NLCDD Bulletin

Leading the Future while Learning from the Past: Part 1

National Leadership Consortium on Developmental Disabilities

July 2026 • Issue 19

About the Bulletin

The NLCDD Bulletin is a free, web-based publication dedicated to providing relevant, trustworthy, and thought-provoking information to leaders, practitioners, and people with disabilities and their families involved in the field of developmental disabilities support services. The Bulletin serves as a bridge between scientific journals and day-to-day leadership, exploring timely research and policy issues in the leadership and disabilities fields with the aim of promoting organizational change and assisting leaders to support people with disabilities to experience inclusive, valuable, and meaningful lives.

About the NLCDD

Great Systems Start with Great Leaders

Founded with an unwavering stance on social justice for people with IDD, NLCDD was created to ensure emerging and established field leaders have the skills, knowledge, connections, and resources they need to create a world where people with disabilities are fully included and have control over every aspect of their lives. Our mission is to cultivate transformational leaders at every level of the intellectual and developmental disabilities field so people with disabilities can live with dignity, choice, and full human rights. NLCDD works to meet this mission through training and development programs for field leaders working at all levels of their organizations and systems, customized support designed to foster transformation and forward movement, and research and evaluation to keep leaders informed and up to date on evidence-based and innovative practices and strategies.

Contact Us

https://natleadership.org/resources/bulletin • bulletin@natleadership.org

Table of Contents

Contributors:

Kristen Loomis Greenidge, MBA, *Co-Director, National Leadership Consortium on Developmental Disabilities (NLCDD)*

Steven Eidelman, MBA, MSW, *Co-Founder, National Leadership Consortium on Developmental Disabilities (NLCDD)*

Dan Hermreck, *Chief Innovation Officer, NADSP*

Sue Swenson, *President, Inclusion International*

Amanda Rich, PhD, *Founder and Principal Consultant, Open Road Inclusive Community Consulting*

Guy Caruso, PhD, *Western Coordinator for the Institute on Disabilities, Temple University*

Sheli Reynolds, PhD, *Director, UMKC-LifeCourse Nexus*

Mary Kay Rizzolo, PhD, *President and CEO, The Council on Quality and Leadership (CQL)*

Monica Mesa-Alvarez, PhD, *Research and Development Assistant, National Leadership Consortium on Developmental Disabilities (NLCDD)*

Nancy Weiss, *Co-Founder, National Leadership Consortium on Developmental Disabilities (NLCDD)*

Caitlin Bailey, PhD, *Co-Director, National Leadership Consortium on Developmental Disabilities (NLCDD)*

Dorothy Hiersteiner, MPP, *Co-Director, National Core Indicators ®(NCI®), Human Services Research Institute (HSRI)*

Valerie Bradley, MS, *President Emerita, Human Services Research Institute (HSRI)*

Laura Vegas, MPS, *Director of Quality Initiatives and Supporting Families, National Association of State Directors of Developmental Disabilities Services (NASDDDS)*

Nancy Thaler, *Consultant to federal and state governments on Medicaid and disability policy, former Executive Director, National Association of State Directors of Developmental Disabilities Services (NASDDDS)*

Mat Rice, *Executive Director and Advocacy Coordinator, People On the Go Maryland*

Tracy Wright, *Deputy Director and Director of Training, People On the Go Maryland*

Managing Editor: **Cory Gilden, PhD**

Consulting Editor: **Amanda Rich, PhD**

If you would like to contribute a reflection, strategy, position piece, or research to the Bulletin please contact us at bulletin@natleadership.org. Even if you have not written for publication before, the team at the Bulletin would love to help you develop your ideas.

Introduction: Leading Toward the Future while Learning from the Past: Part 1

Throughout his career, Gunnar Dybwad, a disability justice pioneer, famously challenged his own previously held beliefs as an educator, expert witness, and civil rights leader. Several times he recognized that his previous stance on education for people with disabilities, the role of parents in determining supports, and more had changed as he learned more with and from people with disabilities. His personal evolution was an example to field leaders and lawmakers of the necessity of learning, shifting, growing, and adapting.

Nancy Weiss, one of NLCDD's co-founders, often quotes Maya Angelou's more well known quote with a similar meaning, "Do the best you can until you know better. Then when you know better, do better," when talking about how far our field has come. She says that all of us can look back on our work from a decade ago and cringe, knowing that what we called best practice then is what we now call underestimating and controlling people with disabilities.

We are a field that, though founded in good intentions, was built on tenets of segregation, exclusion, and disability-shame. Over the years we've learned and relearned that many of our foundational values and practices, though usually well meaning, need to evolve. And it's exactly that evolution that we set out to understand in this and the next issue of the NLCDD Bulletin.

We asked authors who have deep knowledge and were often involved in the founding and early days of key movements and concepts in the disability field to share their perspectives on where these ideas came from, how they changed over time, and where they go next. Steve Eidelman, also an NLCDD co-founder, reflects on the important policy changes that have increasingly recognized and defined the rights of people with disabilities, further looking into how our past shapes our future. Dan Hermreck of NADSP talks about a critical shift in professionalizing the direct support professional role to ensure that those who support people with IDD are recognized, compensated, and credentialed. Sue Swenson's powerful article recognizes the key role that family members of people with disabilities have always had in the field, and the key issues they face related to future trends and federal policy changes.

Amanda Rich, NLCDD Bulletin Consulting Editor, encourages us to change the questions we are asking and examines the creation of the trauma-informed care framework, how it is growing, and what's next. Guy Caruso and Sheli Reynolds' articles focused on two key frameworks that have and continue to shape the work of our field, Social Role Valorization and Charting the Life Course, explore the foundations of these ideas and how they continue to guide field professionals today. Mat Rice and Tracy Wright talk about the evolution of one of Maryland's most impactful self-advocacy organizations and movements and what's next for self advocacy. And finally, Amanda Rich wraps up the issue with an overview of tools and resources, many of which are referenced in previous articles, that can inform leaders working to strengthen policies, improve practices, and support staff development.

This topic is so big and important that we've decided to dedicate two issues to learning from our past to inform our future. The articles in this issue are as moving as they are meaty. We hope they provide a bit of stability in a truly 'up in the air' time in our field, and keep us centered on the fact that we, as a field, have always continued to move forward, even in the most challenging eras of our history.

Kristen Loomis Greenidge

Kristen Loomis Greenidge *is the Co-Director of the NLCDD. She has a Bachelor of Science degree in Human Services and a Master's in Business Administration degree with a concentration in Strategic Leadership from the University of Delaware. Contact Kristen at kloomis@natleadership.org.*

Reflections on Key Policy Issues in the Field

By Steven Eidelman

- People with disabilities have gained important rights over time. Laws have created the right to access public school, expanded access to healthcare through Medicaid, and protected civil rights through the Americans with Disabilities Act (ADA).
- These changes have made a big difference, but challenges remain. Many people with disabilities still face barriers to getting services, and some policies continue to make it harder to receive community-based supports and services.
- Current changes to Medicaid and ongoing legal challenges to the ADA could affect people's access to healthcare, services, and equal opportunities. Changes to eligibility rules and paperwork may make it harder for some people to keep their coverage.
- The future depends on continued advocacy and leadership. Progress is not guaranteed, and protecting the rights, inclusion, and quality of life of people with disabilities will require ongoing commitment from families, service providers, policymakers, and communities.

Where Did We Come From?

Let me begin by disclosing that I am not a trained historian, though I am writing from the historical perspective of someone who has been employed in various leadership roles in the disability field for 50 years.

Regardless of the issue, exclusion and segregation are dominant themes. Considering important issues in the history of the field, I would start with access to public services, specifically public education. Prior to 1975, children with disabilities were mostly excluded from public education. There were many schools that did include children with disabilities, but exclusion was the norm. Children with significant disabilities were mostly excluded. In my elementary school there was a class of students with Down Syndrome. They were physically present but did not participate in school activities. For all of these children, education was not a right. In 1975, P.L. 94-142 created The Education for All Handicapped Children Act, making education a legal entitlement (a guaranteed right to receive a specific benefit or service) at any school district that received federal funds. P.L. 94-142 has been reauthorized, and the name has changed over time, but it was historic. In 1986, P.L. 99-457 lowered the age for the entitlement to age three and created a state option, Part H, to expand the program to children, birth through three. It also created a requirement for an individual family service plan, recognizing that families are a key component of a learning environment for children. A coordinating council for Part H was required and I got to serve as the first chair of that council in Pennsylvania. I still have goosebumps hearing State Representative Ron Cowell, who guided the legislation, Act 212 of 1990, bring the general assembly to vote to adopt the law. In a recession, Governor Robert P. Casey signed it into law.

The second critical issue would be Medicaid. While not a disability specific law, when enacted in 1965 as part of President Johnson's war on poverty and the Great Society agenda, growth in funding for

services came from the Medicaid ICF/MR level of care in 1971. Medicaid ICF/MR funded facility-based services, mostly public institutions. The greatest expansion came through the Medicaid Waiver, enacted in 1981. Medicaid is the only open-ended entitlement program providing services for people with disabilities. For every dollar a state allocates it is matched, more or less, by a federal Medicaid dollar.

The third issue would be civil and human rights. The Americans with Disabilities Act of 1990 (commonly known as the ADA) is a broad civil rights law, establishing that Americans with Disabilities have rights to all that America has to offer and that government, businesses etc. are to provide REASONABLE ACCOMODATION to help people get what they need. The language in the ADA concerning people with disabilities is uplifting and worth reading.

Medicaid is the only open-ended entitlement program providing services for people with disabilities.

Where Are We Now?

Regarding education, all 50 states have passed legislation to implement Part H of the Individuals with Disabilities Education Act (IDEA) (now part C in a reauthorization of the act), so now states operate statewide programs of early intervention services for infants and toddlers ages birth to three with disabilities and their families.

