

National Leadership Consortium **Bulletin**

At the Heart of
Our Field is Business

**NATIONAL
LEADERSHIP
CONSORTIUM**



ON DEVELOPMENTAL DISABILITIES

January 2025 • Issue 13

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.

Contact Us

<https://natleadership.org/bulletin> • bulletin@natleadership.org

All information provided or published by the National Leadership Consortium is for informational purposes only. Reference to any treatment, therapy, program, service, research or research entity, organization, or provider is not an endorsement by the National Leadership Consortium. The National Leadership Consortium assumes no responsibility for the use made of any information published or provided in the Bulletin. We recognize that language in this field is ever changing and has the unintended potential to be stigmatizing or ableist to some people who identify differently. The Bulletin follows recommended APA inclusive language guidelines.

Table of Contents

Introduction: At the Heart of our Field is Business	3
Learning About Leadership	4
Beyond Tokenism: Organizational Support for Disabled Leaders	9
At the Heart of Our Field is Business	12
Expectations Matter: Who is Expecting What from Whom?	15
The Bottom Line IS the People	20
Why is Interest in Nonprofit Leadership Declining? Review of Recent Research	22
The Benefits of Positive Organizational Culture for People with Disabilities	25
Resources to Learn More about Business Acumen	28
What We're Reading, Viewing, and Listening to	31
Upcoming Events.	32

Contributors:

Kristen Loomis Greenidge, MBA, *Co-Director, National Leadership Consortium*

Elizabeth Vasquez, *Partner, Management Consulting Associates*

Cindy Bentley, *Executive Director, People First Wisconsin*

Noah Upchurch, *Advocacy Specialist and Self Advocates of Indiana Administrator, The Arc of Indiana*

Lynne Seagle, *Consultant, Relentless Leadership LLC*

Gail Godwin, *Founder and Executive Director, Shared Support Maryland*

Marian Frattarola-Saulino, *Co-Founder and Executive Director, Values Into Action*

Paul Saulino, *Co-Founder and Chief Financial Officer, Values Into Action*

Caitlin Bailey, PhD, *Co-Director, National Leadership Consortium*

Cory Gilden, PhD, *Research and Evaluation Manager, National Leadership Consortium*

Amanda Rich, PhD, *Founder and Chief Executive Officer, Open Road Inclusive Community Consulting LLC*

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: At the Heart of our Field is Business

In the humanitarian, entrepreneur, and author Dan Pollata's influential Ted Talk "[The Way We Think About Charity is Dead Wrong](#)" and book and recent [full-length film](#), "[Uncharitable](#)," he discusses the forces that have historically separated the business and non-profit mindsets and how that separation has typically not helped nonprofits achieve their mission. The business mindset focused mostly on making the most profit with little regard for the cost or the risk, while the nonprofit sector focused on making the lives of the people left behind by a market economy better with as little risk and cost as possible. We often see the impact of this at the start of our weeklong Leadership Institutes. Leaders come in with an overflowing passion and commitment for the mission of their organization but often report feeling less supported, comfortable, and confident with the skills it takes to run a business.

The separation of skill sets, however, is an illusion because it takes both a commitment to the mission and business leadership and management skills for an organization to make an impact. There is an overwhelming need for innovative support and services for people with intellectual and developmental disabilities, however, every year [thousands](#), and possibly as many as [30% of nonprofits fail](#) within their first 10 years, often leaving the people they were supporting in need. The reality is that nonprofit and for-profit sectors have a lot to teach each other about leadership and management. In this issue of the Bulletin, we explore business acumen, or the leadership skills needed to make organizations work well, and the challenges faced by those leading disability service organizations.

The nonprofit equivalent to business profit is impact and for mission-based organizations to achieve a good impact they need to be a good business. In this edition Cory Gilden shares research that shows the connection between staff management and development and client impact. Marian and Paul Saulino of Values Into Action share how they approach their organization's business model from a starting place of co-production with the people and families they serve. Lynne Seagle, Organizational Consultant and longtime field leader, shares how staff and the people they support can contribute to organizational operation through participatory management practices and how good business and leadership practices are essential for our field. Business and management consultant Elizabeth Vasquez shares her reflections on the core skills that underpin good management across both for and not-for-profit sectors. You will find a wealth of tools and resources to grow your skills such as staff development, fundraising, record keeping, and more.

We also explore some of the challenges leaders in our field face. Caitlin Baily describes the crisis in a shortage of those with the desire to move into executive leadership position in our field and strategies to address that crisis. Gail Godwin describes how current policies often favor organizations that are provider as opposed to person driven and the need for changes as the state and federal level. Noah Upchurch, Advocacy Specialist and Self Advocates of Indiana Administrator with The Arc of Indiana, and Cindy Bentley, Executive Director of People First Wisconsin, discuss the importance of organizational support of people with intellectual and developmental disabilities in leadership positions to move beyond tokenism.

We hope after reading through this issue that leaders feel more comfortable and less alone in bridging the space between what we have traditionally thought of as for-profit sector leadership skills and the skills needed to run disability service organizations.

Kristen Loomis Greenidge

Kristen Loomis Greenidge is the Co-Director of the National Leadership Consortium. 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.



