

National Leadership Consortium Bulletin

Leadership, Services
& The Rights of People
with Disabilities

The National Leadership
Consortium | on Developmental
Disabilities



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National Leadership Consortium **Bulletin**

About the Bulletin

The National Leadership Consortium 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 will serve 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 National Leadership Consortium

Leadership, Values and Vision: Transforming Lives and Organizations

The National Leadership Consortium was founded in 2006 to develop current and future generations of disability sector leaders to have the knowledge, skills, and values needed to transform services and systems to be responsive to the needs, wants, and rights of people with disabilities. Our mission is to provide quality training, technical assistance, and support aimed at the development of values-based leadership in disability sector leaders. The National Leadership Consortium is focused on promoting the rights of people with disabilities to direct their services and lives and to fully belong in their chosen communities. One way the National Leadership Consortium works to meet this mission is through a nationally recognized, intensive leadership development program, the Leadership Institute. These in-person or virtual trainings focus on knowledge, skills, and supports leaders need to transform systems and organizations in the disability service sector.

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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.

Why the Bulletin?

You may wonder why The National Leadership Consortium is creating the Bulletin. Well, throughout my career I have been fortunate to be in jobs where I had both access to a variety of information sources on policy and programs and time to review it. That information has not only educated me but has inspired and broadened my perspectives as a practicing professional. We know that for many leaders this is not the norm.

Most of the people who participate in a National Leadership Consortium training are extremely busy, both in their work and personal lives. Because of their time commitments, they aren't able to read publications that may assist them in their professional roles.

Additionally, journals in many fields are increasingly published by a shrinking pool of for-profit publishers and are behind a paywall, making them not terribly accessible to people without a subscription to the journal or those not at a university that allows access. You can't really measure the utility of an article without paying for it, so many practicing professionals don't regularly read journals, government monographs, or publications from universities, think tanks, and advocacy organizations.

With this new bulletin, we are hoping to provide information on current best practices and research that allow practitioners at all levels of an organization to easily access useful information that will contribute to their work. We aim to give practitioners information in a usable format that is linked to documents and resources that are in the public domain or that we have permission to release. We will also solicit and share articles from Leadership Institute alumni who are demonstrating real-world leading-edge practices, strategies, and accomplishments.

We hope to publish this bulletin three-to-four times a year and will have past issues readily available on our website.

We welcome your comments, critiques, feedback, and ideas that would turn this effort into something very useful in our joint efforts to include people with developmental disabilities in everyday life in their community.

Thanks for reading,

Steven M. Eidelman

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Introduction: Leadership, Services & The Rights of People with Disabilities

Often at our Leadership Institutes and trainings we talk about the connection between our day-to-day roles and our purpose as leaders in this field. There are many ways to identify and consider our purpose – the popular Ted Talk from Simon Sinek, [*How Great Leaders Inspire Action*](#), offers a good framework. Sinek highlights the importance of using our purpose, or our ‘why,’ as the driving force in all our decisions and leadership practices. Fortunately, as disability service sector leaders, our purpose is rather straightforward and has been defined by self-advocacy groups for decades; here are some examples:

...People with disabilities are treated as equals and ... they are given the same decisions, choices, rights, responsibilities, and chances to speak up to empower themselves; opportunities to make new friends, and to learn from their mistakes.

From the SABE Mission Statement

*ASAN continually affirms both that people with disabilities are members of every marginalized group and that disability rights are civil rights. In doing so, we must also affirm that working within the disability rights movement requires us to join forces with our peers who are also members of other marginalized groups in the fight for justice for all. When oppression affects one of us, it affects us all. **Disability rights are civil rights, and civil rights are disability rights.***

From the ASAN statement on Civil Rights

Over the course of the last half century, the United States has made many important promises to its citizens with intellectual and developmental disabilities. These promises are found in the Developmental Disabilities Assistance and Bill of Rights Act, the Americans with Disabilities Act (ADA), the decisions of the Supreme Court and other federal courts, the Individuals with Disabilities Education Act (IDEA), the Rehabilitation Act of 1973, and other laws, rules, decisions, and findings. Those of us on the —receiving end of the promises have taken our Nation’s commitments seriously. We expect that when our country guarantees —access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life [as in the Developmental Disabilities Assistance and Bill of Rights Act] the promise will be kept. We believe that when our country recognizes —the right of individuals to live independently, enjoy self-determination, make choices, contribute to society, pursue meaningful careers and enjoy full inclusion and integration in the economic, political, social, cultural and educational mainstream of American society (as in the Rehabilitation Act of 1973 as amended, 29U.S.C.794), that we will indeed be in control of own lives.

***From the Keeping the Promises:
Self Advocates Defining the Meaning of Community Life 2011 Report***

All of these statements provide a north star for our leadership ‘why,’ to promote and ensure practices, structures, and systems that respect and align with the inherent rights of people with disabilities. Yet, we know that our field and many of our organizations have a long way to go to meet these expectations. And many of us, as leaders, tend to get so bogged down in our work that we struggle to remember or connect our daily emails, meetings, reports, budget reviews, etc., to the critical purpose of our careers.

So in this issue, we wanted to highlight some of the work and leadership practices that are intentionally and explicitly human rights-driven, with the hope that these will kickstart or remind you of your *why*. Tony Sampson shares his thoughts on what human rights for people with disabilities are and how organizations can facilitate or get in the way of those rights. DJ Savarese’s innovation spotlight and David Leamer and Cory Gilden’s research-to-practice articles describe promising efforts in the field to promote the leadership, self-direction, and decision-making of people with disabilities in organizations and initiatives. Donyale Hobson-Garcia and David Ervin provide motivations, lessons, and practices related to transforming their organization to provide services that are more aligned with the rights of people with disabilities to choose how, when, where, and with whom they receive support. And Regina Rodriguez Sisneros offers strategies to meaningfully embed diversity, equity and inclusion into day-to-day organizational practices.