The current Medicaid system has some flaws, specifically an institutional bias, (ICF and Nursing homes are an entitlement; community services mostly are not), but it is hard to imagine our service systems today without it. Medicaid is one of the largest items in state budgets. HR 1, The Big Beautiful Bill Act, Public Law 119-21 has many tax cuts and confusing language throughout. It puts new requirements on Medicaid recipients. It reduced retroactive eligibility from 3 to 2 months for traditional (including disability) and 3 to 1 month for expansion Medicaid. People with disabilities may have less time to enroll and cover past medical bills, increasing the risk of unpaid medical debt if enrollment is delayed. There are also more frequent eligibility checks, going from annual to every six months. Some people with disabilities will lose their Medicaid due to paperwork errors and lack of understanding about the new changes.

There are also work requirements calling for people to work 80 hours a month. This means some people, though no fault of their own, will not be able to keep their Medicaid or will not be able to get it quickly. For a full summary of this legislation see this article by the Center for American Progress.

The ADA is not legislation providing services directly. It is about rights and access. Many state governments are challenging the ADA and are also challenging Supreme Court Cases coming out from the ADA. The ADA has “teeth” but so many of its provisions depend upon the good faith efforts of our state and federal governments. The ADA was not, and is not, a magic cure all for discrimination and segregation of people with disabilities. But it is a benchmark and expresses positive things about people with disabilities.

Where Are We Going?

We are at a crucial point in the history of people with disabilities in America. Recent action by the U.S. Department of Justice changes their stance on the integration mandate made possible by the ADA. As of this writing, backlash from advocates, legislators, and some states is opposing this change. Every day we

see people benefiting from Medicaid, the right to education and improvements in healthcare. We also see new segregation, cutbacks in services and in service programs, and a combination of not enough staff and high turnover, both of which can diminish the quality of services and the quality of life for people with disabilities. We also see the takeover of many service providers by venture capital firms, putting pressure on containing costs and limiting services. Experience in other fields bears this out.

We have come far, but continued progress is not guaranteed, and some falling back to old ways is likely.

There are many laws, court decisions and programs that impact directly the lives of people with disabilities. The three mentioned above are important, but I do not pretend that others would pick these three as the most important. What do you think?

Steven M. Eidelman *is a founder of the National Leadership Consortium on Developmental Disabilities and a retired professor at the University of Delaware. He is a past President of AAIDD, serves as Senior Advisor to the Chairman of Special Olympics International, and serves as the Executive Director of The Joseph P. Kennedy, Jr. Foundation. Contact Steven at sme@udel.edu.*

Building the Direct Support Profession

By Dan Hermreck

- Despite the professional knowledge, skills, and ethics that direct support professionals (DSPs) use every day, they have historically not been recognized as true professionals.
- While DSP training has traditionally focused strictly on regulatory compliance, the future is pivoting toward true professional growth and national certification.
- The expectations of funders, providers, and DSPs themselves will drive the future of direct support professional training and development.

Where Did We Come From?

Historically, the training of direct support professionals (DSPs) has focused on ensuring that licensing requirements have been met, and that their employer was meeting all its obligations related to training under local, state and federal regulations. Training topics might include things like CPR/first aid, bloodborne pathogens, fire safety, responsibilities as a mandated reporter, and expectations around confidentiality. These trainings would often be presented to the DSP during an initial set of orientation classes, and then again as needed to maintain compliance with the relevant regulations. While the exact regulatory requirements differed from state to state, these mandatory trainings typically focused on the health and safety of the people being supported by DSPs.

While health and safety are certainly an important part of the direct support role, there are many other aspects of daily life in which a DSP might be providing support. While providers could offer additional training on other useful topics, severe staffing shortages often got in the way. Consequently, DSPs were typically only pulled away from their regular duties for mandatory sessions. This resulted in situations in which a DSP might know exactly what to do in a particular type of emergency but had much less guidance about how to approach their work in more common, non-emergency scenarios.

In most cases, these training courses were not standardized. Each organization employing DSPs was likely to have their own version, with its own title, structure, and content. Typically, the credit for completing these training classes did not travel with the DSP if they changed jobs or worked more than one job. This led to many DSPs being retrained even more frequently than regulations required. DSPs would often take similar training on the same topics again and again. In many cases, the focus was more on making sure attendance was documented than learning anything new.

Where Are We Now?

Now, the professional development of DSPs is in an era of transition. National certifications based on validated competency sets are available. Some states have created incentives based on DSP certification or enhanced training. Certification pilots in New York, Tennessee and Georgia have shown encouraging results. Pennsylvania uses performance-based contracting to pay higher rates to providers who have met certain requirements, and one of those requirements is tied to the percentage of their direct support workforce that has been nationally certified.

Even in states without such incentives, there are trailblazing providers who see DSPs as true professionals who need ongoing professional development. Some DSPs can now earn certifications that are recognized across state lines, provided their new employer participates in the same certification effort. It's still a patchwork effort, but the patches are getting bigger.

Where Are We Going?

Nothing is certain, but if current trends continue, many more states will be incentivizing and supporting DSP professional development and certification. Additional states will likely adopt funding models that consider the percentage of certified DSPs within a provider organization. Staff trainers will find themselves in a coaching role as new DSPs work toward certification. Training departments will also need to look beyond licensing requirements to provide opportunities for ongoing professional development as DSPs need continuing education to maintain certifications.

Those sorts of funding models also make turnover even more costly to organizations. Recruiting certified staff and supporting more staff to become certified will not be enough if those staff cannot be retained. There will be an even greater financial imperative to cultivate a culture that truly values direct support professionals.

Ideally, that mindset of seeing DSPs as skilled professionals spreads to both policymakers and the general public, and direct support transforms into a sought-after, viable career path for the next generation of workers. Organizations across the country are already working to create that future.

Ideally, that mindset of seeing DSPs as skilled professionals spreads to both policymakers and the general public, and direct support transforms into a sought-after, viable career path for the next generation of workers. Organizations across the country are already working to create that future.

Dan Hermreck *is the Chief Innovation Officer for the NADSP. He has worked as an educator in various settings, but has focused on teaching DSPs, frontline supervisors and others since 2022. Contact Dan at dhermreck@nadsp.org.*

Families are the System

By Sue Swenson

- Families have always been at the center of supporting people with disabilities. Throughout history, families have provided care, advocated for change, and helped shape the services and supports that exist today.
- Today's disability support system depends on both public funding and family caregivers. While governments invest billions of dollars in disability services, families still provide most of the day-to-day care, much of it unpaid and often at great personal and financial cost.
- Families have helped create positive change through advocacy. Many of the laws, programs, and services that support people with disabilities today were influenced by families who pushed for better opportunities, rights, and community supports.
- Families need support, reliable information, and respect. Communities and service systems should help families access evidence-based resources, avoid harmful or ineffective treatments, and ensure that both family caregivers and people with disabilities can live with dignity, choice, and full human rights.

Where Did We Come From?

As we celebrate our nation's 250th year, the population of the U.S. has grown from about 2.5 million in 13 colonies to about 350 million in 50 states and territories. How did we build a system that is intended to work for 350 million people? It helps that the people are the system, and that we can change it. We do the work of care and support, and we do the work of democracy to change the formal system. Families are worried, of course. We bear the burden when there is no real help. We participate in inventing what comes next. We always have.

Families are worried, of course. We bear the burden when there is no real help. We participate in inventing what comes next. We always have.

Some families in revolutionary-era Virginia rejected the newly created institutions. Thomas Jefferson's mother and then Thomas himself cared for his sister Elizabeth at home until her untimely death. Elizabeth grew up with intellectual disabilities. She reportedly could speak only a handful of words. "All men are created equal," indeed. Patrick Henry's wife, Sarah, developed an unspecified severe mental illness after giving birth to a sixth child. He rejected an institution and cared for her at home, reportedly in a cell in the basement, until her death. "Give me liberty or give me death," indeed.

President Kennedy grew up with a mentally disabled sister, Rosemary. His mother and sister, Eunice Shriver, urged him to do something to help the nation "overcome" what was called "mental retardation." He formed a presidential panel that included both Robert Cooke, MD, and Elizabeth Boggs, a Manhattan project scientist. Both were geniuses and parents of severely disabled children. Their work led to the founding of the National Institute of Child Health and Disability, for a start. "Ask what you can do for your country," indeed.

Since the beginning of time families do what we can, well or badly. We do what we must, both at home and in the democratic arena. Families provide whatever care they can for disabled family members. This care has been a private responsibility of the family for most of history. This is not to say all cultures are

welcoming, even in the U.S., and infanticide and filicide are still grim, silent realities. Before modern medicine, there were more early deaths and fewer life-saving treatments. There were few specific diagnoses, and few assistance programs for families. People found their own way.

Where Are We Now?

Now, in the 21st century, governments are beginning to understand that the requirements of family care are very stringent, in many cases the community is affected. The actual cost to families can be enormous, both in extra expenses and in lost time.

How can we help family caregivers have the support and care they need to enjoy their own human rights and to support the human rights of their loved one with disabilities? This is not a trivial matter, I think. "Love is the answer," indeed.

The U.S. now provides annually about $100 billion in combined federal and state funds to care for and support persons with developmental and/or intellectual disabilities at home. It is a social investment that pays standardized wages for personal assistance and supports in communities and families across the country. Some of that money may go to family members who are paid to provide care, for example, in extremely rural environments where help is not otherwise available, or overnight or for an hour or two at a time in a family home. None of that $100 billion is a simple gift to families. It supports wages to care providers who contribute to local economies. None of them have a Swiss bank account, or an offshore yacht. They are workers and taxpayers.

Even so, families still do most of the work. It is estimated that if the nation had to pay for unpaid caregiving by families, the cost would be somewhere in the range of $400 billion to $500 billion dollars annually. It would be impossible.

Where Are We Going?