Learning About Leadership

A consultant's reflections on a long career in leadership development

By Elizabeth Vasquez

- Leadership is the most important thing to an organization because leaders influence the quality of work produced and the quality of the employees' experience that makes the good work possible.
- Knowledge, experience, and skills are important for excellent leaders, but an often-overlooked value that is also important is essential human regard, or sincerely caring about the needs, interests, and development of others.
- There are many ways to become a stronger leader, for example, by reflecting on what you know about yourself, doing a 360-degree assessment, and working with a professional mentor.

My first real job was as assistant to the president of a mid-sized consulting firm. The company had about 200 employees led by 27 managers, four vice presidents and an administrative (or “overhead”) staff of 10, of which I was one. The president of the company was a Harvard Business School graduate and that was lucky for me because, in addition to paying attention to client products and services, he gave a lot of thought to the organization itself, and much of the work associated with that fell to me.

For example, I had assignments that included: developing a performance appraisal system, designing and conducting an annual staff survey, developing and facilitating a new employee orientation program, and organizing the employee development day each year. Once, after three managers in three separate conversations had confided to the president that they felt like chucking the whole high stress job thing and finding a quieter, better quality of life, I got an assignment to research mid-career crisis among management. Then I had to brief the president before he went to New York to meet with a big-time consultant, Abraham Zeleznik, about what to do to keep the managers on board. In that job, I got a first-rate education in how organizations should be run.

That job also set me on the course of becoming an Organizational Development Consultant, which has been my work for the past many years. I've consulted mainly in nonprofit and public sector organizations — every size from small, like a private high school for neuro-diverse teens, to pretty big, like a 50,000-member safety and health advocacy organization, to full-scale federal agencies with budgets in the billions of dollars. It is by working with hundreds of managers and executives over the years that I have continued to add to my understanding of leadership.

Realizing that Leaders are the Most Important Thing

Working as a consultant in the years that followed that first job, I came to realize how important leaders are — that they are ones who can make an organization, or at least their part of it, the best place to work and a valued resource to its customers and community. I have learned that leaders are more important than policies, more important than pay, more important than the organization's benefits, location, or just about anything else, with the possible exception of the mission. Somewhere around mid-career I began to narrow my focus from all things management to a specific interest in



developing and supporting leaders. I saw, and still see, leadership development as a way to make the biggest difference in organizations and in the work lives of the people in them.

So, here's what I've learned working with leaders in lots of different organizations: there are four main building blocks to great leadership:

- **Knowledge of the field** — the principles and best practices, professional standards, regulatory environment, risks, rewards, and more that are associated with the organization's operating environment.
- **Experience in the field** — learning how to deal with the different kinds of issues, people, and situations that need to be effectively navigated and managed. Some lessons can only be learned through experience.
- **Essential human regard** — arguably one of the most important and often overlooked values associated with excellence in leadership. Leadership is very difficult; having a sincere appreciation for the needs and interests of others — peers, employees, customers, partners— along with respect for everyone's humanness and belief in everyone's ability to grow and do better — makes the work of leadership much more rewarding for the one doing the leading, and much more meaningful in terms of its impact on the people and organizations being led.
- **Leadership skills** — the interpersonal and thinking skills that make it possible for leaders to make good use of their knowledge and experience.

“One of the criticisms I've faced over the years is that ... because I'm empathetic, it means I'm weak. I totally rebel against that. I refuse to believe that you cannot be both compassionate and strong.”

*— Jacinda Ardern,
Former Prime Minister of New Zealand*

Zooming In on Leadership Skills

There are lots of ways to identify and define leadership skills. However it's done, breaking leadership as a concept into its parts is essential to understanding it in practical, learnable terms. These are a behaviorally anchored set of leadership skills I have been observing, analyzing, defining, and designing leadership development programs around over the last several years:

- **Influencing others** — the ability to persuade others and to provide guidance to individuals and groups that they want to follow.
- **Flexibility** — the ability to be persuaded, change one's thinking, work with different kinds of people, and collaborate with others as part of a group.
- **Communicating** — the ability to express information, ideas, and feelings clearly and persuasively, in spoken words and in writing.
- **Thinking strategically** — the ability to look ahead and to think conceptually and intentionally about future events or conditions.
- **Thinking critically** — the ability to recognize relevant and unbiased information and make good use of it to solve problems and decide on courses of action.
- **Thinking creatively** — the ability and openness to think about things in new ways.

While these are certainly not the only leadership skills, we know that they are among the most important ones, especially if we are thinking of skills that, with effort, can be learned or strengthened. My business partner, Barbara Upston, and I have asked people in our client organizations and these skills have consistently risen to the top of the list. We have done the “asking” through:

- **Written surveys** of executives and managers in which they rate 50 or so management and leadership skills in terms of their importance, difficulty, and frequency of use. We have also conducted similar surveys among employees to get their ranking of skills they think their leaders should have.
- **Consensus sessions** with executives and managers in which they reach agreement on the most important leadership skills. We have held similar sessions among employees to get their consensus on essential leadership skills for their managers.
- **Interviews** with executives in which they respond to questions about leadership and leadership skills.
- **Observation and feedback** in over 100 leadership skills assessment centers we’ve conducted.

