and the 1990 Television Decoder Circuitry Act. In addition, he led the critical negotiations to ensure passage of the Americans with Disabilities Act in 1990.

On December 4, 2012, Mr. Dole made an appearance on the Senate floor to advocate for ratification of the Convention on the Rights of Persons with Disabilities (CRPD). While it was not ultimately ratified, he brought national attention to the scope and importance of the CRPD.

State: Kansas

## 2020 National Honorees



### **Steven M. (Steve) Eidelman, MSW, MBA**

University of Delaware

*Having made an overall contribution  
through service, public policy, and training*

Mr. Eidelman is the H. Rodney Sharp Professor of Human Services Policy and Leadership in the Department of Human Development and Family Sciences and the Biden School of Public Policy and Administration and is the Faculty Director of the National Leadership Consortium on Developmental Disabilities. In these roles, he teaches and mentors the next generation of leaders. Mr. Eidelman's research interests focus on community-based and inclusive supports for people with intellectual disability and their families.

Mr. Eidelman's previous roles have included Executive Director of the Joseph P. Kennedy Jr. Foundation, Executive Director of The Arc of the United States, Interim Executive Director of the Association of University Centers on Disabilities (AUCD), and Deputy Secretary for the Pennsylvania Department of Public Welfare. He has delivered numerous presentations to national audiences and has authored or co-authored numerous books, book chapters, white papers, and peer-reviewed articles concerning full inclusion of people with IDD, public policies, and the development of leadership.

A Fellow of AAIDD, Mr. Eidelman has served as President of its board of directors (2008–2009), on the President's Committee for People with Intellectual Disabilities (1996–1998), and on numerous boards of directors and advisory committees. Mr. Eidelman earned a master's degree in social work from the University of Maryland, a master's degree in business administration from Loyola College (Maryland), and a post-master's certificate in the administration of social services from Temple University (Pennsylvania).

State: Delaware



### **Cathy Ficker Terrill, MA**

Independent Court Monitor

*Having made an overall contribution  
through service and advocacy*

Ms. Ficker Terrill has been the Court Monitor for *Lane v. Brown* since 2016. In this role, she monitors the ongoing implementation of a settlement agreement between the U.S. DOJ and the state of Oregon regarding Medicaid-funded supports for transition youth and its individuals from sheltered workshops to competitive employment. Ms. Ficker Terrill has held academic appointments at the University of Illinois and Elmhurst College.

Ms. Ficker Terrill's previous roles include CEO of the Council on Quality and Leadership (CQL; 2013–2017), CEO of the Institute on Public Policy for People with Disabilities (2010–2013), CEO of the DuPage and Kendall Housing Authority (2011), CEO of the Ray Graham Association for People with Disabilities (2001–2010), Vice President of the Brain Injury Association of America (1999–2001), and Director of the Illinois Planning Council on Developmental Disabilities (1989–1992). In these roles, she successfully advocated for state and federal systems change and led the development of quality outcome standards for people with IDD.

A Fellow of AAIDD, Ms. Ficker Terrill served two successive terms on the President's Committee for People with Intellectual Disabilities (1995–2002), on the board of directors of AAIDD (President 200–2001) and HSRI (current Chairperson). A parent of an adult daughter with IDD and a professional who has experienced a traumatic brain injury, Ms. Ficker Terrill earned a master's degree in disability studies and a certificate in maternal and child health from the University of Illinois at Chicago. She volunteers in numerous countries around the world to establish and improve systems for people with disabilities.

State: Illinois

## 2020 National Honorees



### Chester Finn

New York State Office for People with  
Developmental Disabilities  
*Having made an overall contribution  
through advocacy*

Mr. Finn currently works for the New York State Office for People with Developmental Disabilities (OPWDD) and serves on the board of directors of the National Alliance for Direct Support Professionals (NADSP).

A disability rights activist, Mr. Finn has worked diligently to educate people with disabilities about their right to vote, to mentor young advocates, and to influence disability policy at the state and national levels. His efforts have resulted in positive outcomes for people with IDD in housing, employment, and quality of life.

Mr. Finn was appointed by President Obama to a term on the board of the National Council on Disability, served three terms as the President of the board of directors of Self Advocates Becoming Empowered (SABE), and served one term as President of the Self-Advocacy Association of New York State.

State: New York



### Flame

L-R: Debbie Woodruff, Karl Blanchard, Adrienne Phillips,  
Andrew Carpenter, Michelle King, David LaGrange,  
Shawn Lehr, & Nick Robinson  
*Having made an overall contribution  
through advocacy*

Formed in 2003, Flame is a band of musicians that has performed around the world and changed public perceptions of disability through its performances.

Flame showcases its members' abilities as talented musicians and provides a platform for their self-advocacy. Each time they perform, the band members talk about how Flame has changed their lives and helped them achieve goals and dreams, and they encourage others to set and meet their own goals.

Flame has been featured in *People* magazine and on ABC's *Good Morning America*, and they have performed at the Rock and Roll Hall of Fame (Ohio). At the request of the Kennedy-Shriver family, Flame also performed at two separate events recognizing the 50th anniversary of Special Olympics.

In its 17 years, Flame has released six CDs and a single. The group travels on a custom tour bus when performing in the greater Northeast area of the United States. In addition to performances at over 80 venues per year, Flame hosts a "Rock for Abilities" concert during national Developmental Disabilities Awareness Month at The Arc Lexington (New York).

State: New York

## 2020 National Honorees



### **Martha (Marty) Ford, JD**

The Arc of the United States  
*Having made an overall contribution  
through public policy*

Ms. Ford is currently Senior Advisor for Public Policy at The Arc of the United States (The Arc). She joined the national public policy office in 1984 and during her tenure has worn many hats, including Director of Legal Advocacy (2003–2010) and Senior Executive Officer for Public Policy (2011–2019) focused on federal legislative and regulatory efforts to improve the lives of people with IDD and their families. Ms. Ford also chaired the Consortium for Citizens with Disabilities (2007-2009), a policy-focused coalition of over 100 national organizations.

Ms. Ford is strong advocate for effective public policies concerning long-term services and supports for people with IDD. She has extensive knowledge of Titles II, XVI, XVIII, and XIX of the Social Security Act—including Medicaid, Medicare, Supplemental Security Income, Social Security disability programs, and the solvency of the Social Security trust funds—and is a skillful advocate for and strategist regarding the preservation of funding to entitlement programs. For a decade, Ms. Ford has guided development of the legislative policy goals and the position statements of The Arc; staffed the joint The Arc–AAIDD Policy and Positions Committee; and, for many years, led the Disability Policy Seminar, an annual conference jointly planned by a consortium of major national disability organizations.

A sibling of a man with IDD, Ms. Ford earned a bachelor's degree from the University of Virginia, a master's degree from the Pratt Institute (New York), and a juris doctor degree from the George Washington University National Law Center (Washington, DC).

State: Washington, DC



### **Joni Fritz**

American Network of Community Options  
and Resources (Emerita)  
*Having made an overall contribution  
through service and public policy*

Ms. Fritz served as the CEO of the American Network of Community Options and Resources (ANCOR) for 25 years before her retirement. In this role, she built a community of providers who are committed to the continuous improvement of community supports and the full inclusion of people with IDD. She is currently a consultant focusing on Federal Labor Standards Act and the Life Safety Code of the National Fire Protection Association.

During her tenure at ANCOR, Ms. Fritz worked with legislators and federal regulatory agencies to advance community living opportunities for people with IDD. An expert in the work of the Wage and Hour Division of the U.S. Department of Labor, she helped to shape public policies and practices concerning the delivery of community-based residential supports as the states deinstitutionalized. Among her many accomplishments, Ms. Fritz played a key role in shaping and clarifying federal regulations to assure that overnight work by direct support professionals (DSPs) was a Medicaid-reimbursable service.

Ms. Fritz was among the founders of the Consortium for Citizens with Disabilities (CCD), a coalition of national organizations that works to assure that federal public policies advance the self-determination, independence, empowerment, integration, and inclusion of children and adults with disabilities in all aspects of society. In addition, she served on CCD's first board of directors and chaired a number of its standing and ad hoc committees over the years. Ms. Fritz is a graduate of George Washington University (Washington, DC).

State: Washington, DC

## 2020 National Honorees



### **Suellen Galbraith, MSW**

(1949–2015)

*Having made an overall contribution  
through public policy*

Ms. Galbraith worked for nearly three decades at the American Network of Community Options and Resources (ANCOR), serving in a number of roles including Director of Public Policy, Director for Government Relations, and Senior Public Policy Advisor. A respected disability advocate, Ms. Galbraith worked diligently to improve supports and services for people with disability, and she played a key role in the development and enactment of the Community Living Assistance Services and Supports (CLASS) Act.

Ms. Galbraith was a noted expert in Medicaid and served on a number of advisory committees for the Centers for Medicare & Medicaid Services (CMS). She was among the founders of the Consortium for Citizens with Disabilities (CCD), a coalition of national organizations that works to assure that federal public policies advance the self-determination, independence, empowerment, integration, and inclusion of children and adults with disabilities in all aspects of society. Ms. Galbraith served in a number of leadership roles within CCD, including several terms as Chair of its task forces on housing and long-term supports and services.

Ms. Galbraith routinely testified before Congressional committees on health, housing, and long-term services to promote effective policies and to preserve appropriations to entitlement programs. She earned a master's degree in social work at the University of Alabama.

State: Washington, DC



### **Sharon Gomez**

Evergreen Life Services

*Having made an overall contribution  
through service*

Ms. Gomez joined Evergreen Life Services in 1987, holding a number of roles there over her tenure, including Program Supervisor; Division Director; Quality Enhancement Officer; Regional Vice-President of Operations; Regional Vice President/Executive Compliance Officer; and most recently, Chief Compliance and Privacy Officer. In each of these roles, Ms. Gomez has promoted inclusion and the use of quality-of-life metrics. In Louisiana, she oversaw the closure of a private residential institution and assisted with the closure of a large state residential institution.

Prior to joining Evergreen, Ms. Gomez served as court monitor (1986–1987) in a class-action decision that determined that agencies within Louisiana had violated the constitutional and statutory rights of children with IDD by placing them in Texas institutions, where they were subjected to poor living conditions and denied adequate treatment.

A Fellow of AAIDD, Ms. Gomez has served as President of the AAIDD Louisiana Chapter, the AAIDD Region V Chapter, and the national AAIDD board of directors (2011–2012). She served as a member of the ad hoc committee that authored the 11th edition of *Intellectual Disability: Definition, Classification, and Systems of Supports* (AAIDD, 2010), which has been translated into over a dozen languages.