One of the challenges that remain is to make good ideas available to caregiving families so that they don't waste their or their disabled family member's precious time on bogus treatments or other strategies designed to "cure" or control what is a natural part of the human experience. How can we help families support a child or adult member with disabilities without undue control or coercion? How can we help family caregivers have the support and care they need to enjoy their own human rights and to support the human rights of their loved one with disabilities? This is not a trivial matter, I think. "Love is the answer," indeed.

Sue Swenson *is president of Inclusion International and has been appointed in three presidential administrations. She holds an MBA from the University of Minnesota and an MA in interdisciplinary humanities from the University of Chicago. Sue and her husband raised three sons, one of whom had complex support needs his whole sweet life. Contact her at sue.swenson@inclusion-international.org.*

Trauma-Informed Care in Intellectual and Developmental Disability Services

By Amanda Rich

- People with intellectual and developmental disabilities (IDD), their family members, and people who provide support services are more likely to experience trauma, chronic stress, and adversity, yet the effects of trauma are often overlooked.
- Trauma-informed care (TIC) is not therapy; it is an approach to support that promotes safety, trust, choice, collaboration, and empowerment for everyone involved in a service system.
- While awareness of trauma-informed care has grown across the disability field, many organizations continue to face challenges such as workforce shortages, high turnover, limited resources, and difficulty moving from training to practice.
- The future of trauma-informed care lies in whole-system change, where organizational culture, leadership, policies, workforce well-being, and person-centered practices work together to support healing, belonging, and quality of life.

Imagine for a moment that you are supporting a person who suddenly becomes withdrawn, angry, or fearful. They may refuse support, lash out, or struggle to trust the people around them. Traditionally, disability service systems have often asked, "What is wrong?" or "How do we change this behavior?"

Trauma-informed care invites us to ask a different question:

"What might have happened, and how can we create conditions that support safety, healing, and growth?"

Over the past three decades, trauma-informed care (TIC) has become one of the most influential frameworks in human services. It has transformed approaches in mental health, addiction treatment, child welfare, education, and healthcare. While the intellectual and developmental disability (IDD) field was slower to adopt trauma-informed approaches, there is growing recognition that trauma-informed care is not simply another program or training topic. It is a way of understanding people, organizations, and systems that can fundamentally improve the quality of support we provide and help to create dignity-affirming spaces.

What Is Trauma-Informed Care?

Trauma-informed care (TIC) is a framework for service delivery that recognizes the widespread impact of trauma and seeks to create environments that promote safety, trust, empowerment, and healing.

Importantly, trauma-informed care is not trauma treatment. Staff do not need to become therapists to practice trauma-informed care. Instead, trauma-informed care asks everyone within an organization, from direct support professionals to executives and board members, to understand how trauma and chronic stress may affect people's experiences and behavior and to take steps to reduce unnecessary harm and promote well-being.

The Substance Abuse and Mental Health Services Administration (SAMHSA) describes trauma as resulting from events or conditions that are experienced as overwhelming and that have lasting effects on a person's functioning and well-being. Trauma-informed approaches recognize that these experiences can shape how people feel, think, behave, relate to others, and respond to services.

Across settings, trauma-informed care is typically guided by several core principles:

- Physical and emotional safety
- Trustworthiness and transparency
- Choice and self-determination
- Collaboration and partnership
- Empowerment and strengths-based practice
- Cultural humility and responsiveness

These principles align closely with many of the values that have long guided person-centered disability supports.

Where We Came From: How Did Trauma-Informed Care Develop?

The roots of trauma-informed care emerged from growing awareness that trauma is both common and consequential.

Researchers studying veterans, survivors of violence, and children exposed to adversity found that traumatic experiences can have long-term impacts on physical health, mental health, relationships, and quality of life. Over time, scientists and practitioners began recognizing that many people seeking support from human service systems had extensive trauma histories.

At the same time, an uncomfortable reality emerged: systems designed to help people sometimes unintentionally cause additional harm.

Practices such as coercion, excessive control, lack of choice, restraint, seclusion, abrupt transitions, and environments that undermine trust can contribute to re-traumatization. In response, trauma-informed care emerged as a framework for redesigning services around safety, dignity, and healing.

The disability field shares many of these concerns. Historically, people with intellectual and developmental disabilities have often experienced segregation, institutionalization, exclusion, abuse, neglect, bullying, discrimination, and loss of control over important life decisions. Many have also experienced disruptions in caregiving relationships, frequent staff turnover, residential transitions, medical trauma, and social isolation. These experiences can increase vulnerability to trauma and its effects.

As awareness grew, advocates, researchers, and leaders began asking whether disability services should adopt trauma-informed approaches in the same way that other service sectors had.

The answer increasingly became yes.

At the same time, an uncomfortable reality emerged: systems designed to help people sometimes unintentionally cause additional harm.

Why Trauma-Informed Care Matters in Disability Services

Research consistently demonstrates that people with intellectual and developmental disabilities are at increased risk of exposure to violence, abuse, neglect, and other adverse life experiences.

At the same time, trauma often goes unrecognized.

The effects of trauma may be mistaken for symptoms of a disability, mental health condition, or "challenging behavior." This phenomenon, sometimes called diagnostic overshadowing, can make it difficult for people to receive appropriate support.

Trauma-informed care encourages organizations to move away from asking:

"How do we control this behavior?"

and toward asking:

"What might this behavior be communicating?"

This shift is powerful because it emphasizes understanding before intervention and relationship before compliance.

Where Are We Now?

The good news is that trauma-informed care has gained significant momentum across the disability field.

Compared to a decade ago, more organizations are:

- Providing trauma-informed care training
- Incorporating trauma-informed language into mission statements and strategic plans
- Exploring alternatives to restrictive practices
- Investing in workforce wellness and psychological safety
- Recognizing the importance of organizational culture in service quality

At the same time, substantial challenges remain.

Several years ago, colleagues and I surveyed leaders from more than 100 disability organizations across North America regarding trauma-informed care. The findings revealed strong support for trauma-informed principles but also highlighted a gap between awareness and implementation. Leaders often believed trauma-informed care was important, yet many reported that their organizations struggled to fully embody those principles in everyday practice.

Leaders identified several persistent barriers, including:

- High staff turnover
- Workforce shortages
- Limited access to trauma-informed mental health services
- Financial constraints
- Insufficient training opportunities
- Restrictive funding structures
- Organizational stress and burnout

Many of these challenges remain familiar today.

In fact, workforce instability may be one of the greatest obstacles to trauma-informed transformation. It is difficult to build trust, consistency, and healing relationships when staff are overwhelmed, under-resourced, and frequently leaving the field.

The field has also learned that trauma-informed care cannot be achieved through a single training session. Training is important, but sustainable change requires attention to organizational culture, policies, supervision, quality improvement, leadership practices, and system design.

Where Are We Going?

The future of trauma-informed care in disability services is likely to move beyond individual practices and toward whole-system transformation.

Several emerging trends are particularly promising.

From One-Off Trainings to Organizational Culture Change

Organizations are increasingly recognizing that trauma-informed care is not just something staff do; it is something organizations become. This means examining hiring practices, supervision models, crisis response procedures, physical environments, quality assurance systems, and strategic priorities through a trauma-informed lens.

Greater Focus on Workforce Well-Being

Trauma-informed organizations recognize that staff well-being and service quality are inseparable. Leaders are increasingly exploring approaches that support psychological safety, reflective supervision, workforce resilience, and organizational health. There is growing recognition that supporting those who provide care is essential to supporting those who receive it.

Integration with Person-Centered Practices

Trauma-informed care and person-centered supports are natural partners. Both approaches emphasize dignity, choice, voice, autonomy, strengths, relationships, and belonging. Future efforts will likely continue to integrate these frameworks rather than view them as separate initiatives.

Increased Use of Data and Evaluation

The field is also moving toward greater accountability and evidence-building. Organizations are beginning to ask:

- How do we know if we are becoming more trauma-informed?
- What outcomes should we measure?
- How do trauma-informed approaches affect quality of life, workforce stability, and organizational culture?

Program planning and evaluation tools, such as theory-of-change logic models, can help organizations intentionally connect trauma-informed values to measurable actions and outcomes. Rather than relying solely on staff training, organizations can embed trauma-informed principles into program design, implementation, and continuous improvement efforts.

From Trauma-Informed to Healing-Centered

Perhaps the most exciting evolution is a growing emphasis on healing, resilience, connection, and hope. While trauma-informed care asks us to understand adversity and reduce harm, many leaders are also exploring healing-centered approaches that focus on strengths, relationships, culture, community, and possibility. This shift does not ignore suffering. Rather, it reminds us that people are more than the difficult experiences they have endured. Every person, family member, direct support professional, supervisor, and leader carries strengths, wisdom, dreams, and the capacity for growth.

Final Thoughts

Trauma-informed care has challenged the disability field to reconsider some of its most basic assumptions about behavior, support, leadership, and organizational culture. At its heart, trauma-informed care is about creating conditions where people can feel safe enough to learn, connect, heal, contribute, and thrive. The field has made meaningful progress, but the work is far from complete. As we move forward, the greatest opportunity may be to view trauma-informed care not as a destination or certification but as an ongoing commitment to curiosity, compassion, reflection, and human dignity. For leaders, that commitment begins with a simple but powerful question:

How can we build organizations where people, both those who receive support and those who provide it, can experience greater safety, trust, belonging, and hope?

The answer to that question may help shape the next chapter of disability services.