Learning How to Be a Better Leader — A Practical Approach

If you are thinking about becoming a better leader and want to know what you can do to make that happen, the first step is to figure out what you should focus your learning efforts on: the knowledge, experience, values, or skills that, if you gained proficiency in, would make the biggest difference in your ability as a leader. You can learn about where to focus your efforts several ways, for example:

- **Reflecting on what you know about yourself** — considering the leadership framework described above — the knowledge, experience, skills, and values important for leadership in your work — make an objective assessment of areas in which you believe you could grow. Don’t limit yourself to areas you perceive as weaknesses; some of the greatest gains in effectiveness are available through focusing on and further developing your strengths.
- **Asking a trusted supervisor or peer** — one person or a few people whose leadership ability you appreciate and who know your work as a leader and can offer useful insights.
- **Working with a professional leadership coach** who can help you assess your leadership strengths and areas for development.
- **Conducting a staff survey** if you are a manager or part of a team to get feedback from the people who experience your leadership on a regular basis.
- **Conducting a 360-degree survey**, in which your supervisor, selected peers, and direct reports (again, if you are a manager) complete a questionnaire providing feedback about your leadership practices. 360-degree surveys are typically administered by an outside management consultant or consulting organization.

Once you have decided on one or a few competencies to develop, the next step is to identify or create opportunities to use and strengthen the targeted capacity. Of course, there are lots of books you can read or courses you can take—all of which have value. But according to the Center for Creative Leadership, a respected North Carolina-based research and consulting organization, your best bet for growing as a leader is in your current job. Based on their research, they developed the now widely accepted 70-20-10 rule about leadership learning:

- **70% of learning about leadership occurs at work** — skill gains that come from having leadership roles and doing leadership tasks.
- **20% of learning about leadership comes from observations or interactions with others** — for example, supervisors, mentors, or respected others.
- **10% of learning about leadership comes from formalized learning settings**, like training or education programs.

With that construct in mind, logic says that the most fruitful opportunities for developing as a leader can be found or created in your job. Some ways that might work include:

- **Job enrichment** — seeking additional responsibilities that will provide a chance to learn about leadership in ways that your job as currently structured doesn't provide. For example, if you wanted to strengthen your understanding and relationships in the field in which your organization operates, you might seek to add a new responsibility to your job description, to develop community partnerships.
- **Developmental assignments** — arranging to work in another part of your organization or in another organization in or associated in some way with your field. For example, if you wanted to learn more about how to navigate the state legislative processes, you might seek an assignment in an office of a State Senator or Assembly member. If you wanted to gain greater understanding of how to manage change, you might propose or seek assignment to a task force in your organization working on a major change initiative.
- **Acting assignments** — filling in where a position is vacant whether because of vacation, promotion, departure, or other reason. For example, if you wanted to learn more about leading people, you might seek an acting assignment at a higher level in your organization where the supervision responsibilities would be greater.

Creating Leaders in Your Organization

If you are a manager and you have read this far, chances are you have a real interest in leadership. If that's the case, the best thing you can do is share that interest with the people in your organization — your counterpart managers, your external partners, your supervisor or board. Starting up leadership book clubs, roundtables on leadership topics, special board events to highlight strategic issues, annual (or more frequent) leadership retreats for managers — all of these activities help keep leadership perspectives in the forefront of leaders' thinking and make organizational leadership a more interesting and engaging and less exhausting experience for you and your colleagues in leadership roles!

"I start with the premise that the function of leadership is to produce more leaders, not more followers."

— Ralph Nader

Most important of all is what you can do to help build leadership awareness and skills among the people who report to you. Research shows, and we know from our own work in client organizations, that most people at every level want to learn and grow on the job. If you help people in your organization understand the leadership elements in their jobs and give them opportunities to grow in their roles and skills, they will get more satisfaction from their work, be more engaged as employees, and make greater contributions to the organization and its mission. Some examples of employee-level leadership skills that are relevant to every job are:

- Communicating
- Work planning
- Teamwork and team leading
- Problem solving
- Business writing
- Thinking creatively
- Managing conflict
- Customer service

The same strategies that will work for you in building your leadership capabilities will work for the people in your organization as well — job enrichment, developmental assignments, and acting assignments are all just as valuable for employees as for managers. So is the chance to take part in forums focused on leadership matters, for example, staff meetings dedicated to discussing a particular leadership challenge or accomplishment employees have experienced in their work. The more you make leadership development opportunities available to your employees, the more they will grow, the more they will be engaged, the more your organization will benefit, and the more you will grow as a leader.

Check out these additional leadership resources:

[Developmental Activities to Strengthen Leadership Skills](#)

[Developmental Activities for One the Job Learning](#)

[Research on Engaged Employees](#)

[A Leadership Bibliography](#)

Elizabeth Vasquez has over 30 years of experience as a management consultant working with not-for-profits, government agencies, and companies in the U.S. and internationally. Contact Elizabeth at emgvasquez@yahoo.com.



Beyond Tokenism: Organizational Support for Disabled Leaders

We asked [Cindy Bentley](#), the Executive Director of People First Wisconsin, and [Noah Upchurch](#), Advocacy Specialist and Self Advocates of Indiana Administrator with The Arc of Indiana, to share their thoughts and expertise on leadership for people with disabilities. They talked about what meaningful leadership roles look like, how to overcome tokenism, and supports and changes that are needed to ensure more people with disabilities have opportunities to lead. Their insights can help organizations think about the practices that support and get in the way of leaders with disabilities.