Ms. Gomez was instrumental in establishing a new AAIDD journal, *Inclusion*, that provides research-to-practice information to promote the full inclusion of people with IDD. She served on the inaugural editorial board and wrote the first article published in the new journal.

State: Louisiana

## 2020 National Honorees



### **Margaret J. (Peg) Gould, MEd**

The VISIONS Center for Creative Management  
*Having made an overall contribution  
through service and advocacy*

Ms. Gould directs the Training Collaborative for Innovative Leadership, a multi-stakeholder project led by ADAPT Community Network and accredited by the National Alliance for Direct Support Professionals (NADSP), that trains emerging leaders in the state on achieving quality outcomes. She also is President and CEO of the VISIONS Center for Creative Management, a consulting firm specializing in effective management and the development of quality supports for agencies in the field of disabilities. Ms. Gould holds adjunct positions at the City University of New York (CUNY) and the State University of New York (SUNY) at Albany and is a blogger. Her *Subjects on Sundays* blog addresses current issues in the field.

Ms. Gould was instrumental in convening both the *20th Century Recognition Project* and the *National Historic Recognition Project: 2000–2020*. These projects recognized significant trends and contributions in the field and created a record for future generations.

Ms. Gould was a key player in the development of centralized archives for historical documents in the field from New England, now held at The Arc New York (NYSARC) and People, Inc. (Buffalo, New York). She served as a consultant to the Joseph P. Kennedy Jr. Foundation for the development of historic displays at the John F. Kennedy Presidential Library. Ms. Gould earned a bachelor's degree from SUNY Oswego and a master's degree in counseling from Virginia State University.

State: New York



### **Susan Havercamp, PhD**

The Ohio State University  
*Having made an overall contribution  
through scholarship, teaching, and service*

Dr. Havercamp currently holds the following positions at The Ohio State University (OSU): Associate Professor in the Departments of Psychiatry & Behavioral Health and Psychology, Associate Professor in the College of Medicine's genetic counseling program, and Director of Health Promotion and Healthcare Parity and Director of Behavior Support Services in the Nisonger Center (UCEDD). Before she joined OSU in 2009, Dr. Havercamp's career included appointments in the Department of Psychiatry at the University of North Carolina at Chapel Hill and the Department of Child & Family Studies at the University of South Florida.

Dr. Havercamp conducts research and public health programs to improve the health of people with IDD and provides disability training to improve healthcare for people with disabilities. She served as the Principal Investigator on several state and national research projects; made significant contributions to the IDD research literature through publications and scientific presentations; and mentored many students and early career professionals.

A Fellow of AAIDD, Dr. Havercamp co-founded the Student and Early Career Professionals Interest Network of AAIDD in 2002. She is a past President of the AAIDD board of directors (2017–2018) and the Alliance for Disability in Health Care Education. Dr. Havercamp has also served on the board of the National Association for the Dually Diagnosed (NADD) and on numerous national committees and workgroups.

State: Ohio



## 2020 National Honorees



**Tamar Heller, PhD**

University of Illinois at Chicago

*Having made an overall contribution  
through scholarship, teaching, and service*

Dr. Heller currently holds the following positions at the University of Illinois at Chicago (UIC): Distinguished Professor and Head of the Department of Disability and Human Development and Director of the Institute on Disability and Human Development (UCEDD), the Family Support Research and Training Center, and the Developmental Disabilities Family Clinic.

Dr. Heller's research focuses on policies and practices to support individuals with disabilities and their families across the life course, particularly self-directed and family supports, managed care, and health promotion. She has served as the Principal Investigator on numerous national research projects, including the Rehabilitation Research and Training Center (RRTC) on Developmental Disabilities and Health (previously the RRTC on Aging and Developmental Disabilities); authored or co-authored numerous books and peer-reviewed publications; taught and mentored many students; and delivered numerous presentations at state and national conferences.

Dr. Heller is a founding member of both the Sibling Leadership Network and the Bridging Aging and Disability International Network. Currently the Vice President for the Americas of the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD), she has served as President of the Board of the Association of University Centers on Disabilities (AUCD).

State: Illinois



**Amy Hewitt, PhD**

University of Minnesota

*Having made an overall contribution  
through scholarship, teaching, and service*

Dr. Hewitt currently holds the following positions at the University of Minnesota: Professor, Director of the Institute on Community Integration (UCEDD), Director of the Minnesota Leadership in Neurodevelopmental Disabilities (LEND), and Director of the Research and Training Center on Community Living (UMN RRTC). In these roles, Dr. Hewitt promotes the full community inclusion of people with IDD through the enhancement of training, practices, and public policies that affect direct support professionals (DSPs).

Dr. Hewitt is the lead author of the *National Community Living Training Curriculum* (Elsevier, 2013). This curriculum is a framework for the College of Direct Support on the Elsevier online learning platform's DirectCourse, which is used by across the country to move staff training beyond compliance and toward a world of possibilities for people with IDD. The courses offered on this platform offer DSPs insight and nationally recognized best practices and prepare their organizations to meet national competency-based credentials such as CQL, the Council on Quality and Leadership accreditation. Dr. Hewitt has also authored or co-authored a number of books, book chapters, and peer-reviewed articles on competency-based training and worker turnover; wages, benefits, and stability of DSPs; and outcome-focused evaluation of DSP quality.

A Fellow of AAIDD, she has served on the boards of directors of the Association of University Centers on Disabilities (AUCD; President 2018–2019), AAIDD (President 2014–2015), The Arc Minnesota, and The Arc Minnesota Greater Twin Cities Region.

State: Minnesota

## 2020 National Honorees



### **John Kemp**

Viscardi Center

*Having made an overall contribution  
through service and advocacy*

Mr. Kemp has been the President and CEO of the Viscardi Center in New York since 2011. The Viscardi Center is a nonprofit organization that provides education for children with IDD and medical complexities, job training and employment supports for adults with disabilities, and technology services that support people with disabilities.

A person with a disability who uses four prostheses, in 1995 Mr. Kemp co-founded the American Association of People with Disabilities (AAPD) to advocate for civil rights for the over 60 million Americans living with disabilities by promoting equal opportunity, economic power, independent living, and political participation. In 2001, Mr. Kemp became a partner in the Washington, DC, law firm of Powers Pyles Sutter & Verville PC, where he developed an active federal legislative and lobbying practice.

Mr. Kemp has served on the boards of directors of a number of disability and nonprofit organizations. He graduated from Georgetown University (Washington, DC) in 1971 and Washburn University School of Law (Kansas) in 1974. He has received two honorary doctoral degrees: a doctorate of law from Washburn University School of Law (2003) and a doctor of humane letters degree from the University of Connecticut (2018).

State: New York



### **Edward M. (Ted) Kennedy**

(1932–2009)

United States Senator from Massachusetts, 1962–2009

*Having made an overall contribution  
through public policy*

Mr. Kennedy served as a U.S. Senator from Massachusetts for almost 47 years. He was the brother of President John F. Kennedy, the brother of U.S. Attorney General and U.S. Senator Robert F. Kennedy, and the father of U.S. Representative Patrick J. Kennedy.

In the U.S. Senate, Mr. Kennedy and his staff wrote more than 300 bills that were enacted into law. Mr. Kennedy was champion of social justice issues—including health, education, civil rights, and disability.

Mr. Kennedy played a major role in the passage of several pieces of landmark legislation, including the Immigration and Nationality Act of 1965, the Consolidated Omnibus Budget Reconciliation Act of 1985 (COBRA health insurance provision), the Americans with Disabilities Act of 1990, the Civil Rights Act of 1991, the Mental Health Parity Act of 1996, the Children's Health Insurance Program (CHIP; established in 1997 under the Social Security Act), and the No Child Left Behind Act of 2002.

Mr. Kennedy's oldest sister, Rosemary Kennedy, had intellectual disability. He earned a bachelor's degree from Harvard University (Massachusetts) and a law degree from the University of Virginia.

State: Massachusetts

## 2020 National Honorees



### **Robert F. (Bob) Kennedy**

(1925–1968)

United States Senator from New York, 1965–1968

*Having made an overall contribution  
through public policy*

Mr. Kennedy served as a U.S. Senator from New York for 3 years (1965–1968), as U.S. Attorney General for one term (1961–1964), and as the Chief Counsel of the Senate Labor Rackets Committee (1957–1959). He was the brother of President John F. Kennedy and U.S. Senator Ted Kennedy.

In his relatively short career in public service, Mr. Kennedy was a strong advocate on human rights and social justice issues. As Attorney General, he played a large role in the White House's response to the Freedom Rider protests and sent U.S. Marshals to enforce a federal court order requiring the admittance of the University of Mississippi's first black student.

As a Senator, Mr. Kenney worked to address poverty and worker's rights. He was a key player in an amendment to the National Labor Relations Act and the Voting Rights Act of 1965. Mr. Kennedy supported the integration of all public facilities and antipoverty social programs designed to promote education and develop opportunities for employment. He was assassinated during his campaign for President of the United States in 1968.

Mr. Kennedy's earned a bachelor's degree from Harvard University (Massachusetts) and a law degree from the University of Virginia. His oldest sister, Rosemary Kennedy, had intellectual disability.

State: New York



### **K. Charlie Lakin, PhD**

University of Minnesota (Emeritus)

*Having made an overall contribution  
through scholarship, teaching, and service*

Dr. Lakin's career has included the positions of teacher, researcher, consultant, and advocate in services for people with IDD. He served the University at Minnesota (UMN) for 35 years, and for 22 of those years he directed UMN's Rehabilitation Research and Training Center on Community Living in the Institute on Community Integration (UCEDD). In 2011, he was appointed Director of the National Institute on Disability and Rehabilitation Research. Following his term of federal service, he returned to Minnesota and continued his advocacy for the full community inclusion of people with IDD.

In his role at UMN, Dr. Lakin oversaw a number of national research projects on long-term services and supports. He directed dozens of additional research, training, and technical-assistance projects and authored or co-authored numerous books, book chapters, monographs, and peer-reviewed articles on topics related to promoting full inclusion of people of with IDD.

Dr. Lakin was the driving force in the creation of the College of Direct Support curriculum, and he has served on countless local, state, and federal advisory committees to improve policies and practices for people with disabilities, including two terms on the President's Committee for People with Intellectual Disabilities.

Dr. Lakin earned a bachelor's degree from the University of Northern Iowa; an MA in special education from Teachers College, Columbia University (New York); and a doctorate in education psychology from UMN.