Amanda J. Rich *is the owner and CEO of Open Road Inclusive Community Consulting and the Managing Editor of the National Leadership Consortium Bulletin. Amanda holds a Ph.D. in Human Development and Family Sciences and is interested in the health and well-being of the human service workforce, trauma-informed and healing-centered practices, and disability justice. Contact Amanda at openroadicc@gmail.com.*

From Normalization to Social Role Valorization: Obtaining the Good Things in Life Through Valued Roles

By Guy Caruso

- The idea of "Normalization" started in the 1960s to help people with disabilities live everyday lives that were more like those of other people, instead of being separated in large institutions. This helped move services toward smaller, more personal community settings.
- Later, Social Role Valorization (SRV) expanded on this idea by focusing on helping people with disabilities gain respected roles in their communities. The main belief is that people are more likely to be treated well and have good opportunities when others see them in positive and valued roles.
- SRV is still used around the world today, but it requires long-term learning and effort rather than quick fixes. Supporters believe it can help people with disabilities build relationships, take part in community life, and have better chances to enjoy the same good things in life as others.

Where Did We Come From: Normalization to Social Role Valorization

Dr. Wolf Wolfensberger, who was exposed to the Scandinavian idea of Normalization for people with intellectual disabilities, embraced and expanded the principle to include all people who were devalued. In 1972 his book *The Principle of Normalization in Human Services* was published, greatly impacting service provision in North America and elsewhere leading to deinstitutionalization and the serving of people in smaller group and more individualized settings. Wolfensberger realized that even though his principle of Normalization was widely embraced it had not changed how people with disabilities were perceived by society. People with disabilities had more opportunities to be in the community versus segregated settings, yet they were still friendless and seen as devalued by most of society.

In 1983, as a successor to Normalization, Wolfensberger created a new concept, Social Role Valorization (SRV). SRV is the application of empirical knowledge to enable, establish, enhance, maintain, and defend societally valued social roles for individuals at risk of devaluation, primarily by upgrading their personal competencies and social image. Wolfensberger realized that throughout history people with disabilities have been cast into devalued roles, such as subhuman, menace, eternal child, pity, charity, ridicule, and often, sick. These devalued roles, even if they allowed a person to be in the community, did not result in people being part of community – so close and yet so far.

SRV states that how people are perceived and treated by others, and whether they are accorded the good or the bad things of life, depends largely on the social roles they are seen to fill. If people are in valued and positive roles, then they are likely to be seen as valued and to receive the good things of life, and if devalued, they do not receive the good things of life. For example, if a person with a disability has been supported in the role of gardener and actually gardens and has the competence and skills around gardening and clothes and items a gardener would wear or possess, then they might

be seen by other gardeners as a gardener and perhaps be invited to be part of a community garden or other garden club activities leading to the good things of life – meaning, friendships, involvement, valued activities.

SRV is not a quick fix, although it can be tempting to look for quick solutions, it entails in-depth learning and getting into the shoes of the people one serves to honestly ask are we helping people to have valued roles, to participate in their communities and to have an opportunity for the good things of life.

Where We Are Now: SRV Today

SRV activities take place worldwide in the United States, Canada, Australia, France, Netherlands, India, and elsewhere. Since 1994 there have been eight international conferences and one virtual conference held in Canada, the United States, Australia and the next being planned in France. The International SRV Association's (ISRVA) purpose is to promote SRV development, education, assessment, and leadership to assist people and organizations to implement SRV concepts so that vulnerable people may have access to the good things of life." ISRVA has a YouTube site, blog, on-line journal, and a website that provides information on SRV, PASSING (a specialized SRV training), resources, events, and training groups around the world dedicated to SRV.

There is a North America SRV Development, Training & Safeguarding Council made up of SRV trainers and associates from Canada and the United States who were associated with Wolfensberger's teachings and meet twice a year to set policy regarding SRV theory training and providing accreditation of SRV trainers and teachers.

Also, there is the Australia SRV Association that believes what is key to the future of SRV is a sense of social justice, leadership development, and working for change with individuals, services, systems, and citizens.

Keystone Human Services founded Keystone Institute in Pennsylvania which provides national and international education and consultation in the areas of deinstitutionalization, creating responsive community supports, Social Role Valorization, and respectful individualized planning. Keystone Institute India, a project of Keystone Human Services International, serves as a catalyst for developing supportive services in India that better serves people's true needs, respects the voices and perspectives of people with disability and their families, and facilitates India's movement toward a society where all people matter and have the opportunity to build the lives they want to live.

The Southern Ontario Training Group (SOTG) and SRV Implementation Project (SRVIP) are two other organizations in Canada and the United States, respectively, that provide SRV and related training.

People and organizations that invest in learning and applying SRV often become more intentional about whether their practices truly help people move toward valued roles and meaningful lives. SRV offers a broader perspective than many contemporary human service approaches that emphasize rights, choice, independence, and inclusion. It also examines how competency enhancement, positive social image, and the reduction of devaluation influence people's access to the good things of life.

Values are what you bring to your work, and SRV is a framework from which to think about how your values either positively or negatively impact people who are disabled. SRV does not tell you what to do, or what values to hold. Rather, it acts as a useful roadmap to address the social devaluation experienced by persons who are disabled. SRV offers specific ways to think about what you do, an "If this, then that" perspective, that calls forth an honest reflection of how one's personal values impact the lives of people who are disabled.

Where Are We Going: Where Will SRV be in the Future?

As much as we want the devaluation of people with disabilities to end, unfortunately it is sticking around. We readily see such devaluation increasing with the cuts to services and support to people and the people who support them. How can people with disabilities best be protected? Is their inclusion and integration into society, increased independence, and practice of rights going to protect them? What really has a chance of making life better for people with disabilities? SRV is a powerful tool for social good, especially in dire times like these.

SRV is not a panacea for this, however its emphasis on how people get perceived is. When people identify with someone because of a valued role, then the chances of being accepted and asked to join a group or activity increase. It's about relationships and people often relate because of the roles they hold. For example, the Do For One citizen advocacy related program in New York City uses SRV concepts in connecting people with and without disabilities to enter meaningful relationships. SRV provides Do For One with a framework to work outside of the formal human service network and to work with families and friends to develop relationships.

The devaluation, oppression, and wounding process that people with disabilities often experience deprives them of their citizenship, as well as strips them of any valued social roles in life. SRV does not pretend to be the only way to address such negative forces. However, it is a comprehensive way to address such forces to prevent, minimize and reduce devaluation, by providing a value free theoretical framework from which a person can decide what to do to address such negative forces using their own personal values.

Today we often hear the term "valued roles," people having the good things in life, but words are not enough. People and agencies desiring this must stop looking for quick fixes and invest in deeper leadership development based upon understanding and being fully conscious of the wounds and devaluation of people with disabilities, which is at the heart of SRV.

It is a comprehensive way to address such forces to prevent, minimize and reduce devaluation, by providing a value free theoretical framework from which a person can decide what to do to address such negative forces using their own personal values.

Many young families do not see human service systems as the path for their child, as it is a road to clienthood and not community. The tenets of SRV provides families with an avenue to assist their child to develop positive and valued relationships. Families resonate with the idea of focusing on creating and supporting valued roles for their child, versus segregation and congregation that lead to devalued roles.

As discussed earlier, SRV has an international presence, meaning the theory has practicality in many cultures and with many different disabilities. The creation of the ISRVA and other like-minded groups around the world hold promises for SRV to increase its international reach and provide a vision for what is possible.

Wolfensberger believed that leadership in human services requires ongoing study, reflection, and disciplined practice. For that reason, SRV will not appeal to everyone. It asks practitioners to examine critically whether what they are doing is truly helping people move toward valued social roles and fuller participation in community life. While this level of commitment is demanding, those individuals and organizations who embrace it continue to demonstrate SRV's enduring relevance and value."

Guy Caruso *is the Western Coordinator for the Institute on Disabilities at Temple University. He holds a Ph.D. From Syracuse University and is a Fellow of the American Association on Developmental Disabilities. Guy has used the concepts of Normalization and then Social Role Valorization in the work he has done over the last 50 years in supporting people with disabilities to have the good things of life. Contact Guy at guycaruso@aol.com or guy.caruso@temple.edu.*

Charting the LifeCourse: A Framework for Good Lives and Better Systems

By Sheli Reynolds

- Charting the LifeCourse (CtLC) grew from decades of person-centered thinking, family leadership, and disability advocacy focused on helping people live good lives in the community.
- The framework is being used not only in disability services, but also in aging, education, child welfare, health, and other systems to improve outcomes for people and families.
- The future of CtLC is the creation of better systems working together to support people, families, and communities across the lifespan.
- CtLC helps everyone think about all of life, not just services, using integrated supports.

Where Did CtLC Come From?

For decades, people with disabilities, families, advocates, and allies challenged assumptions and pushed systems to think differently. They wanted opportunities to live, learn, work, and participate in their communities and helped shape approaches focused on people's strengths, preferences, and goals rather than diagnosis or limitations. Person-centered planning emerged from this movement, helping people identify what was important to them and how supports could be organized around their vision for a meaningful life. Charting the LifeCourse (CtLC) is rooted in this essential shift in the disability field of moving from service-centered systems to person-centered lives.

For many years, disability services were often built around programs, placements, and eligibility. People were too often described by what they could not do, what service they qualified for, or what system they belonged to. Families were expected to navigate complicated systems while also trying to imagine and build a good life for their loved ones. Person-centered planning helped shift that conversation. It reminded us that planning should begin with the person, not the program. It helped people name what is important to them, what supports they need, and what kind of life they want to build. These approaches transformed disability services, but many people and families continued facing a common challenge. Planning conversations often centered on services, eligibility, and immediate needs rather than on the broader question of what it takes to live a good life. Families frequently navigated multiple systems with limited support for thinking about life transitions, future possibilities, relationships, community connections, and the many resources that exist outside formal services.

CtLC emerged from these experiences. Developed through collaboration among people with disabilities, families, practitioners, researchers, and system leaders, the framework built on the values of person-centered planning while expanding the focus. Rather than asking only what services a person needs, CtLC asks what a person wants for a good life and how a variety of supports can help make that vision possible. CtLC builds on that foundation. At the heart of CtLC is a core belief: all people and their families, no matter their ability, age, or circumstance, have the right to live, love, work, play, learn, and pursue their life aspirations in their community. That belief is what moves the conversation beyond services and toward a vision for a good life. It also came from listening to families. Families shared that they needed more than service plans. They needed a way to think about the whole person, the whole family, and the whole lifespan.