- “Nothing about us without us” requires that people with disabilities are involved in leading disability-related organizations. People from many different backgrounds should be included in leading organizations, including on boards of directors.
- People with disabilities are experts in their disabilities. They often have to navigate complicated systems and have important expertise and perspectives.
- There is no one way to support people with disabilities in succeeding in leadership positions. Every person is different.
- Selecting people to serve in a leadership role because of one part of their identity without providing the support they need to succeed in that role is sometimes called “tokenism.”
- Organizations can provide support to help leaders succeed in their roles by breaking information down into smaller pieces, making sure it is presented in a way people can understand, and organizing meetings to go at a pace in which everyone can share their ideas.
- Some people with disabilities are prevented from serving in leadership roles due to limited transportation and inadequate staffing. Organizations should support those interested in leadership roles in navigating transportation and staffing barriers.

What Does it Look Like for People with Disabilities to Meaningfully Lead, Instead of Hold ‘Token’ Positions?

Cindy First of all, people with disabilities need to be around the table. I used to find that I was around the table, but I was not respected. And sometimes, organizations need to fill a position on their board — and I just put it out there. I’m African American, and they need an African American person, so they come to me. That’s not how organizations should be filling positions. I’m not going to be a token on your board. If you’re going to have me on your board, you have to want my expertise and my gifts; I think I bring a lot of gifts to a board. All people with disabilities of all races need to be around the table. It might be more work, but you need everyone around the table; we need all different kinds of people around the table. People from different nationalities, races, disabilities, gender identities, work experience, cultures, and more. Having different points of view around the table makes it better.

Our conference ([the Self Determination Conference](#)) was about people having a seat at the table. Nothing about us without us! We are the experts on our disability; you are not. We were born with disabilities, so we are the experts at teaching other people about disability. We live this every day. Our disability is not going away tomorrow or the next day. If people want to learn about us, we have to teach people about us.

Noah To me, I think it's all about being taken seriously, not infantilized and assumed to be only able to comment on small matters. People with disabilities have to navigate extremely tough systems and that experience is an inherently important perspective that needs to be shared to try to improve services and systems. To meaningfully lead is for our lived experiences to be valued, and our strengths respected and highlighted.

What Support and Development is Needed to Help People Succeed?

Cindy You need to break it down for people with disabilities — a lot of people don't have some skills that others take for granted. You need to put things in plain language. We [[People First Wisconsin](#)] have a grant to help with plain language. We are working with the medical college to rewrite their materials in plain language. If you want to support someone with a disability to lead, you need to make sure people can read or understand the materials. If one side of the group can understand, but the others can't, that's not good. Also, some people use communication boards and alternate communication. Everyone has to be patient when people are using a communication board because it might take them a while to get out their words. Give everyone a chance to participate and have the resources and support they need to communicate.

You also need to focus on accessibility. Some people need interpreters, job coaches, and sign interpreters to participate. We should normalize having support and mentorships in leadership roles.

Noah I think the most important thing is getting to know the individual, learning their leadership style, and their strengths and weaknesses so that you can work with them to best develop a plan to help them succeed. For me, a big support is having things on my calendar so I know what I'm supposed to be working on and what meetings I have so I can truly organize my schedule and day. As with most things in life, I believe good communication is key.



Are There Still Gaps and Challenges in Supporting People with IDD in Leadership Roles?

Cindy There are a lot of gaps. You often see one person represented on a board but don't see people from different backgrounds [like people of different races or different types of disabilities]. I also think a lot of boards are filling positions right now so they can be in compliance with what they say they will be, but that's not right. Some organizations say they will have, for instance, 50% of their board made up of people with disabilities so they will just try to find anyone with a disability willing to serve in that role. People who want to bring their gifts should be in leadership roles.

Lots of boards and groups don't provide needed accommodations and aren't used to providing them or don't have people who know how to; that's a big gap. If you want this person to lead, though, you'll make [needed accommodations] happen or at least try to.

There is also still fear of people with disabilities. The person drools — so what? That doesn't mean the person isn't going to contribute great things. I think we've sort of improved, but not enough; not at all. I still think we have a long way to go. More people with disabilities should be in top leadership roles — you're listening to us, and what we say, we're not just listening to you. Some boards and organizations do this well, but it needs to happen for more people. You listen to what we're saying instead of us listening to you and you making the decisions.

Noah Systemically, there is still that previously mentioned belief that people with IDD are only capable of being in token positions. Fighting that stigma and highlighting the idea of assumed competence can truly go a long way in opening the pathway for people with IDD to assume leadership positions. From there, I'd say that one of the big challenges is that there are a lot of individuals who could be in leadership positions but aren't able to due to barriers like transportation and inadequate staffing. So, any form of help that can be offered to take down some of those barriers can really allow people with IDD to get the opportunity.

Cindy Bentley is the Executive Director of People First Wisconsin. She is a lifelong advocate and has impacted advocacy and public policy in Wisconsin for more than 40 years. Contact Cindy at peoplefirstwi@gmail.com.



Noah Upchurch is the Advocacy Specialist and Self Advocates of Indiana Administrator with The Arc of Indiana. Noah is also the past President of Self Advocates of Indiana where he worked to lead the group to advocate for the rights of people with disabilities across the state. Contact Noah at nupchurch@arcind.org.



At the Heart of Our Field is Business

By Lynne Seagle

Lynne Seagle, a long-time faculty member and supporter of the National Leadership Consortium, served as the executive director of Hope House Foundation in Virginia for more than four decades until her recent retirement. Under her leadership, Hope House has become a model for other organizations around the world, not only for the quality and innovation of their person-centered services, but for how businesses can be run and how employees should be treated. In this article, Lynne shares why a business mindset matters in running good services for people with disabilities.