We hope that when you read these articles, you see more connection between your leadership role and your overall why and purpose. We also encourage you to share this issue of the National Leadership Consortium Bulletin with your coworkers and colleagues; maybe it can inspire some conversations in your teams and organizations about how the work of your organization contributes (or could contribute more or better) to the realization of human rights for people with disabilities. As ever, we are glad to hear your feedback and thoughts on the issue.

Thanks for reading,

Caitlin Bailey

Co-Director, National Leadership Consortium

Caitlin Bailey is the Co-Director of the National Leadership Consortium. 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.



Human Rights and Support Services Agencies from the Perspective of Someone Who Uses Services

A conversation with activist and author Tony Sampson

By Amanda Rich

The following article is a summary of a series of conversations with and writing from Tony Sampson, an activist, author, person with a disability who uses support services, and Home Depot employee on human rights and the service system. When Tony Sampson and I spoke, and he shared his writing on the nature of human rights and the service system, I was reminded of a quote from human rights activist Monica Raye Simpson who said in a [Ms. Magazine](#) interview, “We’re not asking for anything anymore, because it’s inherently ours anyway.”



Support service agencies do not “give” people rights. Rights are inherent to all people on the basis of being human, regardless of ability or any other group status. However, as Tony Sampson describes, support service agencies and systems of care play a powerful role in the lives of many people with disabilities and as such, may shape access to their rights. Support services may make it easier for people to be able to move freely, vote and participate in civic life, express themselves, make informed choices, be with the people they love, access needed resources and live safely. Services may also be a barrier to Disabled people’s access to their rights. For instance, some may be a source or location of violence and abuse. Some service providers may punish people for expressing themselves, or be set up in a way that limit people’s ability to earn a living, move freely, engage in activities, be with people they love, and access opportunities and/or information about their civil and human rights. In our conversation Mr. Sampson called on leaders of support service agencies to think carefully about the power they hold in the lives of the people they support and emphasized, “It’s time to eliminate the status quo. It’s time for a change.”

What are Human Rights?

Mr. Sampson describes human rights by providing examples. He said “They are things like:

- Being able to express your emotions
- Being able to say what you think
- Living free from emotional, verbal, and physical abuse and violence
- Working jobs for real wages and using money to buy what you want and to travel where you want
- To do things you like with people you like
- To make choices about your life
- To be your own guardian.”

[The United Nations](#) defines human rights as “rights we have simply because we exist as human beings - they are not granted by any state. These universal rights are **inherent** to us all, regardless of nationality, sex, national or ethnic origin, color, religion, language, or any other status. They range from the most fundamental - the right to life - to those that make life worth living, such as the rights to food, education, work, health, and liberty.” Many of us do not notice human rights in our daily life. Human rights are often quiet and invisible until we witness or experience their denial or violation. Tony Sampson described many of these rights through his story of involvement with the service system, in some instances being supported in his rights and in other instances where his rights were violated.

How May Support Services Interfere with Human Rights?

Tony began our conversation by providing a description of his journey with the service system. He discussed graduating from high school, going to the Vocational Rehab for a short time, moving across several different group homes, jobs and agencies until meeting Gail Godwin who is the director of Shared Support Maryland and starting to receive support to direct his own services and move into his own apartment.

Mr. Sampson noted that in some ways the service system has not been designed to fully support people’s rights to pursue work and earn a living, due to income limitations for benefits. Tony noted that it was hard to thread the needle between *“making money and qualifying for benefits. If you make too much money you lose your benefits but it’s still not enough to live on and get what you need.”* Despite these limits and the continuous effort to make sure he is not working too many hours or earning too much money, Tony has held several jobs and has been a valued Home Depot employee for many years.

If people rely on support staff for transportation and to get out to participate in their community, Mr. Sampson shared that there can be a conflict between a person’s right to move freely and do activities that bring them joy and the preferences and beliefs of their staff. He asked, *“What happens when a counselor won’t take a client to an event, even a local one, because that person does not like crowds, traffic, and long lines aka all the hubbub or because of their belief? For instance, they may not be favorable to Halloween or other holidays. I respect a person’s beliefs and they have a right to their beliefs, but if I was a client, I should not miss out because of that.”*

Tony Sampson also described violations of rights often came during times of conflict with staff. He noted that there is often a double standard and a stark difference in power between staff and the people using services. He asked, *“What happens to a client when he yells back at a counselor who yelled at him or engaged him in an ugly argument? It is usually the client who gets blamed.”* He said that people with disabilities often must walk a line between their rights to express themselves, stand up for themselves and the right to be respected, and to be safe from violence. He asked, *“How do you speak up when you are being disrespected by staff? If you speak up and get yelled at or say nothing and put up with living without that respect.”* Tony described the pain and struggle of being hurt by those who claim they are helping. He said, *“Helping by hurting? Being embraced by the same people who verbally abuse me. How can I forgive myself for mistakes when others won’t let me live it down?”*



Mr. Sampson also described the service system interfering with his rights through having staff set him up to take the fall for things he did not do, steal things, take verbally abusive tones, and use dehumanizing tactics to try to control the people they supported. He said in some cases it was service agencies that violated the Americans with Disabilities Act, but that people who use supports do not always have the support they need to do anything about it.

Tony shared that many support service agencies are built on a hierarchy where people who run the agencies are on the top and have the most power and people who use services are on the bottom with the least amount of power. He said that in cases where people who use services are involved in the criminal justice system, the power difference can become greater. He asked the question of what happens when someone who uses services gets involved with the criminal justice system and placed on probation. He noted that support staff may think of their role now as a probation officer and that may not change even after the probation period has ended.

How Can the Service System Better Support The Human Rights of the People Who Use Their Services?