A key milestone came in 2011, when national and state leaders united at the Wingspread Family Support Summit to develop a shared vision for supporting families. The resulting *National Agenda for Supporting Families* laid out the foundation for the National Community of Practice for Supporting Families, launched in 2012. The Community of Practice was supported through a partnership among the National Association of State Directors of Developmental Disabilities Services (NASDDDS), the University of Missouri–Kansas City Institute for Human Development (UMKC-IHD), and the Human Services Research Institute (HSRI). Participating states and national partners, including individuals and families with lived experience, led the Community of Practice as the vehicle for refining, testing, and scaling what became the CtLC framework. The framework was—and remains—a way of thinking about people, families, supports, and systems starting with the premise that everyone deserves the opportunity to live a good life. It was never just a set of tools. The tools are helpful, but the framework is really a way of thinking. It asks us to start with a person's vision for a good life and then think about the supports, relationships, opportunities, and systems that can help make that life possible.

Where is CtLC Now?

Today, CtLC is used across the United States and internationally, by individuals, families, professionals, organizations, and systems. What began as a framework to support families of people with intellectual and developmental disabilities has evolved into a broadly applicable approach for supporting people of all ages and circumstances. A key reason for its growth has been the partnership between people with lived experience and public systems. Through NASDDDS, the National Community of Practice, state developmental disability agencies, and many other partners, CtLC has moved beyond individual planning to a framework for systems transformation. States have used CtLC concepts to guide strategic planning, family support efforts, workforce initiatives, quality improvement activities, and cross-system collaboration.

The framework's influence has also expanded well beyond developmental disability systems. CtLC principles and tools are now being used within and across human service systems, including aging, education, early childhood, maternal and child health, higher education, child welfare and foster care, behavioral health, and employment. These sectors use different words, rules, and funding streams to serve different populations, operating under different policies, but they share the common challenge of helping people and families identify what they want for their lives and aligning supports around those goals in ways that lead to real outcomes and meaningful lives. The broad adoption of CtLC demonstrates that its core concepts of person-centeredness, family partnership, integrated supports, and planning across the lifespan resonate far beyond any single service system.

The framework's influence has also expanded well beyond developmental disability systems.

The framework gives people a common language and shifts conversations from services to outcomes, from programs to people, and from deficits to possibilities. It helps families and professionals look beyond a single issue or crisis and think about life domains such as daily life, employment, community living, safety, health, relationships, advocacy, and social connections. Concepts such as life trajectories, integrated supports, life domains, and the role of family have provided practical ways for people to think about planning and decision-making while helping organizations and systems align their work around what matters most to the people they support.

Most importantly, CtLC reinforces the idea that services are only one source of support. A good life is shaped by integrating supports and looking at personal strengths and assets, relationships, community resources, technology, and economic resources. When we only

focus on formal services, we miss many of the everyday supports that helps people live full lives. This broader understanding continues to influence policy discussions, organizational practices, and systems-change efforts across the country. CtLC widens the lens. It helps people and families see more possibilities. It helps professionals ask better questions. It helps organizations and systems look at whether their work is truly helping people move toward the lives they want.

Where is CtLC Going?

The future of CtLC is closely connected to the future of the disability field as well as the growing movement toward person- and family-centered systems across health, education, aging, and human services. As communities seek better ways to support people through life transitions and challenges, the need for a common framework that bridges systems and focuses on whole-life outcomes will only become more important. It is about better planning and better systems. People live in families and communities, not service categories. Their lives are shaped by relationships, housing, employment, health, transportation, caregiving, safety, belonging, and opportunity. No single system can support all of that alone. The next challenge is not simply making services more person-centered. It is creating systems that are person- and family-centered from the start. This means designing policies, funding structures, quality measures, workforce strategies, and technologies that reflect what people say they need to live good lives.

It is a framework that helps us ask better questions, see people within the context of their whole lives, and align our efforts around what matters most.

CtLC supports cross systems of work grounded in the person's vision. It is well positioned to support this evolution because it encourages us to think beyond individual programs and consider the larger conditions that influence quality of life. Questions about belonging, relationships, employment, housing, health, caregiving, and community participation cannot be solved by any one service system alone. They require collaboration across sectors and a shared commitment to outcomes that matter to people and families. It helps identify what exists and what may be missing. It centers the voice of the person in their own life through inclusive conversations and allows systems to partner rather than relying on individuals and families to create all the connections.

CtLC reminds us that planning is not a one-time event. People's goals, circumstances, and support needs change throughout life. Future approaches must be flexible enough to support people through transitions while recognizing the diversity of experiences and pathways that make up a good life. More than a decade after its national launch, CtLC continues to evolve through the leadership of people with disabilities, families, practitioners, researchers, policymakers, and system leaders. Its enduring contribution is not simply a collection of tools. It is a framework that helps us ask better questions, see people within the context of their whole lives, and align our efforts around what matters most. As the disability field looks to the future, the promise of CtLC remains both ambitious and practical, helping people pursue good lives while helping systems become better partners in making those lives possible.

Michelle 'Sheli' Reynolds *is the Associate Director of the University of Missouri-Kansas City's Institute for Human Development and Director of the UMKC-LifeCourse Nexus. She holds a Ph.D. in Public Administration and Sociology from the University of Missouri-Kansas City, and is passionate about advancing person- and family-centered change through research and evidence-based practices. Contact Sheli at reynoldsmc@umkc.edu.*

The Evolution of Measuring Quality in Disability Services

How quality is defined reflects what is valued. In the disability services field, quality measurement has evolved from regulatory compliance and program standards to understanding whether people with disabilities are truly experiencing self-determination, inclusion, and lives of their choosing. As expectations for person-centered supports, community inclusion, and human rights have grown, so too have the tools used to evaluate service quality. The three sections of this article demonstrate how evaluating the people receiving supports, the organizational culture and leadership providing supports, and the performance of entire service systems all contribute to provide a better understanding of quality in the field and offer practical tools for continuous improvement.

The Personal Outcome Measures® (POM)

By Mary Kay Rizzolo

The Personal Outcome Measures® (POM) is an internationally recognized, person-centered discovery tool, created by CQL, The Council on Quality and Leadership. It's used by human services organizations and systems all over the world to gain life-changing insights about the people they support. Then, agencies can turn that insight into action, to strengthen services and transform lives. Through interviews with people receiving services and support providers who know them best, the POM explores the presence, importance, and achievement of personally-defined outcomes and related supports. It covers 21 quality-of-life indicators, organized under 5 factors. Topics include health, safety, self-determination, relationships, rights, respect, community inclusion, employment, and more. When agencies learn about people's goals tied to these topics, they can ensure their services are both responsive and effective, helping facilitate meaningful and fulfilling lives.

Where Did We Come From?

In the early 1990s, CQL began work on the POM. We invited people with intellectual and developmental disabilities, people with psychiatric disabilities, families, and other thought leaders to participate in focus groups and discuss quality measures. We discovered a significant difference between what really matters to people receiving services, compared to professionals. As a result of that process, the POM was then developed as a quality measure set focused on personally-defined outcomes and individualized supports. It was piloted in two states at three organizations and then field tested in the United States and Canada. While the POM has been revalidated over the years involving its factors and indicators, the values, intent, and purpose of the POM has remained consistent since its inception.

Where Are We Now?

The utilization of the POM is substantial and its impact is far-reaching. CQL's PORTAL Data System includes approximately 40,000 POM interview surveys, meaning that thousands upon thousands of people receiving services have benefited because of the tool. The full POM manual, which is available for free online, averages around 800 downloads each year. Hundreds of disability service professionals have gone on to achieve POM Certification, ensuring the validity and reliability of how they apply it in their work. CQL consistently produces extensive POM resources such as research, webinars, guides, and articles, along with offering training, workshops, and e-learning courses to enhance people's understanding and use of the POM. But the current state of the POM is best captured by the people it benefits. Laurie, a person receiving services from the Iowa agency One Vision, shares "I liked my Personal Outcome Measures® interview. I show my goals to staff and my guardian. I'm planning my own life."

Where Are We Going?

As the disability services sector increases its emphasis on evaluating quality based on the individual outcomes of people receiving services, the POM will continue to be a preeminent, relevant, evidence-based measure set in the field. Organizations utilizing the POM have identified numerous ways that the tool can transform services and systems, and shared how they leverage the power of the POM for improving supports, and most importantly, improving people's lives!

Mary Kay Rizzolo *is the President and CEO of The Council on Quality and Leadership | CQL. She holds a Ph.D. in Public Health from the University of Illinois at Chicago. Mary Kay is passionate about supporting organizations to provide quality services and supporting people with disabilities to have great lives. Contact Mary Kay at mkrizzolo@thecouncil.org.*

The Organizational Priorities and Practices Inventory (OPPI)

By Monica Mesa-Alvarez, Nancy Weiss, and Caitlin Bailey

The OPPI is a 360-degree survey designed to aid disabilities organizations in aligning priorities and practices with field best practices. It is a nationally validated assessment tool, designed specifically to help disability sector organizations understand how their walk matches their talk, and what to do about it. With insights gathered directly from employees at all levels, the OPPI gives agencies a clear, holistic understanding of their strengths, areas of need, and strategic next steps.

Where Did We Come From?

National Leadership Consortium on Developmental Disabilities

Years before NLCDD, when Nancy Weiss, Co-Founder of the NLCDD, was still at TASH in the early 2000's, she was giving thought to and writing about what defined the shift from traditional, congregate supports to person-directed, individualized supports. She began working on a list that described the move away from traditional approaches and toward progressive supports.