- Well run businesses are good for their employees, the people they serve, and the community.
- It is important for a business' values to match its organizational culture and practices.
- Participatory management is an approach to managing organizations where everyone in the organization has a say in decisions about the organization.
- Participatory management requires all people at the organization to have the information and support to have an informed say about the organization.
- Leaders of nonprofits can support a business mindset by understanding the rules and regulations in their community and learning from organizations outside of the disability field.

A Well-Run Business is Good for All

I'm going to start off by saying that I don't care really what business you are in or what customer base you have, the only thing that benefits that customer base is a well-run organization. You cannot have a badly run organization that benefits a customer. It's impossible. Now in this article, I am not going to be able to answer all the questions or provide all the answers, but I will share what has worked for me and what has worked for Hope House Foundation.

Creating a Culture in Which Voice Matches Touch

As the Executive Director, I considered many things 'my duty' in the organization. These were formalized roles and responsibilities, and roles and responsibilities that made the organization better and benefited the people who we were supporting and our employees. The first duty that I felt and worked to instill in the culture of the organization is to **match voice with touch**. You cannot speak about how important people with intellectual disabilities are and the kinds of services and support they should receive when it is an exact opposite or in conflict with how direct support professionals, or any others in the organization, are treated. If you want people with disabilities to have a voice about how their lives look and support to direct their life, then the very employees that you're expecting to help them do that need an example of that in your own organization.

Define Your Management Philosophy

To achieve this, I started by defining **what our management philosophy is as an organization**. For me, this meant learning through advanced education, reading books, doing research, and ultimately finding a good fit with the philosophy of [participatory management](#). How do you implement something that is not hierarchical management, not benevolent bureaucracy management, but truly something that was real, that people could see? This helped to combat the fact that democracy was going to always eliminate the minority viewpoint. And we had to have another way to weigh in on decisions.

Once that was defined, it **needed to be put in writing** including its policies, its procedures, its guardrails and there needed to be opportunities and intention in **teaching everyone how to do it**. For us this was important because often people in not-for-profit work don't understand this process well. This philosophy is much more common in for-profit companies like Google and Proctor and Gamble. Having no decision made that affects the entire organization without everyone having a say, having more emphasis on staff development versus staff training — people from the business world do understand these things, but not so much in not-for-profit.

Culture is Created by the People Within the Organization

This idea of creating a culture that values and supports employees is not new. In fact, we know that culture is the most important thing when working to develop and sustain a well-run organization. Peter Drucker, a management guru and business visionary, said, "[Culture eats strategy for breakfast](#)." It's so true because **culture isn't something one person can create. It's not what a leader can create, it's what a leader can encourage, promote and most importantly, adhere to**. But culture is created by the people within the organization. And that culture is key to people with disabilities getting excellence. Culture has informal leaders. And they can emerge as toxic. Or they can emerge as moving this whole mission. I think participatory management underlines that. I think investment in retreats, leadership summits, staff development exercises at the start of every meeting, a great retirement plan so people can retire as a DSP, all of those things matter. **It's not one thing that creates culture, but it is one thing that defines it, and that is the employees.**

Align Your Practices with Your Philosophy

To support a positive culture, a participatory management philosophy, and our sustainability (a key component of a successful organization), we did a few things differently than many other organizations. We had self-directed teams who decided on strategic goals and plans and how best to spend their budget. We also required every new employee within the first six months to understand the agency budget. Now, I'm not saying understand it like a CPA because you don't have to present it that way. You can say, "Here's where our money comes from. Here's how we spend it." People understand their own checkbook. They can review it at team meetings: Where did we under bill? Where's our overtime? People understand that and can contribute, especially with the management philosophy of participatory management, to decision making more competently. When everybody is involved in that, because money drives everything, it drives every decision. It drives your sustainability. It drives your attractiveness to donors because donors do not want to give to a losing organization or an organization in crisis. Big donors want to give to successful organizations to do more, not to stay alive. When everyone's involved in the budget and decision making, you have a better outcome. In all of the organizations I've consulted with, I've never met a DSP that knew their budget. Ever. It's a public document. Anybody anywhere can access that document by just googling it, but your own employees are totally ignorant. That was a major change we made.

After the first 10 years of operation, we put in place an expectation where people know what it takes to get a 1% raise. For everybody, what is it? What are our other costs as a team? Where is this overhead going? What's it for? If you find out that 6% is for the IT guy, you will expect more timely support if a computer breaks or you need help. I think knowledge is power and I don't know why we're so afraid of it.

We also should have the knowledge to understand what it means to be sustainable, and we should not be afraid to consult people outside of our industry. Use them to better understand things like how much you should have in reserves. There are formulas for that. There are percentages for that.

Being a sustainable business that is still relevant and can stay relevant now and in the future is important. How do you stay relevant and keep up with the times of what's next? Businesses do that all the time. The disability field rarely does that likely because for 40 years we haven't changed most of the models for people with disabilities in this country. So, where's the motivation or incentive to reach out to experts from other sectors? States could do a lot more around that. State leadership in some states does a lot more around that. But most organizations have set up their legacy arrangements and there's not a lot of push to do something different.

Good First Steps to Shifting to A Business Mindset

So, what could be a good first step for you to take if you want to shift to more of a business mindset, while still prioritizing great supports and services? First, I would say **know your state or your community's rules and regulations better than the people that enforce them** is number one. At Hope House, because of the suggestion of another leader there, that was the best thing we ever did.