State: Minnesota

## 2020 National Honorees



### **Ruth Luckasson, JD**

University of New Mexico

*Having made an overall contribution  
through scholarship, teaching, and service*

Ms. Luckasson holds the following positions at the University of New Mexico (UNM): Distinguished Professor, Regents' Professor, Professor of Special Education, and Chair of the Department of Special Education. Ms. Luckasson has literally "written the book" describing the condition of intellectual disability, co-authoring the internationally respected 9th, 10th, and 11th editions of *Intellectual Disability: Definition, Classification, and Systems of Supports* (AAIDD, 1992, 2002, and 2010, respectively), each translated into over a dozen languages. She also served on the World Health Organization workgroup (2010–2012) charged with recommending revisions to the classification of intellectual disability for the 11th edition of the *International Classification of Diseases (ICD-11)*.

Ms. Luckasson has authored or co-authored numerous peer-reviewed books, book chapters, and reports and monographs designed to inform stakeholders on special education, human rights, clinical judgment, assessment, and the criminal justice system. She has authored, co-authored, or contributed to a number of amicus curiae (friend of the court) briefs for cases in which a court's decision became the foundation for subsequent laws and practices across the country, including the Atkins decision.

A Fellow of AAIDD, Ms. Luckasson served on President's Committee for People with Intellectual Disabilities (1994–2001) and on the boards of directors of the Human Services Research Institute (2018–present), the Judge David L. Bazelon Center for Mental Health Law (2003–2006), and AAIDD (President 2002–2003). She earned a master's degree in special education from UNM and a doctor of jurisprudence from the UNM School of Law, and she has been admitted to the bars of New Mexico and the Supreme Court the United States.

State: New Mexico

National Historic Recognition Project 2000-2020



### **Joseph (Joe) Macbeth**

National Alliance for Direct Support Professionals

*Having made an overall contribution  
through service and advocacy*

Mr. Macbeth became the first President and CEO of the National Alliance for Direct Support Professionals (NADSP) in 2011. He began his career in the disability field in 1983 as a direct support professional (DSP) and immediately prior to coming to NADSP spent many years as the Assistant Executive Director of the New York State Association of Community and Residential Agencies (NYSACRA).

Mr. Macbeth was the driving force to expand and integrate the NADSP Code of Ethics and redefine a national credentialing program. To increase the nation's understanding of the number of its DSPs and their working conditions, he is leading an effort to add DSPs to the U.S. Bureau of Labor Statistics' Standard Occupational Classification (SOC) system as national data is gathered, calculated, and disseminated by federal agencies on the occupations listed in the SOC.

Mr. Macbeth co-authored the President's Committee for People with Intellectual Disabilities' 2017 report to the President, *America's Direct Support Workforce Crisis: Effects on People with Intellectual Disabilities, Families, Communities and the U.S. Economy*. He currently serves on the boards of directors of the Council on Quality and Leadership (CQL) and the Learning Community for Person Centered Practices, and he also serves on the advisory board of the College of Direct Support. He graduated from The Sage Colleges in Albany (New York).

State: New York

## 2020 National Honorees



### **Jack Markell**

Governor of Delaware, 2009–2017  
*Having made an overall contribution  
through public policy*

Mr. Markell served the state of Delaware as Governor from 2009 to 2017 and as State Treasurer for three terms (1999–2009). As Governor, he proposed and signed a number of laws to ban discrimination, improve transparency in school districts, and update building codes.

Mr. Markell also signed legislation that made Delaware an Employment First state by requiring state agencies that provide services to persons with disabilities to promote, as the first option, employment in an integrated setting.

Mr. Markell served as Chair of the National Governors Association from 2012 to 2013. During his term, he initiated the *A Better Bottom Line: Employing People with Disabilities* project, which aimed to increase employment among people with disabilities. A major emphasis of the initiative was to develop solutions to provide people with IDD and significant support needs with additional job coaches and personal attendants in order to allow them to live and work in the community. As part of this initiative, Mr. Markell held two regional summits to share best practices and chart a path forward in employment for people with disabilities.

State: Delaware



### **Gerry Morrissey**

The MENTOR Network  
*Having made an overall contribution  
through service and advocacy*

Mr. Morrissey joined the MENTOR Network in 2007 as Vice President of Quality Assurance and Service Development and is currently its Chief Quality Officer. Previously, he served the Commonwealth of Massachusetts for over 30 years, including 4 years as the Assistant Secretary for Disabilities and Community Services and more than a decade as the Commissioner of what is known today as the Department of Developmental Services.

One of his first acts as Commissioner was to establish an Investigation Advisory Panel to conduct a full review of the department's response to abuse and mistreatment of people with IDD, signaling change and innovation within state government. He then created a statewide strategic alliance with district attorneys and local law enforcement to provide mandatory training for investigators and first responders, allowing people with disabilities to live more safely in their communities. In his current role, Mr. Morrissey oversees quality-improvement and customer-assessment programs across 37 states, implementing the principles of continuous quality improvement and meaningful benchmarks.

Mr. Morrissey is past President and a current member of the board of directors the of the National Association of State Directors of Developmental Disabilities Services (NASDDDS), and he also currently serves on the boards of the Massachusetts Association of Mental Health, Community Resources for Justice, Special Olympics Massachusetts, and the Boys & Girls Clubs of Dorchester.

State: Massachusetts

## 2020 National Honorees



### **Beth Mount, PhD**

Graphic Futures

*Having made an overall contribution  
through service and advocacy*

For more than 30 years, Dr. Mount has provided consultancies across the country on person-centered systems, organizational change, and personal change. She is the sibling of a man who was born with complex medical and cognitive challenges. In her consultancies, she helps organizations to demonstrate values, practices, and innovative policy initiatives related to person-centered planning and development.

Dr. Mount has engaged in long-term consultancies with nonprofits and state agencies, including Job Path, AHRC New York City, The Arc Westchester (New York), Northern California Training Institute, the New York State Association of Community and Residential Agencies, the Massachusetts Department of Developmental Services, the New York State Office of Mental Retardation and Developmental Disabilities, the New Mexico State Department of Developmental Disabilities, and the Wisconsin Developmental Disabilities Network.

Dr. Mount has authored or co-authored numerous books and articles on person-centered planning, bridge building, direct support, transforming systems to be person-centered, school-to-work transition, and circles of support. In addition, she promotes the use of graphics, photography, film, and fiber art as ways to help people to share their perspectives and stories through art.

Dr. Mount earned a bachelor's degree at Mercer University (Georgia), a master's in special education at the University of North Carolina at Chapel Hill, and a doctorate in political science at the University of Georgia.

State: New York



### **Ari Ne'eman**

*Having made an overall contribution  
through service and advocacy*

Mr. Ne'eman is an autism rights activist who co-founded the Autistic Self Advocacy Network (ASAN) in 2006 and served as its first President and CEO until 2016. ASAN is a national advocacy organization run by and for autistic youths and adults. Under Mr. Ne'eman's leadership, ASAN's work focused on both public policy priorities and social and cultural change, particularly in the areas of civil rights, education, research, positive supports, and inclusion.

Mr. Ne'eman was appointed by President Obama to a term on the National Council on Disability, beginning in 2010; he was the first autistic person to serve on this council. He has worked against the use of aversives, restraints, and seclusion in any context, and he has provided testimony to the Food and Drug Administration (FDA) against the use of electric shock devices.

Following his departure from ASAN, Mr. Ne'eman served the American Civil Liberties Union as a consultant on disability policy. He has advised several presidential candidates on disability policy, including Hillary Clinton (2016) and, in 2020, Bernie Sanders and Elizabeth Warren.

Mr. Ne'eman earned a bachelor's degree in political science from the University of Maryland, Baltimore County, and is currently completing a doctoral program in health policy at Harvard University (Massachusetts).

State: Massachusetts

## 2020 National Honorees



**Tia Nelis**

TASH

*Having made an overall contribution  
through service and advocacy*

Ms. Nelis is a disability rights activist who currently services as the Policy and Advocacy Director of TASH. In this role, she advocates for human rights and inclusion for people with significant disabilities and support needs. Ms. Nelis previously (1992–2016) held the position of Self-Advocate Specialist at the University of Illinois at Chicago (UIC) Institute on Disability and Human Development (UCEDD). In this role, she also served as a co-Investigator on the UCEDD’s Research and Rehabilitation Training Center on Aging and Developmental Disabilities project (2012–2017).

Ms. Nelis routinely presents on self-advocacy issues at regional and national conferences and in webinars. She has delivered keynote presentations at conferences in all 50 U.S. states on topics including self-advocacy, leadership, employment, voting, and closing institutions. She has served on the boards of directors of Self Advocates Becoming Empowered (SABE; 1993–2000, 2008–2010, Chair 1997–2000), TASH (2000–2002), and the Illinois Council on Developmental Disabilities (1991–1995).

A professional who has intellectual disability, Ms. Nelis earned a high school diploma and was the first person with a cognitive disability to be certified as a Stephen Covey Leadership Institute Facilitator (2001). She earned a certificate in the Illinois Leadership Education in Neurodevelopmental Disabilities (LEND) Program at UIC (2011).

State: Washington, DC



**Margaret A. (Maggie) Nygren, EdD**

American Association on Intellectual and  
Developmental Disabilities

*Having made an overall contribution  
through service and scholarship*

Dr. Nygren has served as the Executive Director and CEO of the American Association on Intellectual and Developmental Disabilities (AAIDD) since 2010. Her prior roles include two progressively responsible positions at the Association of University Centers on Disabilities (AUCD) and a Fellowship in the Disabled and Elderly Health Programs Group at the Centers for Medicare & Medicaid Services (CMS) in Baltimore.

During Dr. Nygren’s tenure at AAIDD, the organization has advanced the knowledge base of effective strategies to improve the inclusion and quality of life of people with IDD through its publications and educational offerings and provided policymakers and the public with evidence to inform policies that impact people with IDD and their families.

Dr. Nygren has authored or co-authored numerous technical reports, issue briefs, and peer-reviewed articles concerning IDD and public policy. She currently serves on a number of national advisory and scientific committees, and has served on the boards directors of the Alliance for Full Participation and the Maryland Coalition for Inclusive Education.

A Fellow of AAIDD, Dr. Nygren earned a bachelor’s degree from Beloit College (Wisconsin), a master’s degree in clinical psychology from West Virginia University, and a doctorate in organizational leadership from Nova Southeastern University (Florida).

State: Washington, DC

## 2020 National Honorees



### **Barack Obama**

President of the United States of America, 2009–2017

*Having made an overall contribution  
through public policy*

Mr. Obama’s public service included two terms as President of the United States (2009–2017), one term as a U.S. Senator from Illinois (2005–2008), and as a member of the Illinois Senate (1997–2004).