Early in NLCDD's work, particularly during the Leadership Institutes, we saw a complicated trend; leader after leader agreed that people with disabilities have rights to autonomy and control over their lives, choice in how, where, and when they are supported, and meaningful relationships that have nothing to do with formal services. However, there was no consensus about what those supports look like in action. Further, many leaders were unsure of where to start.

Talking about concepts and ideals related to supports that were responsive to recipients' wants and needs only got people so far. We knew it would be important for field leaders to be able to honestly assess their organizations' strengths and needs based on evidence-based practices in our field.

Where Are We Now?

The first tool, developed by Nancy, helped leaders understand how person-centered their organization's practices were, on a continuum from traditional to, what we called, progressive. This tool was based on our best thinking, but it was certainly not scientific. It also taught us an important lesson about intention vs. action. When using the tool, participants often asked, "Should we select our responses based on what our organization *says* we do or what *actually happens*?"

Over several years, the NLCDD team refined the tool and, eventually, created the OPPI. With input from users, field experts, and a whole lot of literature, we added measures to make the assessment more comprehensive, and we modified our descriptions to be more specific and clearer. As it grew, new categories were included to assess both the outward and inward operations of organizations in our field. We realized that, as an organization whose mission is to advance human rights through leadership development, we needed to create an assessment that provides a more holistic picture of how an organization walks its talk in its services, partnerships with people with disabilities, governance, culture, and leadership practices.

We also expanded the questions so that leaders assess both the priorities (values and intentions) of their organizations, as well as practices (action and implementation) from every level. In our field, people want to do right by people, so our agencies' policies and mission statements often describe ideals. But what is being done on a day-to-day basis tends to fall short of best intentions. What's more, different roles within an organization bring different perspectives on organizational priorities, communication, and implementation; frontline leaders don't have the same experiences as those in executive roles. Designing the assessment to consider an organization's priorities and practices from employees at every level helped users begin to point directly to the differences between what their organizations say they do, and what they do in reality.

The final step in building the OPPI was testing its validity (to make sure the OPPI effectively measured the most important concepts). Monica Mesa-Alvarez, NLCDD's Research and Development Associate, led this analysis that included running several statistical models and interviews with field experts.

Where Are We Going?

Disability sector organizations today face increasing pressure to keep up with quality, often while dealing with shrinking budgets, complex government demands, and determination to remain grounded in person-centered values, community inclusion, stakeholder engagement, and human rights principles. To be responsive to the complexities of leading in our field, NLCDD reframed how we share and support organizations to use the OPPI to answer three critical questions:

1. **Are we doing what we say is important?** The OPPI helps organizations examine how their priorities are reflected in practice and how they relate to organizational performance, leadership, workforce engagement, and culture. This helps organizations better understand how their values shape day-to-day operations and organizational effectiveness.

2. **Do leaders, supervisors, and frontline staff experience the organization in the same way?** The OPPI provides a structured way to examine where perspectives align and where important differences exist among agency employees. By incorporating perspectives across an organization, leaders gain a more complete understanding of how decisions are experienced in practice, and hidden gaps in quality exist.

3. **Where should we focus our efforts first?** The OPPI helps organizations identify areas where change may have the greatest impact, helping leaders to prioritize improvement efforts, build on existing strengths, and pursue organizational change in a practical and sustainable way.

Since its inception, the OPPI (and earlier iterations) was designed to help organizational leaders take a hard look at how they live up to the values of inclusion and human rights that drive our work in this field. As disability services continue to evolve, the OPPI provides organizations with more than a measurement tool. It offers a framework for understanding alignment, strengthening organizational culture, and translating values into action.

Monica Mesa-Alvarez *Monica Mesa-Alvarez is the Research and Development Associate for the NLCDD. They hold a doctorate in Urban Affairs and Public Policy from the University of Delaware. Contact Monica at mmesa@natleadership.org.*

Nancy Weiss *is a founder of the NLCDD and a retired professor at the University of Delaware. Nancy has more than 40 years of experience in the disabilities field and has worked relentlessly to end the use of aversive procedures and promote supports and policies that inspire inclusive communities and the rights of people with disabilities. Contact Nancy at nancyrobinweiss@gmail.com.*

Caitlin Bailey *is the Co-Director of the NLCDD. She holds a Ph.D. in Human Development and Family Science. Caitlin is passionate about enhancing leaders' skills and evidence-based practices in our field. Contact Caitlin at cbailey@natleadership.org.*

The National Core Indicators (NCI)

By Valerie Bradly, Dorothy Hiersteiner, Laura Vegas, and Nancy Thaler

The National Core Indicators-Intellectual and Developmental Disabilities® (NCI-IDD®) is a collaborative effort between the National Association of State Directors of Developmental Disabilities Services (NASDDDS), the Human Services Research Institute (HSRI), and state developmental disabilities agencies that works to measure and improve the performance of developmental disabilities agencies.

Where Did We Come From?

In 1997, there was public scrutiny of community programs for people with intellectual and developmental disabilities (IDD), including questions about the quality of services. State Developmental Disabilities (DD) directors were worried that these questions about quality could result in the loss of public trust and support for community services. At the time, nothing existed to measure the performance of state DD systems other than licensing and certification standards. The state directors decided that they needed a better definition of what "quality" in state DD services should be and how it could be measured. They decided to develop survey instruments that would assess not just compliance with regulations but also measure whether state DD systems were resulting in positive outcomes for the people served. They determined that to answer that question they needed to listen to the voices of people receiving services.

A steering committee, supported by staff from the National Association of State Directors of Developmental Disabilities Services and the Human Services Research Institute, met to agree on system values, quality domains and specific outcome indicators. That work resulted in the National Core Indicators (NCI) Adult Consumer Survey (now the In-Person Survey (IPS)) which elicited the experiences of system participants.

Where Are We Now?

As of 2026, almost 30 years after NCI's inception, 48 states and the District of Columbia have collected NCI-IDD IPS data in recent years. In addition to the In-Person Survey, the NCI-IDD suite of tools now includes 3 family surveys collecting data on the experience of families with a family member receiving services, and a State of the Workforce Survey examining the stability of the workforce and the provider base supporting the DD system.

Where Are We Going?

NCI will soon roll out a Cross Population State of the Workforce survey examining the stability of the LTSS workforce across populations and providing states with critical data needed for compliance with workforce reporting requirements in the HCBS Access Rule. NCI-IDD measures are included in federally recognized measure sets such as the Adult Core Set and the HCBS Quality Measure Set and the NCI team plans to support states to use those data to develop targeted quality improvement plans.

NCI's continued use across the country reflects a sustained commitment to listening to people with disabilities and their families, measuring the quality of services and supports, and holding systems accountable for delivering on their promises. At a time when home and community-based services

(HCBS) face ongoing challenges and the right to live, work, and participate in the community is increasingly scrutinized, NCI data provide critical evidence of the value and impact of quality services. These data help demonstrate how effective supports can expand opportunities, promote community inclusion, and enable people to lead the lives they choose.

Valerie Bradley *is the President Emerita of the Human Services Research Institute. She has worked for over 50 years as a policy analyst in the IDD field. She was one of the early developers of the National Core Indicators. She has been President of AAIDD and was the Chair of the President's Committee on People with IDD. She recently co-authored a book on self-direction. Contact Valerie at vbradley@hsri.org.*

Dorothy Hiersteiner *is the Co-Director of the National Core Indicators ®(NCI®) at Human Services Research Institute. Dorothy also developed and currently directs the NCI State of the Workforce Surveys, used to help states collect data on workforces supporting adults with IDD and the workforce supporting the Aging and Physical Disability population. Dorothy is passionate about data, outcome measurement, evidence-based policy and social justice and uses these interests to guide her work with NCI. Contact Dorothy at dhiersteiner@hsri.org.*

Laura Vegas *is the Director of Quality Initiatives and Supporting Families for the National Association of State Directors of Developmental Disabilities Services (NASDDDS). She holds a master's degree from Middle Tennessee State University. She is passionate about improving the quality of supports and services for people with intellectual and developmental disabilities and their families. Contact Laura at lvegas@nasddds.org.*

Nancy Thaler *is a consultant to federal and state governments on Medicaid and disability policy and brings both direct service experience and senior leadership expertise to her work. Ms. Thaler has held senior positions including State Director of Pennsylvania's Office of Developmental Programs; Director of Quality Improvement at the U.S. Department of Health and Human Services' Centers for Medicare & Medicaid Services (CMS); Senior Policy Advisor in the HHS Administration for Community Living (ACL); and Executive Director of the National Association of State Directors of Developmental Disabilities Services (NASDDDS). Contact Nancy at nthaler49@gmail.com.*

Building Disability-Led Advocacy in Maryland: The Past, Present, and Future of People on the Go

A Conversation with Mat Rice and Tracy Wright of People on the Go

By Cory Gilden

- People on the Go is an advocacy organization led by people with disabilities in Maryland.
- People on the Go played a major role in Maryland's deinstitutionalization movement and in ending subminimum wage for workers with disabilities in the state.
- Today, People on the Go is transitioning into an independent nonprofit fully led by disabled people.
- Leaders say the future of advocacy depends on ensuring people with disabilities are meaningfully included, compensated for their expertise, and empowered to lead.

For more than three decades, People on the Go (POG) has worked to advance the rights, leadership, and inclusion of people with intellectual and developmental disabilities in Maryland. The organization's work has ranged from supporting deinstitutionalization efforts to advancing employment rights and leadership training. We recently spoke with Executive Director Mat Rice and Deputy Director and Director of Training Tracy Wright about the organization's history, its current transition into an independent nonprofit, and their vision for the future of disability-led advocacy. Both Mat and Tracy have cerebral palsy, and have been with the organization for more than a decade.

Where Did We Come From?

The roots of People on the Go trace back to 1989, when it began as an advisory panel connected to The Arc Maryland. Eventually, members decided they wanted to create an independent self-advocacy organization led by people with disabilities themselves.