Mr. Sampson said that for service agencies and the system itself to better support the human rights of the people who use their services they need to look closely at how power is used within their system and agency. He said, *"We must work to eliminate the hierarchy rules. The highest point on the totem pole is up there and the lowliest point is down there and that needs to change...Those who support people with disabilities need to use guidance and coaching instead of abusing authority and barking orders. Offer problem solving tactics instead of barking orders or blaming the clients. When people play the blame game no one wins."*



Additionally, agencies and the service system at large need to examine how they support people with employment and eliminate barriers to supported employment with competitive wages. He said, *"Eliminate piece work. At the end of the week the pay rate is so low that they will make only 3 bucks. Eliminate contracts and enclaves and instead offer real employment opportunities. Clients who are in an enclave or contract should get out of the enclave and get a real job. Provide some career counseling. Some agencies support, assist and or even deny clients of opportunities to get jobs and careers they want, and people should be supported."*

Tony described that people with disabilities, like all people, need to understand their rights and what they can do if their rights are being violated, especially when the rights are being violated by people and systems that hold a lot of power over them.

When support service agencies do their job well, are supportive and “get out of the way” of the people they support, great things can happen. He shared how some staff and support services helped him gain the tools to stand up for himself, negotiate conflict, make moves when needed, understand his rights, and support his goals. Tony travels across the country, engages in work and activities he enjoys. He shared, “I won the MACS lifetime achievement award. I became a contributing writer for *Apostrophe*. I became a volunteer with the SPY museum.” [Nelson Mandela](#) said, “To deny people their human rights is to challenge their very humanity.” For organizations to achieve their missions, leaders must continually reflect on how their services impact the human rights of the people they support.

Tony Sampson is an employee of Home Depot, writer for a column in *Apostrophe Magazine*, salesperson for Art Enables and conducts presentations on rights in the field of disabilities. Mr. Sampson is a person with a disability. Contact Tony at tonysampson@comcast.net



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Rebranding and Refocusing: Building Organizational Capacity for Self-Determination

By Donyale Hobson-Garcia and David A. Ervin



[Makom](#) was created in 1982 by families of young adults with intellectual and developmental disabilities (IDD) who shared a vision for their children and others with IDD having the same community living opportunities as adults without disabilities. Forty years ago, these families knew intimately that community opportunities were too few, and that people with IDD deserved much more. Four decades later, Makom is in the midst of an exploration of its roots, its role and aspirations for its future. We seek to deepen our impact, to strive toward achievement of our mission to support and empower people with IDD to achieve the quality of life to which they aspire. We also recommit ourselves to the inalienable rights of people with IDD—like everyone—to determine, choose, decide, dream, and live lives of abundance. While we’ve always committed ourselves to championing the rights of people with IDD, we have also had to come to grips with ways in which we’ve done so less elegantly, less intentionally, and with a lesser focus on the intersection of those rights and actual, meaningful self-determination.

Makom was founded as Jewish Foundation for Group Homes (JFGH) at a time of great tumult in the history of supports for people with IDD. Our focus then was to create a community alternative to institutions. The human rights fight of those days was basic — people had a right to lives in the communities into which they were born. Institutions had been exposed as horrible places in which horrible things happened to people with IDD. As attention shifted to the community, especially in the early years of JFGH, paternalism (where health and safety was the central focus of bureaucratic and heavily regulated systems of ‘care’) ruled the day. Forty years later, we have learned quite a lot, as a system of supports and as an organization.

Anchored in a recently engaged strategic planning process, we have dived headfirst into the deep end of organizational transformation through reimagining, redesigning, and reengineering virtually everything necessary to progressively support people with IDD to achieve actualization of their human rights and lives of abundance. To do this work, Makom has undertaken the arduous, sloggy work of challenging and changing organizational tradition and bucking “the way we’ve always done it!” In fact, among the very first choices we made was to change the name of the organization, which reflected priorities and a vision that was innovative and leading edge in 1982 and for years following, to Makom, which means “place” in Hebrew. Not “place” like a point on a map or a house, but “place” in the *gestalt* of humanity. That is, everyone has their place in society. Everyone. All means all.

Sounds Great! But Wait.

Over the last two years or so, through observation and inquiry, Makom has had to face glaring weaknesses in the frameworks through which we engage our work. We’ve had to acknowledge that our expectations and the education, protocols and support we provide to our employees to resource them to meet those expectations have become antiquated and fed organizational inertia and tradition far more than driving at the heart of lives envisioned by people we support. Our Direct Support Professionals (DSPs), front line leaders, and others work too often on goals that have little impact on the person with IDD in her or his pursuit of a life to which they aspire.

This realization, as hard as it's been to face, has prompted a re-think of everything. It has also provided an essential catalyst for the organization, from its Board of Directors to its employees, for needed change and for focusing on and investing in building operational and human capacity consistent with re-envisioned and a commonly embraced vision, mission and values. Imagined in our strategic planning process through countless and ongoing conversations with people we support, with our staff — including, critically, substantial input from our DSPs — and with stakeholders and thought leaders in our community, Makom's strategy, and virtually all of the pieces of its architecture, focus on a single, simple truth: People with IDD decide. Among our core values is what we fundamentally believe should be at the core of every decision the organization takes: self-determination, where we recognize the value of dignity for all people and support *each person's right to make their own life decisions*.

Self-determination will not occur without intentional development of professionals in the most progressive ideologies in the field of IDD. We also commit to investing resources to support people with IDD to advocate for themselves, to be causal agents, and to (unapologetically!) assert themselves in the pursuit of their aspirations. Understanding that a strategic initiative on its own merits won't alleviate resistance to change or the fears that fuel it, Makom has made a priority of up-skilling and reskilling strategies for all employees, but especially DSPs and front-line leaders through continuous training and group engagement activities that include a weekly career development series, an ongoing National Leadership Consortium in Developmental Disabilities series on transformational leadership skills and approaches, coaching and servant leadership, and more.

A focus on leadership that isn't based on title will, we believe, fuel the evolution of Makom to a culture of self-determination where people with IDD are the true leaders of their lives. And, so far, so good in our journey. Although, it's most assuredly not so far, so perfect! Re-invention is hard work. Many areas of our transformation are well planned and well underway. Others are halting, stop-start, and sometimes feel like pushing rope. In such circumstances, we lean into our failures, learn from them and move on. People we support have been telling us their expectations and demands for a very long time. And, while we are only at the beginning stages of our transformation, we are finally beginning to listen.