Mr. Obama signed in to law the Patient Protection and Affordable Care Act (ACA) of 2010, which, together with the Health Care and Education Reconciliation Act of 2010, represented the most significant regulatory overhaul of the U.S. health system and expansion of coverage since Medicare and Medicaid were enacted in 1965. Among other things, the ACA prohibited insurers from denying coverage due to preexisting conditions and banned coverage caps on essential benefits.

In 2010, Mr. Obama also signed Rosa’s Law, which removed the term “mental retardation” from federal health, education, and labor regulations—replacing them with “intellectual disability”—and the Twenty-First Century Communications and Video Accessibility Act (CVAA), which updated federal communications law to increase the access of people with disabilities to contemporary communication vehicles.

Mr. Obama graduated from Columbia University (New York) and the Harvard Law School (Massachusetts).



### **Regis Obijiski, MA, MTh**

New Horizons Resources (Emeritus)

*Having made an overall contribution  
through service and advocacy*

Mr. Obijiski served the residents of state of New York for 45 years; from 1987 to 2013, he served as the CEO of New Horizons Resources (NHR). In 1988, he co-founded and led the Mid-Hudson Coalition for Direct Support Practice (MHC), a seven-county consortium of organizations advancing a competent direct support workforce. With MHC, he shaped credit-bearing concentrations in human service at the State University of New York at New Paltz and at two community colleges.

Mr. Obijiski participated in the writing of the *Community Support Skill Standards* (HSRI, 1996). As a board member of the National Alliance for Direct Support Professionals, he helped design the first national credential for direct support professionals (DSPs) in 2007. Mr. Obijiski co-wrote the 2010 U.S. Department of Labor standards for DSPs, contributed to the development of two DSP state apprenticeship programs, and served on the national team that wrote the *Direct Service Workforce Core Competencies* (Centers for Medicare and Medicaid, 2012).

From 2013 to 2016, Mr. Obijiski lead a workforce project for the New York State Office for Persons with Developmental Disabilities. In this capacity, he developed six Regional Centers for Workforce Transformation to upgrade the competencies and ethical standards of thousands of DSPs. He earned a bachelor’s degree from St. Hyacinth College (Massachusetts), a master’s degree at the University of Notre Dame (Indiana) and second a bachelor’s and master’s degrees at St. Anthony-on-Hudson (New York).

State: New York



## 2020 National Honorees



### **Susan B. Palmer, PhD**

University of Kansas (Emerita)  
*Having made an overall contribution  
through research, teaching, and public policy*

Dr. Palmer currently holds the following positions at the University of Kansas (KU): Research Professor Emerita and Research Affiliate of the Life Span Institute. Her previous positions include the following: Associate Director of Applied and Translational Research Support for the Kansas UCEDD and Courtesy Professor in the Department of Special Education at KU, Lecturer in Special Education at the University of Texas at Dallas, Project Director and Early Childhood Specialist at The Arc of the United States, and Early Childhood Specialist at the Warren Center (Texas).

Dr. Palmer has promoted effective strategies for inclusive education for children with moderate-to-severe disabilities and self-directed learning for people with IDD across the lifespan. She has served as the Principal Investigator, co-Investigator, or Project Director on 10 federally funded research, demonstration, training, or technical-assistance projects with the goals of improving K–12 educational instruction and student success and of promoting self-determined learning and career planning. Dr. Palmer has authored or co-authored numerous books, book chapters, issue briefs, position statements, and peer-reviewed articles concerning inclusion in schools and early childhood programs, facilitation of self-directed learning and career planning, and self-determination.

A Fellow of AAIDD and past President of its board of directors (2015–2016), Dr. Palmer earned a doctorate in human development and communication sciences at the University of Texas at Dallas and teaching certificates in the states of Texas and New York.

State: Kansas



### **Fred Pelka**

*Having made an overall contribution  
through scholarship*

Mr. Pelka writes nonfiction and poetry. His work has appeared in the *Boston Globe*, the *Christian Science Monitor*, the *Humanist*, *Mainstream*, *Poets & Writers* and elsewhere.

Three of his works concern the disability rights movement. *The ABC-CLIO Companion to the Disability Rights Movement* (1997) provides a grounding in the movement over the latter half of the 20th century. The work contains almost 500 alphabetically arranged entries describing landmark laws and court cases, leading figures, historic events, issues, notable programs, key concepts, and centers of disability culture and education.

The *Civil War Letters of Charles F. Johnson, Invalid Corps* (2004) provides an introduction into a little-known facet of civil war history, documenting the experiences of soldiers disabled during the course of that conflict who made substantial contributions to Union victory.

Mr. Pelka's 2012 book, *What We Have Done: An Oral History of the Disability Rights Movement* (University of Massachusetts Press), addresses the disability movement's struggle for human rights through the testimonials of people with disabilities about their lived experiences. Focusing on the decades immediately before the passage of the Americans with Disabilities Act, Mr. Pelka compiles narratives that illustrate important elements of the disability rights movement.

Mr. Pelka was a 2004 Guggenheim Fellow.

State: Massachusetts

## 2020 National Honorees



### **Elizabeth Perkins, RNLD, PhD**

University of South Florida

*Having made an overall contribution  
through scholarship and public policy*

Dr. Perkins is an Associate Research Professor at the University of South Florida (USF) College of Behavioral and Community Sciences and the Associate Director of the Florida Center for Inclusive Communities (UCEDD) at USF.

Dr. Perkins' work has focused on improving health supports for people with IDD as they age through the enhancement of training, practices, and public policies that affect health care professionals and family caregivers. She has authored numerous peer-reviewed articles, books and book chapters, policy briefs, fact sheets, and position statements, on topics related to aging and IDD, supporting family caregivers, and training health care professionals.

A Fellow of AAIDD and of the Gerontological Society of America, Dr. Perkins served on the AAIDD board of directors (President 2018–2019), and she co-chaired the Gerontological Society of America's Interest Group on Developmental Disabilities (2008–2011).

Dr. Perkins is a congenital above-elbow amputee who studied at the Hereford and Worcestershire College of Nursing and Midwifery (England) and became one of the first ever nurses with this disability to qualify and practice as a Registered Nurse Learning Disabilities (RNLD; a United Kingdom nursing specialization in IDD). She earned a bachelor's degree in psychology and a doctorate in aging studies from USF.

State: Florida



### **Emily Perl Kingsley**

*Sesame Street* (Emerita)

*Having made an overall contribution  
through service and advocacy*

Ms. Kingsley is a disability activist and a parent of a man with Down syndrome, and was a television writer until her retirement in 2015. She wrote for *Sesame Street* from 1970 to 2015, and with her influence, people with disabilities were included in the *Sesame Street* cast.

Ms. Kingsley wrote "Welcome to Holland" (1987), an essay that compares the experience of having a child with a disability to having a vacation in Italy rerouted to Holland instead. "Welcome to Holland" has been translated into many languages and shared by many parents. Also in 1987, a made-for-television movie that Ms. Kingsley wrote, *Kids Like These*, premiered on CBS. The film's story concerns a middle-aged couple who have a son with Down syndrome and defy medical advice and prejudice to provide him with a typical upbringing their community.

Ms. Kingsley has written over 20 children's books and scripted two *Sesame Street* home video releases, and she has won 23 Daytime Emmys for her work on *Sesame Street*. She co-founded the support group Parents Assistance Committee on Down Syndrome (PACDS) and continues to help young families throughout the country to network with each other and advocate on behalf of their children. She also continues to advocate and speak on enhancing the representation of disability in the media.

State: New York

## 2020 National Honorees



### **Renee Pietrangelo, PhD**

American Network of Community Options and Resources (Emerita)

*Having made an overall contribution through service and public policy*

Dr. Pietrangelo served as the CEO of the American Network of Community Options and Resources (ANCOR) from 1999 to 2014. In this role, she worked to advance quality supports for and full community participation of people with intellectual and developmental disabilities and was instrumental in the passage of significant federal legislation impacting people with IDD.

In her tenure at ANCOR, Dr. Pietrangelo launched a national campaign to advocate for the resources necessary to recruit, train, and retain a healthy, sustainable direct support workforce. She was also a member of original faculty of the University of Delaware's National Leadership Consortium on Developmental Disabilities Leadership Institute.

Dr. Pietrangelo has authored, co-authored, or edited numerous reports, position statements, issue briefs, and articles on important policy issues concerning services for people with IDD. She serves on the board of directors of the service provider CRI, Inc., and earned a bachelor's degree from American University (Washington, DC) and a doctorate from Georgetown University (Washington, DC)..

State: Washington, DC



### **Mary Kay Rizzolo, PhD**

Council on Quality and Leadership

*Having made an overall contribution through research, service, and public policy*

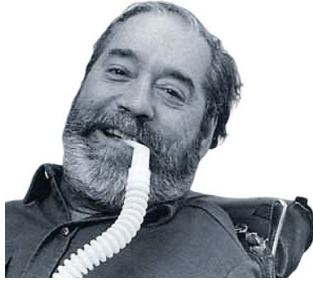
Dr. Rizzolo has served as President and CEO of the Council on Quality and Leadership (CQL) since 2016 and has held an appointment as an Adjunct Clinical Associate Professor at the University of Illinois at Chicago (UIC) since 2011. Her other positions include Associate Director of the IL UCEDD (Institute on Disability and Human Development), Policy Director of the IL LEND Program, Director of Evaluation for the Family Support Research and Training Center, researcher at the Coleman Institute for Cognitive Disabilities (University of Colorado), and a Qualified Intellectual Disability Professional (North Carolina).

Dr. Rizzolo contributed significantly for two decades to *State of the States*, a project of national significance that has collected and analyzed data on over 40 years of revenue, spending, and programmatic trends in the United States. She co-authored ten editions of *State of the States* and has authored or co-authored numerous peer-reviewed articles, reports, monographs, white papers, and issue briefs on her analyses of the project's data as well as on voting, emerging technologies, family support, transportation, employment supports, quality of life, and personal outcomes.

Dr. Rizzolo has served on numerous national advisory committees, task forces, commissions, and boards of directors. A Fellow of AAIDD, Dr. Rizzolo has earned a bachelor's degree in psychology from the University of North Carolina at Chapel Hill, a master's degree in psychology from North Carolina Central University, and a doctorate in public health from UIC.