"The whole genesis of POG is the fact that people belong in the community alongside their friends and peers that don't have disabilities," Mat explained.

The organization's name reflects that history. "People on the Go" referred to people transitioning out of institutions and into community life during the deinstitutionalization movement.

"At the beginning of POG," Mat said, "there were five institutions in Maryland. Now there are only two left."

POG became heavily involved in advocating for institutional closures, particularly the closure of the Rosewood Center in 2009, one of Maryland's largest institutions for people with developmental disabilities.

Tracy recalled mentoring people transitioning from Rosewood into the community. She worked with people with significant support needs as they adjusted to life outside the institution.

Tracy describes one of her proudest moments that involved supporting a man who had spent decades at Rosewood and rarely left except for medical appointments. Initially described as aggressive and requiring intensive support, he eventually became comfortable in his new home and community.

"By the time our last visit was, we actually sat on his front porch," Tracy said. Using a communication board, he was able to share that one of his favorite activities was feeding ducks at the park.

"To be sitting on his front porch of his own house with him was just really empowering. Him allowing me to be a small part of that was awesome," she said.

POG also became a leader in employment advocacy. In 2016, the organization helped pass Maryland's Ken Capone Equal Employment Act, which abolished subminimum wage for workers with disabilities, making Maryland one of the first states in the country to do so.

Mat explained that the legislation emerged directly from a POG study with POG members working in sheltered workshops.

"They said, 'We like being with our friends, but we want to make more money and we want more opportunities,' so we really started pushing for the end of sub-minimum wage," Mat said.

POG organized advocates, collaborated with legislators and providers, and helped negotiate a four-year phaseout period for subminimum wage certificates.

For Mat, one of the most meaningful outcomes of the law was how it shifted conversations around employment and person-centered planning.

"What was really at the heart of the Equal Employment Act," he said, "was having discussions around employment every time you discussed your person-centered plan."

Where Are We Now?

Today, People on the Go is in the midst of a major transition. After years of operating in partnership with the Maryland Center for Developmental Disabilities at the Kennedy Krieger Institute, the organization is becoming an independent nonprofit led by people with disabilities.

"While the partnership has served us well, our membership decided that we wanted to become a nonprofit," Mat said. "Now we're finally at the point where we are our own nonprofit."

The transition reflects a larger philosophy about leadership within the disability community.

"A lot of the work is done on behalf of people with disabilities instead of by them," Mat explained. "We want POG to take a leadership role in forming more policies and coalitions."

Tracy emphasized that meaningful inclusion requires more than simply placing disabled people on committees or advisory boards.

"We want to make sure that when members join a board or are part of an organization, that it's a meaningful part," she said. "And when people give their expertise, they should be compensated just like every other professional at the table."

She noted that people with disabilities are often expected to volunteer their lived experience while others involved in policy work are paid professionals.

"People with disabilities are a lot of times the only ones not being compensated," she said.

The organization continues to focus heavily on advocacy training and leadership development. Through programs like Project STIR (Steps Toward Independence and Responsibility), a training by and for people with disabilities, POG helps people with disabilities learn about their rights, self-determination, leadership, and systems advocacy.

Tracy said those trainings are often transformative because many people with disabilities have historically not been encouraged to see themselves as leaders or decision makers.

"A lot of times, people didn't have the opportunity to understand," she said. "No matter a person's support need, I've always found that people can make choices for themselves."

POG has also developed trainings around abuse prevention and exploitation awareness, designed by and for people with disabilities. The organization has worked with providers to create accessible curricula and train both self-advocates and direct support professionals.

The group also continues to advocate for legislation that improves the lives of people with disabilities, including supporting a new bill that was introduced this session to create alternative pathways for high school diplomas and supporting services for adults with disabilities.

"In the last few years, we've had to fight to hold the line for supports for people with intellectual and/or developmental disabilities in the states and have had to endure some cuts to the budget," Mat said. "We're not happy about that, but I think that if it wasn't for organizations like POG and some of the organizations that we partner with, those things would have been a lot worse."

Where Are We Going?

Looking ahead, Mat and Tracy hope People on the Go can serve as a model for disability-led leadership nationwide.

"We want to show other organizations that people with disabilities really can be in charge and be the leaders of our own organizations," Mat said.

The organization plans to continue expanding partnerships while maintaining its independence and disability-led mission. Mat noted that financial independence is also important for maintaining advocacy freedom and serving the full disability community.

"We want to be inclusive of everyone, regardless of their experience of disability or their background," he said.

Both advocates also see growing momentum within the broader self-advocacy movement.

"I think you're starting to see kind of an awakening, or reawakening, of self-advocacy," Mat said.

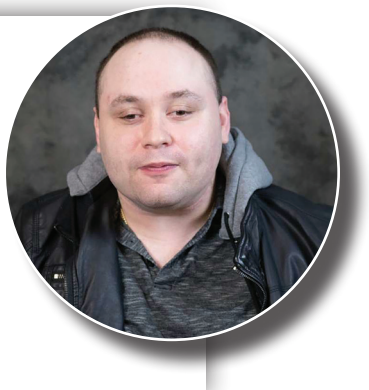
Still, both emphasized that advocacy is about more than labels. While terms like "self-advocate" and "systems advocate" are commonly used, Tracy said people should be able to define themselves however they choose.

"The words should have meaning behind them," she explained. "People should choose how they want to be referred to."

For POG, the future includes continuing to train new leaders, build coalitions, and create spaces where people with disabilities are not simply consulted, but truly empowered.

"The question is always going to be how people get involved," Mat said. "POG wants to be part of that journey for people."

Mat Rice *is the Executive Director and Advocacy Coordinator at People On the Go Maryland. Mat has also served as a support broker for Shared Support Maryland, Inc. and public policy director and project lead at The Arc Maryland. He has been instrumental in educating legislators on issues that impact the quality of life for people with disabilities in Maryland and works to advance equity, voice, and opportunity for people with disabilities. Contact Mat at mat@pogmd.org.*



Tracy Wright *is the Deputy Director and Director of Training at People On the Go Maryland. Tracy also works as a Life Enrichment Consultant for By Their Side Maryland and an advisory committee member and trainer for Expectations Matter, My Life My Choice. She is an advocate, trainer, and leader working to empower people with disabilities to live self-directed and meaningful lives. Contact Tracy at tracy@pogmd.org.*

Cory Gilden *is the Research and Evaluation Manager of the NLCDD. Cory holds a Ph.D. in Urban Affairs and Public Policy and works with local and national organizations, conducting research and advocating for people with disabilities and their families. Contact Cory at cgilden@natleadership.org.*

Practical Tools and Resources of the Developmental Disability Service Field and Directions Forward

By Amanda Rich

- Tools and resources exist to build a stronger understanding of key disability service frameworks.
- These resources introduce important topics and approaches such as self-advocacy, person-centered planning, trauma-informed care, cultural humility, and self-determination that help organizations provide high-quality, value-based support.
- This list provides practical tools you can use in your daily work that can help leaders strengthen policies, improve practices, and support staff development.
- These resources offer ideas and strategies for creating services that honor each person's strengths, preferences, culture, relationships, and goals while promoting a sense of belonging and choice.

Resource & Organization	Paywall	Resource Type			Description
		Trainings, Courses Technical Assistance	Tool Kits	General Info/ Research/ Interviews	
Person-Centered Practices & Self-Determination					
Inclusion: Person-Centered Planning: PATH, MAPS, and Circles of Support	Some	x	x	x	Visual planning approaches that help individuals, families, and teams create a shared vision for the future. These tools support collaborative decision making and can make planning meetings more engaging and accessible.
LifeCourse Nexus	Some	x	x	x	A comprehensive framework and collection of planning tools that help people think about their lives across areas such as relationships, community participation, employment, and health. Leaders can use the LifeCourse framework to support person-centered practices and systems transformation.

ACL/National Council on Aging/Office of Healthcare Information and Counseling: Person-Centered Thinking Toolkit	No		x		An overview of person-centered vs. system centered thinking and provides reflective tools and guides to help teams utilize person-centered thinking.
National Center for Advancing Person-Centered Practices	Some	x	x	x	An initiative from the ACL and CMS that helps states, tribes, and territories implement person-centered thinking and practices. It has tools and resources on topics related to person-centered practices and cultural humility.
Disability Rights/Self-Advocacy/People First & Independent Living Movements					
UC Berkeley Library: Digital Oral History Collections-Self-Advocacy & Disability Rights Movement	No			x	Oral history collections from activists and advocates from leaders of the self-advocacy, independent living, and disability rights movements. This site allows you to learn directly from the words of leaders with developmental disabilities.
MN Department of Administration: Parallels in Time A History of Developmental Disabilities	No			x	Timeline that provides information on the history of societal understanding of developmental disabilities, services, and civil and human rights. It's useful for leaders to see how far the field has come, where it is going, and the vital role of self-advocates as change agents across history.

Staff Development & Professionalization and Management					
Open Future Learning	Some	x		x	Online courses, webinars, and practical learning opportunities focused on supporting people with intellectual and developmental disabilities. Topics include person-centered practices, communication, relationships, trauma-informed care, and leadership development.
National Alliance for Direct Support Professionals	Some	x	x	x	Community, training, certification, and advocacy for direct support professionals.
NYC Participatory Management Resource Directory	No		x	x	Compilation of books and other information on the concept and practice of participatory leadership. This is a useful tool for leaders who want to create a more democratic workplace.
National Leadership Consortium on Developmental Disabilities	Some	x		x	Training opportunities, resources, and learning tools for the development of leaders in the developmental disabilities field.