Donyale Hobson-Garcia, BS, MS, is Chief Programs Officer for Makom with IDD and professionals. Her core belief is that everyone has differences, and those differences are not what should separate us but what should bring us all together to form one complete picture of life's communities. Contact Donyale at dhobsongarcia@makomlife.org



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Embedding Diversity, Equity and Inclusion (DEI)

By Regina Rodriguez Sisneros

Diversity, Equity and Inclusion (DEI) action plans, DEI checklists, DEI goals, and DEI initiatives are concepts that are often a part of an organization's conversation as they work to develop equitable outcomes for supports and services and promote a sense of belonging for those involved with the organization. The truth is that ensuring an organization has an effective commitment to the principles of DEI is not a one and done training or webinar but rather a long-term commitment to establishing DEI core values within the organization. To do this, it is important to embed DEI into as many aspects of an organization as possible. There are many tools available to organizations that leaders may choose to get the process going, but the biggest launching pad for DEI includes a strong mission and vision statement that is supported by an inclusive and diverse leadership, staff, board members, individuals with lived experiences, and community partners. DEI initiatives may fall short of their objectives when key stakeholders do not understand or resist the work. *Some steps to obtain buy-in and ensure support are:*

- Leadership, board members, and staff of all levels within the organization should provide diverse perspectives about communities being served and the processes to accomplish these services and supports.
- Community partners should provide feedback to ensure that the needs of the community align with the strategies and goals of the organization. They contribute to the organizations understanding of barriers and complications for accessing services. This embeds DEI into the relationships and extends the work of equity beyond the organization.
- Individuals with lived experiences should honor the “Nothing about us with us” philosophy and guide health professionals to a better understanding of what individuals need and want to achieve equitable access and services that align with their health needs and self-determination for quality-of-life choices.



When an organization has a diverse group contributing, it is important to consider the supports needed so that everyone can contribute to designing the DEI plan. These supports are related to health literacy, linguistics, plain language materials, cognition such as note taking, scheduling reminders, and/or productive time of day for the group. An organization should also consider social barriers that may limit participation like transportation, childcare, or access to technology. Some communities may prefer to meet in community-based facilities with community-led translation services or on-site childcare for the peace of mind of the participants. Consider the time day and whether transportation is available for those who need it during the meeting times. Work with the participants and determine how the group can optimize collective success by making the necessary accommodations. If it is not their full-time job and they volunteer to contribute, build compensation for individuals with lived experiences into your work plan.

Because diverse workgroups may be developing policies, procedures, communication, and dissemination of information, training, communication styles, and sustainability should be considered. Workgroups should plan to train both internal and external audiences. DEI should be embedded into governing documents, including policies and procedures for organizational accountability. -Budgets should be a priority and plans for sustaining efforts should be at the forefront of planning. -This will demonstrate commitment to supporting the recommendations and needs of staff and community stakeholders. Develop deadlines for accountability reports and community updates. When developing relationships with workgroups, consider how the community communicates and how they best receive and deliver information. Is it a newsletter, community resource center bulletin board, social media, emails, or organized meetings? Develop various avenues for communication to be received by the organization such as a general email address, voicemail line for ideas, and open forum for feedback from partners.

Accountability and pausing to celebrate successes can also contribute to meaningful DEI work. Accountability and follow through to underserved communities create dynamic relationships that can be sustained by consistently engaging them both in initial planning and with updates on outcomes. Celebrate accomplishments along the way and highlight successes. Celebrations keep people feeling appreciated and honor their contributions.

Recognizing that disability is a natural extension of human diversity and promoting the inherent dignity of people with disabilities are key principles to the [UN Convention on the Rights of Persons with Disabilities](#) and should be central to service provision and all DEI initiatives. Equity and inclusion are a long-time commitment. Organizations should embed equity throughout policies, procedures, collaborations, research, and diverse communications. As an organization strengthens their commitment to equitable outcomes, quality outcomes will follow.

For more useful tips, please see “Steps to Creating Inclusive Meetings” developed by Regina Rodriguez Sisneros on the next page.

Regina Rodriguez Sisneros is the Director of Equity Initiatives for the National Association of State Directors of Disability Services. She spent 14 years with the Colorado Department of Human Services as the Contract Manager and Equity, Diversity, & Inclusion Manager for MINDSOURCE Brain Injury Network and is a graduate of Georgetown University’s Leadership Institute for Cultural Diversity & Cultural and Linguistic Competence. Regina is committed to her work creating systems changes that enhance and support the needs of all. Contact Regina at rsisneros@nasddds.org.



Steps to Creating Inclusive Meetings

First remember that diversity is about involving a variety of individuals with different backgrounds and life experiences. Inclusion is actively encouraging engagement by creating a safe space and sense of belonging to foster contributions of various perspectives.

- ❑ “Nothing about us, without us” is the phrase that drives us to ensure individuals with lived experiences are invited to the table. It is important to consider necessary accommodations in advance of your interactions.
- ❑ Disseminate documents such as agendas, Power Point files, and documents for review in advance. Offer the materials in various formats such as email or hard copies. Ask participants which format they prefer and what additional accommodations they require.
- ❑ Consider offering a pre-meeting time so that participants can ask questions and receive clarification on the documents and materials that will be discussed. This creates various opportunities for participants to contribute to the process.
- ❑ Develop a ‘draft’ and detailed agenda that will be finalized together at the start of the meeting to give everyone an opportunity to add discussion topics if needed.
- ❑ Create covenant that will encourage people to talk, learn, and work together over time. Covenant groups offer caring affiliative networks, mutual responsibility, leadership opportunities, and a way for people to build and strengthen their communities.
- ❑ Invite members of diverse groups and ensure that linguistic accommodations are provided.
- ❑ Introduce yourself with your pronouns and preferred name. Create name plates that have individuals preferred name, and pronouns.