State: Indiana

## 2020 National Honorees



### **Edward V. (Ed) Roberts, MA**

(1939–1995)

*Having made an overall contribution  
through service and advocacy*

Mr. Roberts was a disability activist. In 1962, he was the first person with severe disabilities (as a result of polio) to attend the University of California, Berkeley (UC Berkeley), where he led a successful effort to open the university to people with disabilities. In 1970, he co-founded the first Center for Independent Living (CIL)

Mr. Roberts served as the Director of the California Department of Rehabilitation from 1975 to 1983. In this role, he contributed to the development of and implemented transformational public policies and system changes to promote full social and physical inclusion for people with disabilities. He was a key player in the design of California's in-home supports service system.

In 1983, Mr. Roberts co-founded the World Institute on Disability (WID), and he served as its President until his death. As WID's President, he travelled around the world to organize people with disabilities in advocating for system change and full integration. In 1983, Mr. Roberts also co-founded Disabled Peoples International (DPI), for which he served as its first North American Chair.

Acknowledged as an important contributor to the passage of the Americans with Disabilities Act of 1990, Mr. Roberts was a MacArthur "Genius" Fellow in 1984 in the area of civil rights and civil liberties. He earned both a bachelor's and master's degree at UC Berkeley.

State: California



### **Robert (Bob) Schalock, PhD**

Hastings College (Emeritus)

*Having made an overall contribution  
through scholarship, service, and public policy*

Dr. Schalock is the Principal of Bob Schalock & Associates Planning and Evaluation (Washington) and is Professor Emeritus at Hastings College (Nebraska). He also serves as an adjunct professor at the University of Salamanca (Spain), Chongqing Normal University (China), and Ghent University (Belgium).

Dr. Schalock has literally "written the book" describing the condition of intellect disability, co-authoring the internationally respected 9th, 10th, and 11th editions of *Intellectual Disability: Definition, Classification, and Systems of Supports* (AAIDD, 1992, 2002, and 2010, respectively), each translated into over a dozen languages. This work has influenced the nation's understanding of intellectual disability, been referenced in state and federal regulations, and been cited extensively by the U.S. Supreme Court in death penalty cases.

Dr. Schalock has authored or co-authored numerous books, book chapters, and peer-reviewed articles on quality of life, systems change, standardized assessment, program evaluation, adaptive behavior, support plans, and public policy. He has authored or co-authored four standardized instruments to assess quality of life across lifespan and contexts, and his books concerning quality of life and identifying support needs have been published in seven languages.

A Fellow of AAIDD and the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD), Dr. Schalock has served on the boards of directors of both AAIDD (President 1997–1998) and IASSIDD (2005–2007). Dr. Schalock earned a doctorate in psychology from Washington State University and has been awarded two honorary degrees: a doctorate of science from Hastings College (2000) and a doctorate honoris causa ("for the sake of the honor") from the University of Salamanca (2006).

State: Washington

## 2020 National Honorees



### **Karrie Shogren, PhD**

University of Kansas

*Having made an overall contribution  
through scholarship, teaching, and service*

Dr. Shogren currently holds the following positions at the University of Kansas (KU): Director, Kansas University Center on Developmental Disabilities (UCEDD); Professor, Department of Special Education; Senior Scientist, Schiefelbusch Institute for Life Span Studies; and Associate Director, Beach Center on Disability. Prior to joining KU in 2013, she held faculty appointments at the University of Illinois at Urbana-Champaign and the University of Texas at Austin.

Dr. Shogren's work has focused on practices that support and inclusive education for children with severe disabilities and self-determination across the lifespan. She has led many research, demonstration, training, and technical-assistance projects and has authored or co-authored numerous books, book chapters, and peer-reviewed articles on special education, transition, self-determination, supported decision making, quality of life, and assessment.

Dr. Shogren has co-authored standardized instruments to assess self-determination across lifespan and contributed to the development of the *Supports Intensity Scale (SIS, SIS-A, and SIS-C)*. In addition, she has developed instructional materials that are widely used in schools and communities to support the development of self-determination.

A Fellow of AAIDD, Dr. Shogren has co-edited scholarly journals (*Inclusion and Remedial and Special Education*); served on the boards of directors of AAIDD, the Council for Exceptional Children Division on Career Development and Transition (President 2019–2020), and American Psychological Association Division 33 (President-elect 2019–2020); and served as a member of numerous advisory committees. She earned a bachelor's degree from The Ohio State University, a master's from the University of Dayton (Ohio), and a doctorate from the University of Kansas.

State: Kansas



### **Michael Smull**

Support Development Associates and  
Learning Community for Person Centered Practices

*Having made an overall contribution  
through service and teaching*

Mr. Smull is the Chair of the Learning Community for Person Centered Practices (TLC-PCP) and a Senior Partner in Support Development Associates (SDA). His prior positions include Research Assistant Professor at the University of Maryland and Clinical Assistant Professor at the University of Maryland School of Medicine. The TLC-PCP provides continuous learning designed to steer service systems toward person-centered practices.

Mr. Smull is the co-developer of Essential Lifestyle Planning (ELP), a guided process designed to help individuals discover and attain what matters most to them and identify what supports they might need. In 2001 he led the development of training in a set of person-centered thinking skills that are widely used in developing and implementing person-centered plans. He has written extensively on self-determination, person-centered planning, and supporting people with challenging behaviors, and he has delivered numerous trainings on ELP.

Mr. Smull has helped to found three community-based agencies; assisted existing agencies in transitioning from programs to supports; and helped counties, states, and regions to change their structures in order to support self-determination.

State: Maryland

## 2020 National Honorees



### **Sue Swenson, MBA**

Inclusion International

*Having made an overall contribution  
through service and advocacy*

Ms. Swenson is President of Inclusion International. She has served two presidential administrations in key disability appointments in the Office of Special Education and Rehabilitative Services, the National Institute for Disability and Rehabilitation Research, and the Administration on Intellectual and Developmental Disabilities. Ms. Swenson has also served as the chief executive of The Arc of the United States and the Joseph P. Kennedy Jr. Foundation.

Before coming to Washington, Ms. Swenson advocated at local and state levels in Minnesota. She was a Kennedy Fellow in the U.S. Senate, where she had lead staff responsibility for the reauthorization of the DD Act and also contributed to the reauthorization of the Individuals with Disabilities Education Act (IDEA). She has provided testimony before numerous Congressional committees and in legislatures concerning education and disability issues, and she testified with her son at the United Nations to inform the drafting of the Convention on the Rights of Persons with Disabilities (CRPD), specifically on inclusive education and legal capacity.

A parent of a son with profound and complex disabilities, Ms. Swenson contributes speeches, articles, forewords, and other communications to bring a parent's voice to the table. She earned degrees from the University of Minnesota and the University of Chicago.

State: Washington, DC



### **Marc J. Tassé, PhD**

The Ohio State University

*Having made an overall contribution  
through scholarship and service*

Dr. Tassé is the Director of the Nisonger Center UCEDD and a tenured Professor of Psychology and Psychiatry at The Ohio State University. Before joining Ohio State in 2009, he held appointments at University of Quebec at Montreal (UQAM, Canada), University of North Carolina at Chapel Hill, and University of South Florida.

Dr. Tassé's work in the area of adaptive behavior has resulted in increased diagnostic accuracy and has influenced clinical practices, research, and policies in the area of intellectual disability. He has work on the development of several assessment tools, including the *Diagnostic Adaptive Behavior Scale* and the *Supports Intensity Scales (SIS-A and SIS-C)* which has been translated into more than a dozen languages.

Dr. Tassé has authored or co-authored numerous books, book chapters, and peer-reviewed articles, including the 10th and 11th editions of the AAIDD manual. He has also served as an expert witness in several state and federal capital cases where the court's determination of intellectual disability was a key element.

Dr. Tassé is Fellow of AAIDD, the American Psychological Association (Division 33), and the International Association for the Scientific Study of Intellectual and Developmental Disabilities. He is a Past-President of AAIDD (2012-2013). He earned a bachelor's degree at Concordia University (Canada) and a doctorate at UQAM.

State: Ohio

## 2020 National Honorees



**Nancy Thaler, MS**

*Having made an overall contribution  
through service and advocacy*

Ms. Thaler has served the field for more than 40 years. Her career began a direct care position in 1971 at a children’s institution. She later became a group home houseparent and then an administrator in a community agency. In 1987 she joined the Pennsylvania government. As the Deputy Secretary for Developmental Disability Services for almost 14 years, she oversaw the closure of ten public and several private institutions and promoted the concept of “Everyday Lives,” an endorsement of the rights of people with disabilities to live no differently from others in the community.

As Director of Quality Improvement for the Centers for Medicare & Medicaid Services (CMS) from 2003 to 2005, she developed the requirements a state must meet in order to provide Medicaid Home and Community Based Services. As the Executive Director of the National Association of State Directors of Developmental Disabilities Services (NASDDDS) from 2007 to 2015, she assisted states in building person-centered systems for people with IDD and their families.

Ms. Thaler and her husband adopted their (now adult) son with disabilities when he was seven years old. She earned a bachelor’s degree from Misericordia University (Pennsylvania), a master’s degree in human organization science from Villanova University (Pennsylvania), and was awarded an honorary doctorate of humane letters, *honoria causa* (“for the sake of the honor”), from Misericordia College.

State: Pennsylvania



**James R. (Jim) Thompson, PhD**

University of Kansas  
*Having made an overall contribution  
through scholarship, teaching, and service*

Dr. Thompson currently holds the positions of Professor and Senior Scientist at the University of Kansas. He previously served for 20 years in the Illinois State University Department of Special Education as Assistant Professor (1995–1999), Associate Professor (1994–2004), Professor (2004–2015), and Department Chair (2000–2015).

Dr. Thompson has promoted a shift in understanding and meeting the support needs of people with IDD. His work moved the field away from a deficits model (identifying what one can’t do) to a model of assessing and responding to the pattern and intensity of supports that are needed by a person to achieve his or her goals. He is the lead author the *Supports Intensity Scale (SIS, SIS-A, and SIS-C)* and the *SIS Annual Review Protocol*. The SIS has been used as both a measure to assist in the development of individualized support plans and as a tool to help jurisdictions develop individualized resource-allocation models and personal budgets for people receiving community-based services, and it has been translated into more than a dozen languages.

Dr. Thompson has authored, co-authored, or edited numerous books, book chapters, manuals, curricula, white papers, and peer-reviewed articles concerning the support needs people with IDD and public policies and organizational practices that advance a support-need approach to service planning and delivery.

A Fellow of AAIDD, Dr. Thompson has served on the board of directors of AAIDD (President 2013–2014), the Council for Exceptional Children’s Division on Autism and Developmental Disabilities, and the steering committee of the Association of University Centers on Disabilities’ (AUCD) Council on Leadership in Advocacy. He earned a bachelor’s and a master’s degree at Illinois State University and a doctorate at the University of Minnesota.