The second thing I would say is to **understand your budget**. Totally understand how things are spent and why and what revenue is brought in and why and what else is out there. Most grant funds are left on the table in this country for not-for-profits. How is that possible when we have so many needs, especially regarding the workforce? I know these two suggestions are tedious and hard to do, but they will be impactful.

My last recommendation would be to **look outside of this industry**. Visit a startup. Read about Google. Search for things like, "What are the top 10 organizations in the country in terms of employee satisfaction?" You won't find one on that list that is in this industry. Steve Eidelman says that all the time. Read about them. Find out what they are doing. Everything I learned about running a successful organization I learned from outside our industry, not from us.

Lynne Seagle, is a Consultant of Relentless Leadership and Former Executive Director of Hope House Foundation. Lynne has devoted nearly half a century to supporting the full inclusion and participation of people with disabilities in the community. Contact Lynne at lseagle@hope-house.org



Expectations Matter: Who is Expecting What from Whom?

By Gail Godwin

- Leaders without disabilities should be led by people with disabilities. When people with disabilities are in the lead, organizations do better work.
- For leaders to follow people with disabilities, they need to include them in every part of the organization. This means that people with disabilities decide future plans and goals.
- People with disabilities have the right to lead their own lives and services. This means that organizations should not make decisions for them.

Leadership is being led by others. In our work, that means that they are disabled themselves or follow the lead and expectations of people with disabilities. This can look like:

- Following daily directives from people who use our services
- Collaborating with people with lived experience and/or taking their lead to accomplish projects
- Completing tasks that relate to person directed plans driven and developed by people
- Communicating with and about people using the names, pronouns, descriptors, and methods they indicate
- Providing a service to someone so that they get what they want out of life
- Advocating for or enforcing policies that promote the rights and dignity of people with disabilities
- Structuring our organizational operations, processes, schedule, and style, to enable ourselves and coworkers to be responsive to the ideas, needs, and expectations of people with disabilities.

Being led by others is a provider's choice. After all, we as leaders and our entire field wouldn't be here if people with disabilities didn't exist in the world. Our organizations wouldn't exist if people didn't choose to direct their resources to them.

Leading by following is not a dynamic that everyone agrees with. Being led by others is also not always easy or comfortable for some, nor does it always provide consistency. One of the most interesting things I've experienced as a leader is the complexity of fully executing our organizational values, for not only people we support, but for co-workers, contractors, the board — for everyone. It is challenging to value flexibility and responsiveness to people who use our services and in the same company ensure mutual understanding between co-workers, the board, and personnel who also require or want accommodations, necessitating flexibility in how and when we work. We take into account people's personal lives and that complexity. We've found that some people who are excellent at accommodating customers struggle with resentment or feeling that they are pulling an unbalanced load with their coworkers. We know this because people have directly shared this. For those who insist on a "top down" and non-collaborative approach, the appearance is that I "do nothing about this."

Leading this way can cause an exit of workers and you need to be willing to accept those consequences. Employees’ capacity to perform their role in ways that demonstrate the value of human regard for everyone is more important than anything. It is best that those who do not have that depart.

When you lead by being led by others, you are never unauthentic; your organization will never be heading in the wrong direction, because you will always be enacting the values that are core to our field. The difference between leading a business that supports people to truly direct their services and lives and an organization that says it does, is that a person directed organization doesn’t misinterpret or misunderstand what needs to be done because we listen and organize our work around what people with disabilities want, need, and expect from us. As leaders, we may be wrong about some things and we make mistakes, but we’re never going in the wrong direction — there is no confusion about that.

Good news — when you lead this way, nothing you do is “outdated” or “conventional” because our field was by and large not built by following the expectations of people with disabilities; however, as we’ve evolved, we’ve recognized that people with disabilities truly realize their rights when they are in charge. As long as our field keeps moving forward, when priorities, rules, and regulations change, organizations don’t have to change the delivery model or practices since services are led by people who use them.

What Leadership by Being Led Looks Like

So how can leaders structure their leadership, organizational, and systems practices to move away from giving lip service to person-direction and centeredness, and move toward making leadership by being led core to how they operate? First, do not start anything (board, organization, committee, decision making, etc.) without engaging people with disabilities, intending for them to be as directly involved as anyone else, from the beginning. Determine accommodations if they are needed and expect the same of people with disabilities as you would everyone else’s engagement, including leading, taking on assignments, and decision making.

Below is some more advice for reframing leadership and organizational practices. These strategies highlight changes in practices needed to lead in a collaborative way or fully by others and help us to understand where our place is otherwise.

Leadership Strategy & Practice		Conventional Leadership	Leadership by Following
Who we are accountable to	What we do	We are first accountable to rules, regulations, safety, health, and liability.	We are first accountable to the person being supported, then we make sure we are in line with system regulations and challenge those that are barriers.
	What happens	We control people. We make decisions that are easier and more convenient for our organizations that might be at the expense of the rights of people with disabilities.	We recognize there are guidance and rules to follow, but they do not usurp the person. People themselves being are or become accountable as they are supported to learn their own responsibility to the system.