Create an Inclusive and Diverse Environment

Office Space

- ☐ Frame and display your mission, vision and equity statements in multiple languages and large font.
- ☐ Display statements of your commitment to being safe, diverse, and inclusive space.
- ☐ Display art with images that are of diverse individuals.
- ☐ Invite feedback and suggestions through a general email or suggestion box in the office.

Inclusion within Staff

- ☐ Commit to hiring diverse, qualified staff who can offer different perspectives to your processes.
- ☐ Offer trainings that offered by various groups within your community.
- ☐ Offer staff time to participate in community activities and events to be present and get to know the diverse populations.
- ☐ Offer staff time to participate in community activities and events to be present and get to know the diverse populations.
- ☐ Start a book club that reads about various cultures, and their experiences to discuss what is learned.
- ☐ Develop a Diversity, Equity, Inclusion (DEI) initiative collectively and add that to your performance reviews for accountability.

Create a DEI strategic plan and start with your company's mission and vision statements to revise and include the organization's commitment to DEI.

Embed DEI into your daily work and processes of the organization and create a diverse DEI Committee to track the progress.

Cultural awareness starts with you. Examine your own culture and cultural influences and start the learning processes of those who you work with daily.

CELEBRATE~ take the time to honor your successes and achievements!

Developed by Regina Rodriguez of Sisneros,
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Expanding a Vision of Leadership for an Increase in Diverse Leaders

By David Leamer

What Does the Research Say?

Current leaders who want to support more opportunities for people with disabilities may have to check their bias and relinquish some power in order to promote diverse leadership. Over the past decade, many leaders in our field agree that the overall quality of services for adults with neuro-diverse needs are improving in the direction of wider inclusion and person-centered practices. Yet despite these improvements, [the needle has moved only slightly regarding chronic unemployment](#) and underemployment. Post-pandemic we know all too well that this issue is clearly not a result of any lack of need or opportunities for employment as the USA is experiencing a labor shortage. Underemployment has also not improved, though [college degree completion of people with neuro-diversity has kept pace with peers](#) without disabilities at a steady growth of five percent for the last ten years. It may be that solving both employment problems rests in primarily [changing and confronting biases or currently held mindsets and mental constructs](#) about people with disabilities. An efficient and ethical path to changing mindsets is ensuring intentional opportunities for those who self-identify as neuro-diverse to step directly into more visible and meaningful leadership roles in multiple arenas.



Historically marginalized groups like racial minorities and women have increased their leadership representation significantly in recent years though much more needs accomplished. [A survey of Fortune 500 companies](#) found that between 2005 and 2009, those with three or more women directors outperformed those with fewer by achieving an average of 43% return on equity over time. [Arnstein's \(1969\) ladder of citizen participation](#) is still a useful tool to evaluate the progression of marginalized groups. It often begins with non-participation and culminates with decision-making capabilities and full managerial power. Despite these chronicled successes, biases toward individuals labeled as neuro diverse or physically challenged remain firmly entrenched and limit access to leadership or training. While most healthcare professionals report not being biased against people affected by disability (i.e., explicit bias), [a robust analysis of more than 25,000 professionals across disciplines showed that an overwhelming number were biased](#). Nurturing and compassionate leaders of healthcare organizations were equally impacted by these attitudes and underlying beliefs. [Another comprehensive review](#) of public access survey results of implicit and explicit responses of more than 180,000 responders showed similar results, where even family members who emphatically believed they have no negative attitude toward individuals with disabling conditions unconsciously preferred nondisabled people to lead.

These studies reflect how mindsets may be difficult to change but may be quickly redeemable when confronted. What better way to confront these unconscious paradigms than to place front and center individuals from this group who are invited and trained to lead?

One theoretical framework with strong empirical support known as [Implicit Leadership Theory](#) confronts the often-held belief that leadership is a constellation of skills and talents or domain of those skilled in leadership. It stresses that leadership is a phenomenon that always originates in the schemas or expectations of the followers, which are mostly unconscious and mediated by social constructs or personal histories. Expanding and confronting those expectations of the followers, already shown to be quite dynamic and socially modifiable, could prove to be an encouraging and truthful paradigm more welcoming to diverse and expansive models.

What Does it Mean for Our Field?

If we truly believe neuro-diverse individuals can lead in all employment fields, it must be modeled first by those committed to helping and serving these groups. If neuro-diverse learners are denied access or are unsupported in accessing all positions, especially leadership roles, all organizations suffer. Society cannot afford to lose any multi-talented and capable individuals from its leadership pool. Even words like “talent and capability” infer a judgement and bias. People often have flawed and limiting views about usefulness, norms, or ability, but to deny anyone in an inclusive society the voice and capacity to succeed as leaders keeps us from accepting the leaders needed to all. Without expanded influence from the people we serve, human service organizations are only giving lip service to fuller inclusion and truly person-centered practices.

Once committed to the challenge of inclusively developing leaders, confronting the biases in our ourselves and in our organizations, may prove an easier task than imagined. If Implicit Leadership Theory holds true, it creates a workable paradigm for motivating individuals from diverse backgrounds to actively engage in leadership and for existing leaders to create more opportunities for them to do so.

Key aspects of Implicit Leadership Theory include:

- ① *Everyone is capable of being an effective leader.*
- ② *The best leadership style depends on both the characteristics of employees and the environment in which they work.*
- ③ *Leadership is a perception of followers, not just actual behaviors and competencies of people called leaders.*
- ④ *There is no such thing as leadership apart from the expectations and biases of the followers.*

What Can I Do?

There are many ways to begin the process of being more inclusive in leadership at your organization. With the once in a lifetime opportunity to expand training initiatives (currently available here in Pennsylvania through ARPA funding), our organization is leaning heavily into mentoring with strong interpersonal connections through dyads and using eLearning platforms as secondary. One distinct advantage is tailored instruction to the unique learning styles of our staff and meaningful and truly capable instruction to a wider range of learning histories and styles. We believe expanded proficiency in mentoring will serve well as an expanded leadership development curriculum that stretches and challenges our biases and naturally brings in a wider employment pool.