State: Kansas

## 2020 National Honorees



### **Leslie Walker-Hirsch, IMEd, & Marklyn P. Champagne, RN, MSW**

Circles®, a multi-media social/sexual education curriculum series  
*Having made an overall contribution  
through service and advocacy*

Ms. Walker-Hirsch and Ms. Champagne are the co-authors of the Circles® social /sexuality curriculum series designed to increase knowledge and skills about the sexual awareness, rights, and responsibilities for people with IDD. While they are accomplished in their individual capacities, this recognition is for their collaboration and co-authorship of a unique effort in the area of relationships and sexuality. The Circles program, first published in 1980, is in its fifth edition and because of their work in raising awareness, developing materials, and providing training, sexuality is today an important consideration in individualized plans, self-advocacy, family supports, education, and therapies for people with IDD.

Ms. Walker-Hirsch is a consultant who has authored and co-authored numerous publications. She designed and teaches a course in the Department of Education at the University of New Mexico that addresses the complex dynamics between sexual development and social behaviors for professionals who provide special education supports. A Fellow of AAIDD, Ms. Walker-Hirsch earned an individualized master's degree in special education and administration at Rhode Island College.

Ms. Champagne is a consultant and psychotherapist who has authored and co-authored numerous publications. Her consultation and clinical practice address the special educational needs of concrete learners. She also treats mental health issues of this group. A Fellow of AAIDD, Ms. Champagne earned a master's degree in social work at Rhode Island College.

States: New Mexico and Rhode Island



## 2020 National Honorees



**Michael Wehmeyer, PhD**

University of Kansas

*Having made an overall contribution  
through scholarship, teaching, and service*

Dr. Wehmeyer currently holds the following positions at the University of Kansas: Ross and Marianna Beach Distinguished Professor in Special Education and Chairperson, Department of Special Education; Senior Scientist, Schiefelbusch Institute for Life Span Studies and Director, Beach Center on Disability.

Dr. Wehmeyer's research, teaching, and technical assistance on practices that support and promote self-determination and advocacy have informed, challenged, and advanced the work of those in current practice. He has directed federally funded projects and authored or co-authored numerous books, book chapters, and peer-reviewed articles on special education, transition, self-determination, and social inclusion.

Dr. Wehmeyer authored or co-authored multiple standardized instruments to assess self-determination across lifespan and designed numerous interventions to promote self-determination and self-determined learning. He co-authored the internationally respected 11th edition of *Intellectual Disability: Definition, Classification, and Systems of Supports* (AAIDD, 2010) and has served as a member of federal advisory committees and as the editor or co-editor of prestigious scholarly journals.

Dr. Wehmeyer is a Fellow of the AAIDD, American Psychological Association, and International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD). He has served on the boards of directors of the AAIDD (President 2010–2011), the Council for Exceptional Children (CEC) Division on Career Development and Transition (President 2004–2005), the CEC Division on Autism and Developmental Disabilities (President 2019), and IASSIDD (Vice President of the Americas 2012–2016). He earned a bachelor's and a master's degree in special education from the University of Tulsa (Oklahoma), a master's degree experimental psychology from the University of Sussex (England), and a doctorate in human development and communication sciences from the University of Texas at Dallas.

State: Kansas



**Liz Weintraub**

Association of University Centers on Disabilities

*Having made an overall contribution  
through service and advocacy*

Ms. Weintraub is a disability activist who is currently a Senior Advocacy Specialist at the Association of University Centers on Disabilities (AUUCD). Her previous positions include Associate Quality Consultant at the Council on Quality and Leadership (CQL), faculty for the National Leadership Consortium on Developmental Disabilities Leadership Institute at the University of Delaware, and Self-Advocacy Specialist at the Massachusetts Department of Developmental Services.

In her role at AUUCD, Ms. Weintraub hosts *Tuesdays with Liz*, a weekly YouTube video series that highlights current issues and hot topics in disability policies. Ms. Weintraub works to ensure that the voices of people with disabilities are included in the creation, implementation, and evaluation of the public policies, practices, and services that impact them.

Ms. Weintraub currently serves on board of directors of the Maryland Developmental Disabilities Council and has served on the boards of the Jewish Foundation for Group Homes, National Association of Councils on Developmental Disabilities, and TASH. She also served on the President's Committee for People with Intellectual Disabilities.

A professional who has intellectual disability, Ms. Weintraub earned a high school diploma from a boarding school in East Sandwich, Massachusetts and a certificate in the Georgia Leadership Education in Neurodevelopmental Disabilities (GaLEND) Program at Georgia State University. In 2018, she completed a 4-month fellowship in the office of Senator Robert Casey (D-PA) that focused on holding the government accountable for disability stakeholder input into key programs.

State: Washington, DC

## 2020 National Honorees



### **Nancy Weiss, MSW**

University of Delaware

*Having made an overall contribution  
through service and advocacy*

Ms. Weiss is a member of the faculty of the College of Health Sciences and Director of the National Leadership Consortium on Developmental Disabilities, both at the University of Delaware. Her previous positions include Executive Director of TASH; Director of the Department for Community Services at the Kennedy Krieger Institute affiliated with Johns Hopkins School of Medicine in Baltimore; and Executive Director of Community Systems, Inc. in Delaware.

For more than 10 years, Ms. Weiss spearheaded the efforts of national partner organizations to end the use of aversive procedures on people with IDD. The 2020 ban on electric shock devices used for behavior control by the Food and Drug Administration (FDA) is directly attributable to her advocacy efforts.

In her roles at the University of Delaware, Ms. Weiss has facilitated numerous training institutes for the next generation of leaders in the field of IDD. She earned a master's degree in social work from Virginia Commonwealth University.

State: Delaware



### **Colleen Wieck, PhD**

Minnesota Governor's Council on  
Developmental Disabilities

*Having made an overall contribution  
through service and advocacy*

Dr. Wieck has served as the Executive Director of the Minnesota Governor's Council on Developmental Disabilities for nearly 40 years. In this role, she led the development of the *Partners in Policymaking*<sup>®</sup> leadership training program. *Partners in Policymaking* assists people with disabilities and family members in knowing their rights, knowing what to expect in terms of high-quality services and supports, and knowing how to obtain such services and supports within their local communities.

Launched in 1987, *Partners in Policymaking* has been replicated nationally and internationally. The curriculum covers history, inclusive education, effective communication strategies, team building, competitive integrated employment, supported living, community organizing, legislative processes, and assistive technology. Graduates have worked to successfully expand community opportunities and to hasten fundamental changes in supports and services for people with disabilities.

Under Dr. Wieck's leadership, the Minnesota Governor's Council on Developmental Disabilities developed the *Parallels in Time* website, which archives important IDD history. Dr. Wieck has served on numerous national committees including the Pennhurst Memorial & Preservation Alliance and worked on many public policy issues including deinstitutionalization in Minnesota.

State: Minnesota

# Essential Change Agents

Recipients of this honor are recognized for their significant regional contributions to or impact in the field of IDD in the U.S. between 2000 and 2020. These individuals were often engaged in service, public policy, and advocacy initiatives that were significant in their region, contributed to the national dialogue, and enhanced the quality of life of people with IDD.



## 2020 Essential Change Agents



### **Marc Brandt**

The Arc New York

*Having made an overall contribution  
through service and advocacy*

Mr. Brandt has been the Executive Director of The Arc New York (NYSARC) since July 1982. Prior to serving in this role, he was Executive Director of the Sullivan County Arc from 1971 to 1982.

Mr. Brandt testified in the original hearing that led to the consent decree closing of the Willowbrook State School, and his advocacy was instrumental in the ultimate closure of a number of institutions in New York state. He worked closely with Commissioner Thomas Maul on the development of the New York CARES program, launched in 1998 and designed to develop community-based residential services for people on the community waitlist.

Mr. Brandt worked diligently to raise awareness across New York of the 2005 Supreme Court of the United States' decision in *Schaffer v. Weast*, in which the Court held that the burden of proof rests on the party seeking relief in a challenge to an individualized education program (IEP). This decision required school districts challenging an IEP, rather than parents, to bear the burden of proof in persuading an administrative law judge.

Mr. Brandt was a key player in advocating for the passage of New York's Family Health Care Decisions Act of 2010, which allows, when there is a lack of prior instruction and decisional capacity, for medical decisions to be made by a person's family member or close friend.

State: New York



### **Hugh Carey**

(1919–2011)

Governor of New York, 1975–1982

*Having made an overall contribution  
through public policy*

Mr. Carey was the 51st governor of New York, holding office from 1975 to 1982. Prior to this role, he served seven consecutive terms as a U.S. Representative from New York (1961–1974).

While often remembered for his successful handling of New York City's economic crisis in the mid-1970s, Mr. Carey also signed the Willowbrook Consent Decree on behalf of the state and advanced new funding models in home- and community-based services.

The Willowbrook Consent Decree sought to correct unacceptable conditions at the Willowbrook State School in Staten Island, New York, and was effective on behalf of class members on May 5, 1972. Willowbrook was not only a landmark case and a catalyst for the state to reform its service system for people with IDD, it also served to raise national attention about deinstitutionalization and the necessity of having high-quality standards for services and supports.

State: New York

## 2020 Essential Change Agents



### **Donna Colonna**

Services for the UnderServed  
*Having made an overall contribution  
through advocacy and service*

Ms. Colonna has been the CEO of Services for the UnderServed (SUS) since 2002. In this role, she directs and administers services and supports for individuals and families in New York who need assistance due to disability, mental health issues, health issues, homelessness, unemployment, and poverty.

Over the course of more than 40 years in state government and the nonprofit sector, Ms. Colonna has been a vocal advocate for the rights of, and services for, individuals with disabilities. She regularly shares her expertise on statewide bodies addressing health care, homelessness, and developmental disabilities services in New York.

Among her many honors and accolades, Ms. Colonna was named to City & State New York's 2019 Nonprofit Power 100, a list recognizing the top 100 figures making a difference in the lives of the most vulnerable New Yorkers.

State: New York



### **Susan Constantino, MEd**

Cerebral Palsy Associations of New York State  
*Having made an overall contribution  
through service*

Ms. Constantino has served as President and CEO of the Cerebral Palsy Associations of New York State (CP of NYS) since 2004. In this role, she is responsible for the programs and services operated by CP of NYS in New York City and for the State Association, which offers its 24 affiliates technical assistance and opportunities for training, information sharing, and networking. Prior to joining CP of NYS, Ms. Constantino served as the Director of Children's Services at Aspire of Western New York.