Leadership Strategy & Practice		Conventional Leadership	Leadership by Following
How we make decisions	What we do	Decisions are sometimes or often made for the person, especially when risk is involved.	We follow the decisions that people make for themselves and us. When risk is involved, we employ strategies, such as supported decision making, and ultimately follow the lead of the person who is using services.
	What happens	When we make decisions for someone, we are taking ownership of the results of the decision. People cannot be in control of their lives when decisions are made for them.	When we follow the decisions that people make, we avoid power displacement and are directed by people.
How we view rights	What we do	We recognize that people have rights to a point; sometimes we “take away” rights and freedoms, especially when risk is involved.	We recognize that people have the right to control themselves and their environment and we follow their lead to decide what that looks like. Rights are not temporarily on hold until something else happens. All means ALL!
	What happens	We infringe on a person’s rights, even with good intentions. We may not know that we are doing this.	We acknowledge people’s basic human rights, that they are already exercising them and working accordingly. If people are not exercising their rights we work to assist in correcting that.
How we adapt to change	What we do	We change our work when we are compelled by regulations or values of leaders in our organization.	We change our work when people’s expectations change. We do not try to convince people why we do what we do, or that our current practices are the “right way.”
	What happens	We make changes that do not work for people and either need to change again or restrict their rights by staying the course.	We understand that change is constant; being driven by people typically means waiting until the moment to see what’s next. We have confidence that when we do change, it’s in the right direction.

Leadership Strategy & Practice		Conventional Leadership	Leadership by Following
How we design services	What we do	We design services based on the model and funding and offer people “placements,” “beds,” etc. within our models.	We design services with each person; services are different for everyone based on what they want and need. Everyone understands that we have more to learn from each other. We know we are not a match with everyone.
	What happens	Services are tailored to meet the average or highest need of the group. People are often over- or under-supported. We struggle when a person’s support needs change.	Each person receives the type and amount of services they want and indicated that they need. We can adapt to changes in support needs over time by redesigning with the person.
How we future plan	What we do	We hold regular strategic planning sessions with our board and leadership teams to plan for the future.	People with disabilities lead our future plans in equitable collaboration with everyone else. We don’t move forward otherwise.
	What happens	People with the most power and authority in the organization determine its direction.	People who are most impacted by the work have the most power and determine its direction. We learn and grow together.
How we succession plan	What we do	We engage our board, leadership teams, and possibly an external firm to determine future leadership needs of the organization.	Sustainability planning includes people with lived experience. People with disabilities have input into the future vision and operations of the organization.
	What happens	Future leadership priorities and skills are determined by people with the most power and authority.	Future leadership priorities and skills are determined by people who are most impacted by the work of the organization.

Leadership Strategy & Practice		Conventional Leadership	Leadership by Following
What we decide to do	What we do	Grants, projects, and consultation work are obtained to be managed and conducted by managers of the organization.	Grants, projects, and consultation work are developed together and led or co-led together with people with disabilities. People make up the majority of those carrying out the activities.
	What happens	We choose and carry out important work for people with disabilities, but not always with their input into the activities, deliverables, and outcomes.	We partner with people with disabilities to enact activities, deliverables, and outcomes that are in line with their expectations. We promote meaningful leadership of people with disabilities.

People with disabilities remain the only group, as an entire whole, where someone can easily take over and run their life. Having a disability does not preclude you from leading anything, yet people are bypassed on a minute-to-minute basis when it comes to leading in our field, even though they are THE reason for the field.

Leading by being led means that we understand that people with disabilities are the foundation of our work and foundational to where we as leaders, our organization, and the field goes. People with whom we collaborate and are led by, shared “that this is long overdue,” they are representing themselves, and in fact, feel, and are, in charge. Funding will change, rules and regulations will change, but when we lead this way, what propels our organizations are the hopes, ideas, needs, and wants that people with disabilities share.

This model is never more important than it is now, as people as leaders themselves need to lead their advocacy, stand on their own, and be heard as a collaboration of strength.

Leading by being led means that we understand that people with disabilities are the foundation of our work and foundational to where we as leaders, our organization, and the field goes.

Gail Godwin, is the Founder of Shared Support Maryland, Inc. and holds a Training Associate position at the Institute for Community Inclusion UMass. Gail’s MA is from the University of Pittsburgh, School of Education, Program in Severe Disabilities—educational, employment and community inclusion for all. For over 30 years, she has been an advocate in collaboration with people with disabilities in self-directed service provision. Contact Gail at gail@sharedsupportmd.org.



The Bottom Line IS the People

By Marian Frattarola-Saulino and Paul Saulino

- Leaders at provider organizations should center their work around “co-production.”
- “Co-production” means working as equals with people with disabilities to design, develop, and evaluate their services together.
- Prioritizing services that work best for the people with disabilities being supported may not make business sense sometimes but should always be what service providers strive to do.

Starting an organization, Values Into Action, that works honestly and intentionally to provide Home and Community-Based Services (HCBS) *with* the people who use them turned out to be easier than expected. This approach, called [co-production](#), supports civil rights. We based our decisions and organizational choices on it whenever we had the chance.

We began our careers during the [Self-Determination Movement in the 1990s](#), inspired by the [Robert Wood Johnson Foundation’s Self-Determination Projects](#). Pennsylvania was part of this effort and an early leader in sharing power with those affected by policies and services. What we called “self-determination” then is now known as “co-production” of publicly funded services and supports.

Co-production means working as equals with people who use health and care services, their families, staff, and communities. It involves everyone from the very start—designing, developing, and evaluating services together.