Consistent with our mentoring focus, we need to be intentional and committed to providing access to exemplars from all walks of leadership who identify as neuro diverse. There is no shortage of potential leaders if we are committed to looking and spotlighting. As founder of our organization and eyeing formal retirement in a few years, we are engaged in succession planning and leadership transition. We are actively exploring the very complicated but extremely worthwhile and growing move towards Employee Ownership of our organization. I am convinced, more than ever, that representation of more diverse talents and learning styles must be done intentionally and with courage to confront my own nagging mental constructs and foolish notions of what leadership looks and sounds like.

Here are a few first steps for how your organization can begin to have more inclusive leadership:

- Make a commitment to inclusive leadership by setting goals with specific deadlines and numbers of people with disabilities to be represented in leadership positions in the future.
- Implement trainings with staff about implicit and explicit bias and acknowledge how it can impact the leadership pipeline at your organization.
- Create a mentoring program to foster strong interpersonal connections through partnerships between those with a lot of leadership experience and people just starting to build their leadership skills.
- Utilize eLearning platforms, such as the NADSP ebadge program, relias, and medtrainer.
- Tailor assistance to the unique learning styles of new leadership to make training more accessible and understood to everyone.

David Leamer is the founder of Applied Counseling and Consulting Services. He holds an MA from Immaculata University. He is passionate about helping the next generation of leaders emerge and the application of functional and empirically based practices for individuals and organizations move toward their values. Contact Dave at daveleamer@appliedccs.com



Supported Decision Making Empowers Emerging Leaders

By Cory Gilden

What Does the Research Say?

People with intellectual and developmental disabilities (IDD) are rarely given opportunities to practice leadership skills throughout their childhood and adolescence and instead are often stripped of power over their own lives. As children, parents or guardians have control over decision making, and then into adulthood, it is common for school, legal, and disability professionals to promote [Guardianship of the person with disabilities as the default option](#) for decision making. While Guardianship (i.e., [the legal process where a court appoints an individual or organization to make decisions on behalf of an individual because they cannot make decisions for themselves](#)) was designed to [protect vulnerable people from abuse, neglect, and exploitation](#), it has become too [prevalent](#) and [inappropriately used](#). Guardianship is an extreme course of action and [does not allow for a person with disabilities to make independent choices or practice self-determination](#). People have a fundamental right to direct their own life. Guardianship often strips them of that right. If people with disabilities are to be equal citizens with full access to their rights, the practice of Guardianship needs to be reexamined. If the aim of the disability service system is for people with disabilities to be leaders and help guide decision-making on committees and boards as they grow older, then it is counterproductive to strip them of their rights to make decisions about their own lives.



People with disabilities need to practice making decisions for themselves early in their lives for their own wellbeing, and so they can later contribute to making decisions for others when in leadership positions, so alternatives to Guardianship like Supported Decision Making should be encouraged. [Supported Decision Making allows for adults with disabilities to get help from chosen friends, family members, or professionals to make decisions while retaining control over who provides that help and what the ultimate decision will be](#). Making decisions is central to [self-determination, which has been shown to lead to better postschool outcomes](#) such as integrated employment and independent living. The more skilled people with disabilities are at making decisions for themselves, the better prepared they will be to contribute to decisions for organizations, and the more empowered they will be to feel they belong in leadership roles.

What Does It Mean for Our Field?

It is considered best practice for service providers to invite the people they support to join their boards and committees so they can contribute their voice to decision making about their services. However, simply offering someone a leadership opportunity because they should be at the table does not ensure that they will become a leader. People with disabilities need practice developing decision making skills, which are teachable. [Person-directed planning meetings are a form of Support Decision Making](#) and great settings for people with disabilities to be coached in a supportive environment about how to advocate for their choices and exercise control over their lives. To foster decision-making skills, [providers can help](#) create opportunities for everyday choices, present information in an understandable way, help the person being supported think through different options, help the person being supported to communicate a decision, and allow them to learn from the outcome of a decision. If service providers make it the norm for the people they support to have control over decision making, other people in their lives, like family members, friends, and other support staff are likely to get on board.

Additionally, service providers supporting people with disabilities can play a crucial role in educating families and other professionals about Supported Decision Making as an alternative to Guardianship. Agencies that support adults with disabilities often connect with families around the same time of transition into adulthood when Guardianship is discussed so they, along with support coordinators and other professionals, can initiate a discussion about Supported Decision Making as an alternative. Similarly, direct support professionals are often closely involved in the lives of the people they support and could play a key role in helping to develop decision making skills, from small everyday decisions to bigger or longer-term decisions. Making personal decision making a priority not only empowers the person being supported but is a necessary preliminary step to building other leadership skills.

Additional resources for Supported Decision Making

*ACLU Disability
Rights Program:
www.aclu.org/disability*

*National Resource Center for
Supported Decision Making:
supporteddecisionmaking.org*

*Quality Trust for Individuals
with Disabilities:
dcqualitytrust.org*

What Can I Do?

Promoting Supported Decision Making and decision-making skills are both important to developing future leaders with disabilities. There are many things that professionals supporting people with disabilities can do to advance decision making, such as:

- **Advocate for Supported Decision Making.** There is still not formal legislation for supported decision making in all states. Check the status of your state on the [National Resource Center for Supported Decision Making website](#) and see if your organization and the people it supports could contribute to advocacy efforts in your state.
- **Train people to assist in the Supported Decision Making process.** The supporters agree to help the person with a disability understand, consider, and communicate decisions, giving the person with a disability the tools to make her own, informed, decisions.
- **Train employees about the Supported Decision Making process and documents.** While [Supported Decision Making is person centered](#), which many frontline professionals are already familiar with, it can look different in each state and for each person, so DSPs may need training about who should be included in the process, when, and how.
- **Connect families to Supported Decision Making resources.** As early as possible before transition, professionals and family members should be aware of all the options that protect young adults with disabilities. Disabilities organizations can connect families with resources from organizations that focus on Support Decision Making (see references below).
- **Connect people with businesses that already have leadership training programs.** The [Harvard Business Review](#) suggests disability sector organizations should connect with local and national businesses (and vice versa) to strengthen the hiring pipeline for people with disabilities. Once people with disabilities are employed, it is easier for them to enter management and leadership training programs and eventually establish more disability representation at the organization.