Cultural Humility & Competence					
NCAPPS: Cultural Humility	No			x	An overview of cultural humility and how it can and should be practiced in the context of disability service delivery.
Georgetown University National Center for Cultural Competence	No		x	x	Resources on cultural and linguistic competence, diversity, equity, and inclusion focusing on intellectual and developmental disabilities.
Trauma-Informed Care					
Trauma-Informed Care Implementation Resource Center	No		x	x	Resources from leaders on trauma-informed care to help improve outcomes, increase resilience, and reduce avoidable health care service use and costs.
Traumatic Stress Institute	Some	x		x	Comprehensives training, technical assistance and organizational assessment of trauma-informed care. This may be useful for leaders interested in organization-wide adoption of a trauma-informed framework.

Amanda J. Rich *is the owner and CEO of Open Road Inclusive Community Consulting and the managing editor of the National Leadership Consortium Bulletin. Amanda holds a Ph.D. in Human Development and Family Sciences and is interested in the health and well-being of the human service workforce, trauma-informed and healing-centered practices, and disability justice. Contact Amanda at openroadicc@gmail.com.*

What We're Reading, Viewing, and Listening To

Title: Raymond's Room: Ending the Segregation of People with Disabilities

Author/Editor: ***Dale DiLeo (2007)***

Description: *Raymond's Room* tells the story of a man with disabilities who wants more control over his life and future. Through Raymond's experiences, readers learn about self-determination, relationships, and the importance of listening to what people want for themselves. The book encourages person-centered thinking and respect for individual choice.

Title: Costs and Outcomes of Community Services for People with Intellectual Disabilities

Author/Editor: ***Roger Stancliffe, Charlie Lakin & Steven Eidelman (2004)***

Description: This book brings together information about the costs and results of services for people with disabilities in one place. It helps policymakers, advocates, providers, and researchers understand what different services cost and how they affect people's lives. The book can support informed decisions about how resources are used.

Title: A Little Book about Person-Centered Planning

Author/Editor: ***Connie O'Brien & John O'Brien (2014)***

Description: This book explains the basics of person-centered planning, an approach that helps people make choices about their own lives and futures. It introduces practical tools such as PATH and MAPS and shows how planning can focus on a person's strengths, goals, and interests. The book is a useful introduction for anyone interested in supporting meaningful community inclusion.

Title: Roland Johnson's Lost in a Desert World: An Autobiography

Author/Editor: ***Roland Johnson & Karl Williams (1999)***

Description: In this autobiography, disability rights leader Roland Johnson shares his experiences growing up in institutions and his journey toward independence and self-advocacy. He describes the challenges people with disabilities have faced and the importance of being included in community life. The book offers a powerful firsthand perspective on the Disability Rights Movement.

Title: No Pity: People with Disabilities Forging a New Civil Rights Movement

Author/Editor: ***Joseph P. Shapiro (1994)***

Description: This book by journalist Joseph P. Shapiro documents the Disability Rights Movement. It argues that disability is not a personal tragedy to be pitied, but rather an issue of societal prejudice and civil rights.

Title: Nothing About Us Without Us: Disability Oppression and Empowerment

Author/Editor: ***James I. Charlton (2000)***

Description: This book explores the history of the Disability Rights Movement and the barriers people with disabilities have faced. Charlton highlights the importance of self-advocacy and of ensuring that people with disabilities have a voice in decisions that affect their lives.

Title: From Snake Pits to Cash Cows: Politics and Public Institutions in New York

Author/Editor: ***Paul J Castellani (2005)***

Description: If we don't learn from history, we are bound to repeat it. This book examines the history of public institutions for people with intellectual and developmental disabilities in New Jersey and how policies, funding, and politics shaped those systems. Castellani explores both the harms caused by institutional care and the efforts to create more community-based supports. The book helps readers understand how disability services have evolved and why continued advocacy and reform are important.

Title: Christmas in Purgatory: A Photographic Essay on Mental Retardation

Author/Editor: ***Burton Blatt & Fred Kaplan (1974)***

Description: This classic photo essay of legally sanctioned human abuse in state institutions was instrumental in the movement towards community-based services.

Title: Inventing the Feeble Mind: A History of Intellectual Disability in the United States

Author/Editor: ***James Trent (2016)***

Description: This book explains that society's view of intellectual disability has shifted over the last 200 years. The author argues that these changing labels and government policies were driven more by the economic struggles of disabled people and their families, rather than by the actual impairments of their disability. It helps us see the connection between trends in disability services and the social meaning of disability.

Title: Restoring Sanctuary

Author/Editor: ***Sandra Bloom and Brian Farragher (2013)***

Description: This book is the third book in a series about fixing our broken social service systems. Over time, these systems have accidentally made it harder for staff to do their jobs and harder for clients to heal. This book provides an overview of how trauma-informed care can be used to transform systems.

Title: Becoming Citizens: Family Life and the Politics of Disability

Author/Editor: ***Susan Schwartzenberg (2025)***

Description: This tells the story of Seattle families in the 1950s who bravely fought the medical advice of the time to keep their children with developmental disabilities at home rather than sending them to institutions. Schwartzenberg uses photographs, journals, documents, and interviews to showcase how these families struggled, persevered, and became powerful activists who helped change policies and service systems.

Title: A Leadership Guide for Today's Disabilities Organizations

Author/Editor: ***Robert L. Schalock & Miguel Ángel Verdugo Alonso (2012)***

Description: This book offers a practical, organization-level guide for administrators focusing on evidence-based management, person-centered planning, and navigating systemic challenges in disability service agencies.

Title: Power Tools: Thoughts about Power & Control in Services to People with Developmental Disabilities

Author: ***David Hinsburger (2000)***

Description: This short 40-page book is written for direct support providers. The book challenges the reader to continually evaluate their use of power when serving people with disabilities.

Title: Our Fight for Disability Rights-and Why We're Not Done Yet

Author/Editor: ***Judith Heumann (2016)***

Description: In this TED Talk, activist, educator, and author Judith Heumann describes her experience leading a protest called the Section 504 sit-in, where disabled-rights activists occupied a federal building for almost a month, demanding greater accessibility for all. In this personal talk, Heumann tells the stories behind the protest and reminds us that, 40+ years on, there's still work left to do.

Upcoming Events

Leadership Institutes

Join us at an Upcoming Leadership Institute! For 20 years, our flagship multi-day intensive Leadership Institutes have brought together expert speakers, interactive exercises, leadership assessments, and a structured leadership challenge. We have four upcoming Institutes with applications currently open!

The Wisconsin Leadership Institute in Eau Clare, WI

October 25-30, 2026

The Fall Wisconsin Leadership Institute is for Wisconsin-based disability sector leaders. Applications are open now. Click here [Wisconsin Fall Leadership Institute & Development Program - National Leadership Consortium on Developmental Disabilities] for more information or to apply. Due to generous funding through the Common Good Philanthropies, participation in the program is subsidized.

The Fall Leadership Institute in Santa Fe, NM

November 15-20, 2026

The Fall 2026 Leadership Institute will be held with support from the New Mexico Health Care Authority Developmental Disabilities Supports Division. Applications are open now. Click here [The Fall 2026 Leadership Institute - National Leadership Consortium on Developmental Disabilities] for more information or to apply. This Institute is open to all disability sector leaders. If you are a leader with a disability or a Direct Support Professional you can apply for scholarship support to cover tuition and some travel and hotel costs!

The Winter Virtual Leadership Institute

January 27, 2027 – February 18, 2027

The Winter Virtual Leadership Institute will be held on Zoom. Applications are open now.
Click here [The Virtual 2027 Leadership Institute - National Leadership Consortium on Developmental Disabilities] for more information or to apply. This Institute is open to all disability sector leaders. If you are a leader with a disability or a Direct Support Professional you can apply for scholarship support to cover tuition!

The Spring Leadership Institute in Atlanta, GA

April 11-16, 2027

The Spring 2027 Leadership Institute applications are open now. Click here [The Spring 2027 Leadership Institute - National Leadership Consortium on Developmental Disabilities] for more information or to apply. This Institute is open to all disability sector leaders. If you are a leader with a disability or a Direct Support Professional you can apply for scholarship support to cover tuition and some travel and hotel costs!

Workshops

Whatever position and experience, leaders already bring so many strengths to their role. NLCDD Workshops help you, your colleagues, or team members to build on those strengths to enhance skills and practices critical to advancing the disability field.

Leadership Essentials Virtual Workshop

August 13 - 27, 2026

For leaders who are new (or new-ish) to leadership roles with management, supervision, and accountability authority & responsibilities, join us virtually with other leaders from across the country! This three session virtual workshop will cover the leadership strengths you already bring to your role and actionable skills & strategies to foster a cohesive, safe, & accountable culture. Click here [Leadership Essentials Workshop - National Leadership Consortium on Developmental Disabilities] for more information.

Leading Through Feedback Virtual Workshop

September 9 – 23, 2026

Join us virtually if you want to feel more confident giving and receiving feedback! During this three-session workshop, attendees will gain strategies and skills to more effectively give and receive feedback to and from their teams. Click here[Leading Through Feedback - National Leadership Consortium on Developmental Disabilities] for more information!

LEAD Program

Leadership exists at every level, especially where it matters most – in daily interactions with people with IDD. Direct Support Professionals (DSPs) and frontline leaders bring incredible leadership skills to their current and future roles in our field's organizations and systems. LEAD helps Direct Support Professionals (DSPs) and frontline leaders recognize and leverage those strengths to enhance service delivery, create cohesive frontline teams, and build direct support capacity across the IDD system.

LEAD Summer 2026 Cohort

September 16 – November 3, 2026

Join us in Delaware for our next LEAD cohort! Open to direct support professionals and frontline supervisors, this 8- week hybrid program starts September 16, 2026 and ends November 3, 2026. For more information, click here [The Fall 2026 LEAD Program - National Leadership Consortium on Developmental Disabilities].

Contact Us:

https://natleadership.org/resources/bulletin • bulletin@natleadership.org

If you have any trouble accessing the referenced material, please email Amanda J. Rich at openroadicc@gmail.com.