Ms. Constantino has shaped service delivery for people with IDD in New York. She currently serves on a number of governmental task forces, councils, and statewide committees representing the interests of CP of NYS, its affiliates, and the IDD community.

Ms. Constantino has received numerous state accolades over the years. She earned both a bachelor's and a master's degree in special education from the State University College at Buffalo. She is certified as a special education teacher and as a school administrator and supervisor.

State: New York

## 2020 Essential Change Agents



**Steve Cook, MS**

Indiana Association of Rehabilitation Facilities

*Having made an overall contribution  
through service*

Since 2016, Mr. Cook has been the President and CEO of the Indiana Association of Rehabilitation Facilities (INARF), an association of disability service providers in Indiana. His previous roles include leadership positions at Benchmark Human Services, Indiana MENTOR, and New Hope of Indiana. He served the state of Indiana as the Director for the Division of Disability and Rehabilitative Services from 2001 to 2004.

Throughout his career, Mr. Cook has been a key player in assuring the delivery of quality supports and in transforming the Indiana service system to one that embraces person-centered practices.

Mr. Cook is a licensed school psychologist; he earned a bachelor's degree from Indiana University Bloomington and a master's degree in school psychology from Butler University (Indiana).

State: Indiana



**John Dickerson**

Quillo

*Having made an overall contribution  
through service and advocacy*

Mr. Dickerson is the founder and CEO of Quillo, a company launched in 2018. In this role, he administers initiatives that improve services for people with IDD through shifts in organizational culture and a focus on staff well-being.

Mr. Dickerson's prior roles include service as the Executive Director of The Arc of Indiana from 1983 to 2015 and positions at The Arc of South Dakota.

In his role with The Arc of Indiana, Mr. Dickerson was a major contributor to the successful efforts to close the state's residential institutions and develop service capacity across the state to support people with IDD in the community.

State: Indiana

## 2020 Essential Change Agents



**Margaret H. (Peg) Dignoti**

(1936–2014)

*Having made an overall contribution  
through advocacy*

Ms. Dignoti served The Arc of Connecticut for nearly 50 years, beginning her tenure in 1960 and serving as the Executive Director for 25 years until her retirement.

Peg was a pioneer whose work set a standard throughout the country. The Arc of Connecticut was a major contributor to the processes that resulted in the closure of the Mansfield Training School, and she became the public face of the multiple lawsuits fighting for community-based options. She was a key player in the efforts to decrease the census at Southbury Training School.

Ms. Dignoti was successful in challenging a state law regarding the maximum number of unrelated people in one residence that communities had used to deny approval for group homes in their jurisdictions. She also worked to end the segregation of children with disabilities in schools, founding the Connecticut Coalition for Inclusive Education to encourage parents to lobby their legislators for change.

Ms. Dignoti also worked to change public attitudes about people with disabilities. She frequently wrote articles and letters to the Editor, condemning condescending language or attitudes that appeared in their publications.

State: Connecticut



**Annie M. Forts**

(1967–2016)

*Having made an overall contribution  
through advocacy*

Ms. Forts was a motivational speaker and self-advocate who traveled the country spreading her message of living on the “UP” side of Down syndrome. In addition to her speaking engagements, she was active volunteer for several local service organizations, most notably the Moultonborough Lions Club (New Hampshire).

Appointed by President Clinton, Ms. Forts served three terms on the President’s Committee on Mental Retardation. She received numerous accolades for her advocacy work, including the Paul G. Hearne Leadership Award (American Association of People with Disabilities), the Exceptional Merit Award (National Down Syndrome Congress), and Citizen of the Year (The Arc of New Hampshire)

A graduate of Moultonborough Academy, in 1997 Ms. Forts started the Annie Forts UP Syndrome Fund with the support of the Moultonborough Lions Club. The fund has helped to support enrichment opportunities for people with Down syndrome.

State: New Hampshire

## 2020 Essential Change Agents



**Michael Goldfarb**

(1941–2014)

*Having made an overall contribution  
through service*

Mr. Goldfarb served as the Executive Director of AHRC New York City from 1975 to 2011. In this role, he transformed and expanded the organization's approach to service to include residences of many sizes and specialties in all five boroughs, employment supports, services for individuals with traumatic brain injuries, and the openings of Camp Anne and the Katy Isaacson Elaine Gordon Lodge. Mr. Goldfarb's previous positions included Executive Director of the Brooklyn Psychiatric Centers and Executive Director of the Coalition of Voluntary Mental Health and Mental Retardation Agencies.

Under Mr. Goldfarb's direction, AHRC New York City was among those organizations that stepped up to support the residents of the Willowbrook State School in their transition to the community, but it took pains to assure that as it expanded its capacity, both individuals on the waiting list and those moving from the institution were being served. Mr. Goldfarb was a key player in the formation an interagency council to improve planning and coordination of the services that were rapidly expanded in New York City as Willowbrook was closed.

Mr. Goldfarb led efforts to address recruitment and retention challenges for service organizations. In the mid-1980s, he persuaded both the community and senior colleges of the City University of New York to begin providing training for direct support professionals (DSPs) and the John Kennedy, Jr. Foundation to provide seed money for a fellowship program to support students. The training program evolved over time but still supports DSPs in their professional growth.

State: New York



**Ann Greenberg**

(1912–2006)

*Having made an overall contribution  
through service and advocacy*

Ms. Greenberg was a disability activist and parent of a son with IDD. When her son was denied access to education, she put an ad in the *New York Post* looking for other parents in a similar situation. As a direct result of this action, she founded the AHRC New York City in 1948 to meet the needs of young children. Today it is the largest organization in the city that provides services and supports for people with IDD across the lifespan.

As the founder of AHRC New York City, Ms. Greenberg was a leading force behind the joining of thousands of parents, advocates, politicians and individuals across New York State.

Through advocacy, education, and grit, Ms. Greenberg imparted her knowledge and wisdom to families, advocates and policy makers for generations. She continued to work at AHRC New York City well into her 90's and her death in 2006.

State: New York



## 2020 Essential Change Agents



### **Ann Hardiman, MA**

New York State Association of Community and Residential Agencies (Emerita)

*Having made an overall contribution through service and advocacy*

Ms. Hardiman was the Executive Director of New York State Association of Community and Residential Agencies (NYSACRA) from 1995 until her retirement in 2019. In this role, she oversaw the grassroots organization's efforts to provide a unified voice for its members at the local, state, and federal levels on matters relating to services, funding, and legislation.

Under Ms. Hardiman's direction, NYSACRA was a primary resource for information and technical assistance and provided opportunities for collaboration, networking, and continuing education.

Ms. Hardiman was appointed by President Obama in 2011 to a term on the President's Committee for People with Intellectual Disabilities. She earned a master's degree in community psychology from Marist College (New York).

State: New York



### **Elin Howe, MPA**

Massachusetts Department of Developmental Services (Emerita)

*Having made an overall contribution through service and public policy*

Ms. Howe led the Massachusetts Department of Developmental Services (DMS) as its Commissioner for a decade, retiring in 2017. She previously served the New York State Office of Mental Retardation and Developmental Disabilities in a variety of roles, including a term as Commissioner. Ms. Howe played a key role in the development of the New York's first home- and community-based waiver.

During her tenure in Massachusetts, Ms. Howe oversaw the closure of four state institutions, expansion of community residences, closure of sheltered workshops, expansion of access to family supports, and the agency's change in name from DMR to DMS. In addition, she spearheaded the development of the *Blueprint for Success: Employing Individuals with Intellectual Disabilities in Massachusetts*.

Ms. Howe earned a bachelor's degree at Salem State University (Massachusetts) and a master's degree in public administration from the State University of New York at Albany.

State: Massachusetts

## 2020 Essential Change Agents



### **Edward (Ed) Matthews, MS**

ADAPT Community Network  
*Having made an overall contribution  
through service and advocacy*

Mr. Matthews has been the CEO of the ADAPT Community Network, formerly known as United Cerebral Palsy (UCP) of New York City, since 1986. In this role, he oversees and administers the nonprofit's services for people with disabilities in all five boroughs of New York City.

Following the consent decree for the Willowbrook State School, Mr. Matthews was charged with securing community homes for residents with very high support needs. Ten years later, the state was sued over its compliance with the consent decree. In the trial, Mr. Matthews testified about his efforts to establish residences in New York City for residents to move to: He recounted not only community opposition but his reduced support staff (from five site developers down to one) and guidelines from his supervisors that created significant barriers to securing locations for group homes. He testified that if the strict limitations on location (a quarter-mile radius from one of six hospitals in Manhattan and the Bronx) were relaxed, he and his team could have secured many more community-based residential options. In its decision, the court specifically addressed the areas of Mr. Matthews' testimony for remediation.

Mr. Matthews has earned two master's degrees, one in school psychology from St. John's University (New York) and one in American history from Fordham University (New York).

State: New York



### **Thomas A. (Tom) Maul**

New York State Office of Mental Retardation and  
Developmental Disabilities (Emeritus)  
*Having made an overall contribution through  
service and public policy*

Mr. Maul served the New York State Office of Mental Retardation and Developmental Disabilities (OMRDD) in several roles, including Executive Deputy Commissioner, Acting Commissioner (1993–1995), and Commissioner (1995–2006).

During his tenure at OMRDD, Mr. Maul oversaw the closure of the Syracuse Developmental Center, facilitated the development of home- and community-based waiver services, promoted the principles of self-determination, and worked with providers to address the direct support workforce crisis.

State: New York

## 2020 Essential Change Agents



### **Henrietta Messier, MA**

(1925–2015)

*Having made an overall contribution  
through service and advocacy*

Ms. Messier was a disability activist. Her first job, at age 19, was as a labor union organizer. From the birth of her daughter with Down syndrome until Ms. Messier's death, she was a devoted advocate for people with IDD.

Ms. Messier began advocating for educational services for her daughter, then expanded her efforts by co-founding The Arc of Rensselaer County. She was a key player in the development of the legislative advocacy agenda for The Arc New York, including an important bill passed in 2010 that changed problematic language in regulations and the name of the state agency now known as New York State Office for People with Developmental Disabilities.

Ms. Messier served on the board of directors of The Arc of Rensselaer County, The Arc New York, and a number of other organizations. As a nontraditional student, she earned a master's degree in human services and administration from Antioch University (New Hampshire).