Cory Gilden is the Research and Evaluation Manager of the National Leadership Consortium. 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.



Innovative Initiatives: The Lives-in-Progress Collective

A conversation with David James (DJ) Savarese

What is the Lives-in-Progress Collective?

The [Lives-In-Progress Collective](#), hosted through [The Alliance for Citizen Directed Supports](#), was one of two 2022 winners of [The ARC Tank 4.0](#) pitch contest for innovation. The Lives-in-Progress Collective is an essential, sustainable, disability-led, national, grassroots network that, once seeded, will allow self-direction to expand exponentially. Led by the dis/Abled, particularly the multiply marginalized and alternatively communicating, we will establish a national collective of leaders with disabilities focused on transforming self-direction and offer a national resource that allows individuals to build self-direction from the ground up. Seeking to empower, it will pay disabled adults for their expertise and lived experience and dismantle common communication, financial, and cultural barriers to access.



So, How Exactly Does It Work?

Imagine you're an adult in Lewiston Maine, who wants to create a sustainable, self-directed life as an artist. You go to the internet, type in "Maine self-direction" and find a one-page definition of self-direction. That's it. Now, what if that page has a link to the Lives-in-Progress Collective and one click takes you to a national network of possible mentors? You type or choose "artist" in the keyword search. There aren't any artist mentors in Maine, but you see a diverse selection of artists to choose from nationally. In one afternoon, you can learn about all of them from their interviews, webinars, and helpful hints. Or you may want to start a business, so you type "entrepreneur" into the resource keyword search. Up comes a number of individual entrepreneurs whose businesses vary in size. Or, you find Wise (Washington Initiative for Supported Employment) is running a virtual entrepreneur course beginning next month and sign up. Knowing you have a lot of potential advisors to consult with who have real lived experience self-directing their own lives, you feel less vulnerable to failure and less isolated.

Why is the Lives-in-Progress Collective Important?

Self-direction is freedom. We all yearn to be an essential part of something bigger than ourselves. We all want the freedom to pattern our own lives. For those of us with disabilities that freedom is called self-direction. By definition, self-direction needs to be collectively—not just individually—led by people with disabilities. Thirty years after the passage of the ADA, the disability community has the diverse, national leadership needed to make this a reality.

Most disabled adults are forced to live segregated, impoverished lives. This reality is rooted in the systemic, ableist principles that intersect and are further compounded by race, gender, ethnicity, sexual orientation, and socio-economic status. For us, self-direction is not a quality of life issue. For many of our brothers and sisters, it can be a matter of life or death, but historically, self-direction has been viewed as an exception available mainly to the offspring of wealthy, white, educated individuals. 30 years after the passage of the ADA, only 1 in 50 adults with disabilities living in the US self-direct & live the lives they imagined. This allows society to view self-direction as an exception, not a human right. The other 58.8 million, who live lives of convenience for others, deserve the same freedom. If we simply conform to pre-existing systems, processes, & power differentials—systems that rely on unpaid assistance from the most impacted—nothing will ever change.

What Will the Lives-In-Progress Collective Do & How is it Innovative & Disruptive?

Unique and disruptive, the Lives-in-Progress Collective will:

- Create a national collective of leaders with disabilities focused on transforming self-direction.
- Provide a free accessible online national map of diverse, documented paths to meaningful, self-directed lives-in-progress that allows people to search for mentors, resources, and practical ideas by location, interests, talents, and vocations.
- Allow for fast, easy access to the various resources, programs, and supports used by others who are self-directing.
- Be led by the dis/Abled, particularly the multiply marginalized and alternatively communicating, while collaborating with nondisabled allies from other organizations.
- Pay dis/Abled people for their expertise and lived experience.
- Offer multiple pathways and perspectives based on real lived experience.
- Dismantle common communication, financial, and cultural barriers to access.
- Assist people who want to move out of state for college, employment, +/- or other personal reasons.

The Collective will overcome common access barriers regarding cost, culture, and modes of communication as they pertain to self-direction, allowing it to be the type of intersectional, radically inclusive, cross movement project that addresses and counteracts the systemic ableism, racism, sexism, homophobia, and classism at the root of struggles faced by many disabled people across the globe.

As a person interested in self-direction, you choose what to prioritize and from whom or where you find the advice, strategies, and information that work best for you. Meanwhile mentors benefit from camaraderie, added income, and publicity for their own businesses.

What are the Short- and Medium-Term Goals for the Lives-In-Progress Collective?

In 24-36 months, our goal is to complete phases 1 & 2 of the Lives-in-Progress Collective. This will entail the following: a network of at least 10-12 trained self-advocate consultants available to provide paid mentorship and guidance; a national online map created and integrated into the Alliance's website that highlights other diverse, documented self-directed paths; a list of 90 other potential mentors with open recruitment from all 50 states and territories; national presentations and online brochures about the Lives-in-Progress Collective distributed to our current network of organizations; and hyperlinks to the Collective readily available on multiple nonprofit and agency websites focused on adult services and employment.

People often tell us the Lives-in-Progress Collective is too ambitious, but for people with disabilities and our fresh-thinking allies, it's essential. The Collective will enable people with disabilities to be visible, essential members of their local communities, building a national collective with one another and defining what's possible in our own lives.

Who Will Direct the Lives-in-Progress Collective?

David James (DJ) Savarese, who will oversee the project, has successfully designed and completed disability and social justice projects for over a decade as a Herbert Hoover Uncommon Student '09-'10, as an ASAN Scholar Fellow '16-'17, as an OSF Human Rights Initiative Community Youth Fellow '17-'19, and as the *Deej: Inclusion Shouldn't Be a Lottery* Outreach Campaign co-director '17-'20. Savarese also co-produced, narrated, and starred in the documentary, which won a Peabody Award for "unprecedented inclusive filmmaking." His own national base of support and listserv from the *Deej: Inclusion Shouldn't be a Lottery* Outreach Campaign has over 1000 members from 40 different states. Co-Chair of the Alliance, he is a leader in the Neurodiversity Movement who is intimately connected with the broader, national disability community and regularly presents and collaborates at the national, regional, and local levels. One of only two AAC-using autistics to be fully included from kindergarten through college graduation, and a graduate of the *Leadership, Organizing, and Action* course at The Kennedy School at Harvard, he is well-versed in community building focused on empowering others to realize their own life outcomes.

Real change *is* possible when we're motivated by lived experience to break down barriers.

David James "DJ" Savarese is Co-Chair of the Alliance for Citizen Directed Supports. He holds a BA from Oberlin College in Anthropology and Creative Writing. DJ is passionate about artful activism and disability-led initiatives, such as the Lives-in-Progress Collective. Contact DJ at djsavarese@citizendirectedsupports.org.



Photo by Pamela Harvey Photography

What We're Reading, Viewing and Listening To

Title: [How to Lead in a New Era of Employee Activism](#)

Author: *Megan Reitz Ted Talk (2022)*

This brief TedTalk describes practical steps leaders can take to help themselves and their organizations negotiate employee expectations on organizational activism. The talk highlights four key findings from research about employee and organizational activism as well as some pitfalls leaders can avoid.

Link: https://www.ted.com/talks/megan_reitz_how_to_lead_in_the_new_era_of_employee_activism?language=en

Title: [Your Invitation to Disrupt Philanthropy](#)

Author: *Sara Lomelin (2022)*

This talk highlights how communities can work together through “giving circles” to better meet the funding needs of “good ideas” in their community and help to strengthen social ties in the process.

Link: https://www.ted.com/talks/sara_lomelin_your_invitation_to_disrupt_philanthropy

Title: [Teamistry](#)

Author: *Atlassian and Gabriela Cowperthwaite (2021)*

This fun, inspiring, and compelling podcast weaves together stories and research to highlight how leaders can build trust within their teams and the great things that can happen when teams are functioning well together.

Link: <https://www.atlassian.com/blog/podcast>

Title: [Organizational Ethics: Applying a Human Dignity-Centered Framework for Humanistic Leadership](#)

Author: *Robert Olsazk (2021)*

This research-based blog post discusses the importance of centering human dignity in organizational leadership and provides leaders with a practical framework for action.

Link: <https://www.linkedin.com/pulse/organizational-ethics-applying-human-dignity-centered-robert/>

Title: The Myth of Normal: Trauma, Illness, and Healing in a Toxic Culture

Author: *Gabor Mate (2022)*

In this book, physician and celebrated author Gabor Mate explores the social drivers of illness and disease and pathways towards healing.

Link: <https://www.penguinrandomhouse.com/books/608273/the-myth-of-normal-by-gabor-mate-md-with-daniel-mate/>

Title: Lessons on Leadership and Community from 25 Leaders of Color

Author: *Darren Isom, Cora Daniels, and Britt Savage (2022)*

This Harvard Business Review article describes important lessons from leaders of diverse backgrounds on leadership skills, relationship building, and management.

Link: <https://hbr.org/2022/09/lessons-on-leadership-and-community-from-25-leaders-of-color>

Upcoming Events

Leadership Institutes

A select group of future leaders convene with a renowned faculty of national experts on progressive supports for people with disabilities during our intensive in-person or virtual Leadership Institutes. Participants explore leadership in organizations that provide, advocate for, or fund community-based services and supports for people with intellectual/developmental disabilities and their families. Leadership Institutes emphasize:

- Managing and sustaining values-based transformational change;
- Determining organizational and professional direction;
- Experimentation and risk-taking;
- Assessing and honing leadership skills; and
- Building a life-long professional network to sustain career growth.

The focus of the Leadership Institute is on supporting participants to determine and set organizational direction to move their organization to a high-performance model and build a lifetime network of peers and leaders to sustain career growth. Check out our upcoming Institutes and training sessions below.

Upcoming Training Sessions

December 2022

The Illinois Virtual Leadership Institute will be held via Zoom in December 2022. Applications are open now and will close on November 14th. For more information or to apply, [click here](#). This Institute is open to all Disability Sector Leaders.

Winter 2023

The Virtual Canadian Leadership Institute for Developmental Services held via Zoom January 2023. Applications are open now and will close on November 7th. [Click here](#) for more information or to apply. This Institute is open to all Disability Sector Leaders in Canada.

February 2023

The Winter Leadership Institute will be held outside of Philadelphia, PA in Winter 2023. Applications are open now and will close on December 12th. [Click here](#) for more information or to apply. This Institute is open to all Disability Sector Leaders.

Spring 2023

The Midwest Leadership Institute will be held in Spring 2023 in the Midwest. If you would like to be notified when we open applications for this Institute, please add your name to the list [here](#). This Institute is open to all Disability Sector Leader in the Midwest.

Spring 2023

The Virtual Leadership Institute will be held via Zoom in Spring 2023. If you would like to be notified when we open applications for this Institute, please add your name to the list [here](#). This Institute is open to all Disability Sector Leaders.

National Leadership Consortium Workshops

In addition to our Leadership Institutes, the National Leadership Consortium offers virtual workshop sessions throughout the year. Topics of these sessions include:

- Leadership Bootcamp
- Leading Great Teams
- Avoiding Burnout in Yourself and Others
- Trauma-Informed and Healing Center Approaches
- Promoting a Culture of Diversity, Equity, and Inclusion in Your Organization
- Succession Planning with Intention
- Leveraging Your Leadership Strengths

If you would like to learn more about these workshops, please add your name and email to our Workshop List [here](#).



Contact Us

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