State: New York



### **Nancy Murray, MS**

The Arc of Greater Pittsburgh and ACHIEVA

*Having made an overall contribution  
through service and advocacy*

Ms. Murray is a Senior Vice President of ACHIEVA and the President of The Arc of Greater Pittsburgh. Her previous positions include Founder and Coordinator of the Down Syndrome Center at Children's Hospital Pittsburgh, Director of Supports Coordination at Staunton Clinic in Pittsburgh, and Western Area Director of the Office of Developmental Programs in Pennsylvania. In her role at ACHIEVA, Ms. Murray directs its Disability Health Initiative, which seeks to address disparities in people with disabilities' access to health care.

A parent of children with Down syndrome, Ms. Murray serves as co-Chair of the Family Caregiving Advisory Council and is a member of the Governor Wolf's Council on Reform to improve the support and protection of vulnerable Pennsylvanians. She also serves on the board of directors of the Pennsylvania Assistive Technology Foundation and the Pennsylvania Medical Assistance Advisory Council.

Nationally, Ms. Murray serves on the National Council of Executives of The Arc of the United States and the Administration on Intellectual and Developmental Disabilities' (AIDD) RAISE Family Caregiving Council.

State: Pennsylvania

## 2020 Essential Change Agents



### **Ida Rappaport**

*Having made an overall contribution  
through advocacy*

Ms. Rappaport is a disability activist and a parent of a man with IDD.

A seasoned union organizer for the Ladies Garment Workers Union, Ms. Rappaport formed an association for parents and others, Lifespire (formerly ACRMD).

Lifespire's initial mission was to increase educational opportunities for children with IDD; the organization's mission later expanded to include increasing independence for people with IDD in many areas.

State: New York



### **Kay Reed Mirick**

(1947–2005)

*Having made an overall contribution  
through service and advocacy*

Ms. Reed Mirick founded Support Services of Virginia (SSVA) in 1994 and served as its CEO and President until her passing in 2005. In this role, Ms. Reed Mirick sought to use positive behavioral supports and practices to provide individualized supports to people with intellectual disabilities and complex needs.

Ms. Reed Mirick's vision was for all people to have an equal chance at happiness that extended beyond receiving quality supports. Through SSVA, she employed numerous people in the communities the organization served, basing employment more on individual strengths and desire to make the world a better place than on education and experience.

State: Virginia

## 2020 Essential Change Agents



### **Ida Rios**

*Having made an overall contribution  
through advocacy*

Ms. Rios is a disability activist. She is a parent of a man with IDD who resided at the Willowbrook State School and is one of the original group of parent plaintiffs in the landmark case that resulted in the Willowbrook Consent Decree.

Ms. Rios has served on the Willowbrook Task Force since its inception decades ago and on many of its subcommittees. The mission of the task force is to advise the Commissioner of New York State Office for People with Developmental Disabilities on matters of concern, and its actions have often resulted in long-term attention and plans of corrective action.

State: New York



### **Nancy Rosemore**

Lutheran Social Service of Minnesota  
*Having made an overall contribution  
through service*

Ms. Rosemore has served Lutheran Social Service of Minnesota for more than 30 years and is currently its Associate Vice President of Services for People with Disabilities. She is a long-standing member of Lutheran Services in America Disability Network (a national consortium of disability providers) where she acted as a convener for two years and as an observer at the United Nations Convention on the Rights of Persons with Disabilities (CRPD).

Ms. Rosemore played a key role in organizing the cooperation of, among others, Minnesota's Government Training Services and Governor's Council on Developmental Disabilities to assist in the production of *Institutions to Independence*, a 30-minute documentary that tells the story of how supports for people with developmental disabilities in the state have evolved from institutional to community-based services. The documentary, a co-production of the Twin Cities PBS (TPT) and Lutheran Social Service of Minnesota, was first aired in August 2019 and available on-demand on the TPT website.

She has served on the Minnesota Council on Disability (2014–2017); the Minnesota Department of Human Services' (MNDHS) State Quality Council; MNDHS HCBS settings rule review committee, and on the boards of directors of ARRM and the Paul Bunyan Arc.

State: Minnesota

## 2020 Essential Change Agents



### **Lynne Seagle, MSEd**

Hope House Foundation

*Having made an overall contribution  
through service and advocacy*

Ms. Seagle has served as the Executive Director of Hope House Foundation for more than 30 years. In her previous roles, she has served as Director of Residential Services at Hope House, a special education teacher, and a direct support professional.

At the Hope House Foundation, Ms. Seagle led its transition from being a provider of group homes to supporting community living. Under her leadership, the foundation created and seeded a new entity, The Residential Corporation, to purchase apartment buildings for mixed use by people with and without disabilities. This strategy enabled people with disabilities to secure apartments, and it created inclusive communities.

Ms. Seagle has served a term on the President's Committee for People with Intellectual Disabilities and the board of directors of The Arc of Virginia, and she is currently on the advisory board of the Joseph P. Kennedy Jr. Foundation. She earned a bachelor's degree in special education and a master's degree in public administration and educational leadership from Old Dominion University (Virginia).

State: Virginia



### **Arthur Webb**

Arthur Webb Group

*Having made an overall contribution  
through service and advocacy*

Mr. Webb is the Principal of the Arthur Webb Group. He served in New York state government as Commissioner or Director of four separate agencies: the Office of Mental Retardation and Developmental Disabilities, the Division of Substance Abuse Services, the Department of Social Services, and the Health Planning Commission. He also served as Chair of the New York City Regional Advisory Committee of the Commission on Health Care Facilities in the 21st Century—the Berger Commission.

Following his service in state government, Mr. Webb was the President and CEO of Village Care/Village Center for Care and CEO of St. Vincent Catholic Medical Centers of New York.

Mr. Webb has served on numerous advisory committees and was a key player in the closing of seven New York Developmental Centers and the development of Medicaid waiver-funded family support services in New York. He is actively involved in the transformation of the state service system to a managed care model and the building of provider-led coalitions.

State: New York

## 2020 Essential Change Agents



### **Duncan Whiteside**

Maidstone Foundation (Emeritus)  
*Having made an overall contribution  
through service and advocacy*

Mr. Whiteside is a disability activist and a parent of a man with IDD. He founded the Maidstone Foundation in 1984 and served as its CEO for 35 years until his retirement. Mr. Whiteside's previous positions included Director of the One to One Foundation, an organization founded by Geraldo Rivera to provide seed money and training for organizations serving individuals who had resided at the Willowbrook State School or other institutions.

In these roles, Mr. Whiteside oversaw advocacy, strategic planning, fundraising, and grantmaking. In addition, during his tenure, Maidstone developed robust services for Russian immigrant families in New York who had members with IDD. Mr. Whiteside is fluent in Russian, and with his team he provided culturally competent services for this community.

Under Mr. Whiteside's direction, Maidstone provided space and funding to the Self-Advocacy Association of New York State. In addition, he served as Vice Chair of the New York State Developmental Disabilities Planning Council for over 20 years.

State: New York



### **Teresa (Terri) Williams**

Mains'l Services  
*Having made an overall contribution  
through service and advocacy*

Ms. Williams is the founder and CEO of Mains'l Services, a national provider of services and supports for people with disabilities. Over the course of her career, she has led multiple systems change efforts, the creation of financial management services and software that enable people to direct their own services, and the rapid development of community capacity for residential supports to support deinstitutionalization.

Ms. Williams has provided technical assistance on strategies to promote systems change to stakeholders in numerous states. She has served on the boards of directors of The Arc Minnesota, ARRM, the Minnesota chapter of AAIDD, the American Network of Community Options and Resources (ANCOR), and H2O for Life.

State: Minnesota

## 2020 Essential Change Agents



### **Duncan Wyeth**

Michigan Commission on Disability Concerns

*Having made an overall contribution  
through service and advocacy*

Mr. Wyeth is a disability activist and Executive Director of the Michigan Commission on Disability Concerns. In this role he oversees investigations on issues of concern to those with disabilities. Born with cerebral palsy, Mr. Wyeth is a cyclist, a Paralympian, and a strong proponent of people with disabilities being involved in sports.

Since 2010, Mr. Wyeth has served on the board of directors of Peckham, Inc., an organization that provides job training and placement to people with disabilities or other barriers to employment.

He is a member of a member of Michigan AmeriCorps Inclusion Team and an adjunct instructor at Michigan State University (MSU). He earned bachelor's and master's degrees from MSU.

State: Michigan



# Unsung Heroes

Honored here are the numerous individuals and groups who contributed to or impacted the field of IDD in the U.S. between 2000 and 2020. While not named, their efforts to enhance the quality of life of people with IDD is noted with gratitude.



## Recognizing the Unsung Heroes

Margaret J. Gould | The VISIONS Center for Creative Management

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The people recognized in this commemorative booklet have all made significant contributions to the disabilities field; however, many of the successes of the past 20 years have resulted from the actions of those who came before: the many professionals, families, self-advocates, and policymakers who worked tirelessly, often behind the scenes, to enhance supports and quality-of-life outcomes for people with disabilities.

In every setting and in every role in our field, there have been numerous individuals who have promoted and implemented person-first, community-based supports in their region, state, or community. They have done the hard work every day, informed by evidence and inspired by ideals, to improve the quality of life of people with disabilities and make their communities truly inclusive.

It is important to recognize the early community-based providers, both nonprofit and for profit, who mobilized quickly to increase their capacity and their range of services to support people transitioning from institutions to the community. Their efforts created options and opportunities that supported the successful deinstitutionalization of thousands of people with disabilities. These pioneers filled an

important role in the emergence of crucial support provision, often without successful models to emulate, and they generously shared their knowledge with others. One such pioneer is Wayne Nielsen, who opened a provider organization in rural Iowa where little to no community capacity existed. After developing a successful model in an area with limited resources, he then provided technical assistance and consultation to many similar organizations to help them improve and enhance their practices.

Lastly, while today the vast majority of people with disabilities in the United States live and work in their communities, we should recognize the personnel of the remaining institutions for their efforts to increase choice, self-determination, and quality of life among those they serve. Their dedicated commitment to person-centered approaches has resulted in improved outcomes in these settings and successful transitions to the community.

Without the dedication and commitment of all of these unsung heroes, the extent of the effective, community-based supports now available to people with disabilities could not have been developed.

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## Acknowledgements

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American Association on Intellectual and Developmental Disabilities (AAIDD)  
American Network of Community Options and Resources (ANCOR)  
Association of University Centers on Disabilities (AUCD)  
National Association of State Directors of Developmental Disabilities Services (NASDDDS)  
The Arc of the United States (The Arc)  
United Cerebral Palsy (UCP)  
ADAPT Community Network  
Cerebral Palsy Association of New York  
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The Arc New York (NYSARC)  
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