As service providers, we are experts in:

- Knowing local, state, and federal rules for public funding.
- Managing public funds to support people effectively.
- Designing support systems that combine natural and specialized resources.
- Using planning tools and facilitation skills to help groups work well together.
- Supporting self-advocacy by assuming competence in everyone.
- Respecting families’ right to make their own decisions.

We believe people and their families are the experts on their own lives. Our role is to make decisions that align with our expertise, mission, vision, and values.

Why Do We Do This work?

Because everyone has the right to control their own life.

How do we do this work?

We presume competence in everyone we meet. We use our skills and knowledge to help people create and maintain the life they want with their HCBS services.

What do we do?

We provide services and support so people can live, work, play, and worship where and with whom they choose.

Our process always involves those affected by policies, rules, or services. Personal planning helps identify services that meet a person's goals. The person chooses their goal, and we explain which services can help them achieve it and which we can provide.

Our decision making considers whether we can:

- Pay workers a livable wage with the current funding rate
- Meet service standards with available resources
- Deliver services in the best interest of the people accepting services

As stewards of public trust, we carefully balance financial responsibility with the wellbeing of those we serve and employ. We also honor our responsibility to the community, especially as nonprofits. System transformation and adapting to change are essential for organizations committed to supporting their communities.

Sometimes, we offer services that don't cover costs. For example, in 2013, we agreed to provide Supports Broker services even though it wouldn't 'break even' after paying fair wages and covering compliance and administration costs. We made this decision based on our mission and belief in self-direction. With that in mind, we took a long-term view with no expectations for short-term benefits other than helping people using self-direction to have access to a Supports Broker.

Today, we are the largest provider of Supports Broker services in Pennsylvania. State and national policymakers seek our guidance and examples. We help shape policies that enable people using self-direction and HCBS services to have choice and control.

This success wouldn't be possible without the input and leadership of those affected by our services. They are involved in every step — decision making, design, implementation, and evaluation.

We are eager to share our experiences and work with others to build a system where people are always the bottom line.

Marian Frattarola-Saulino is the Co-Founder and Executive Director of Values Into Action. Marian's commitment as a community organization is to first see everyone as the experts of their own lives and experiences, with the capacity to contribute. She helps build coalitions where people can use their power for organizational and systems change. Contact Marian at marians@viapa.org.



Paul Saulino is the Co-Founder and Chief Financial Officer of Values into Action and Values into Action New Jersey. He is a family member of a Pennhurst Plaintiff class member and holds a BA in Finance from Villanova University. For over 40 years Paul has been involved with supporting people with intellectual disabilities, and his focus is on the structure, design, and development of administrative, financial, and information systems. Contact Paul at pauls@viapa.org.



Why is Interest in Nonprofit Leadership Declining? Review of Recent Research

By Caitlin Baily

- People in powerful leadership roles play an important role in their organization's ability to change to better meet the needs of people with disabilities.
- Finding people to lead disability service organizations is getting harder.
- People want to become leaders because of positive experiences or become leaders because of negative experiences they want to change or prevent.
- Organizations must invest and plan for supporting new leaders for executive leadership roles in the field to better meet the needs and interests of people with disabilities.

When we consider important changes that have happened in our field to enhance the rights and dignity of people with disabilities, we're reminded that great leaders have always been the drivers of transformation. And while people certainly lead from all positions, those in leadership positions that are associated with increased power and authority (executives, directors, etc.) are [critical agents of transformation and change \(or conversely, stagnation\)](#) in the disability service sector.

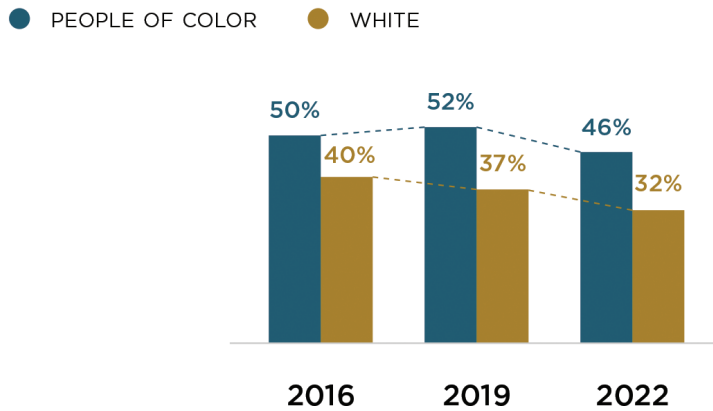
However, supporting the right leaders to move into these critical leadership roles has become increasingly challenging.

For a few decades, researchers have been warning about a leadership crisis in [nonprofits](#) and [government agencies](#), largely due to the large number of past and current executive leaders reaching retirement age and challenges with filling top leadership roles as they open. Traditionally, nonprofit and government agencies have [struggled](#) with succession planning and building bench strength due to lack of time, resources, and direction from boards of directors and executives. Recently experts have noticed another challenge in preparing the next generation of top leaders, particularly in the nonprofit sector: [decreasing interest in senior leadership positions](#).

What Does the Research Say?

[A recent report from the Building Movement Project \(BMP\)](#) that reviews data collected in 2016, 2019, and 2022 provides some important insight into why emerging leaders may show more apathy or even aversion toward higher levels of leadership than in the past. Their data shows that interest in taking over a top leadership role decreased about 4% for BIPOC leaders and 8% for white leaders from 2016 to 2022 (the figure from the report below shows these results in graphic form). And as people grow in their careers, they tend to be less interested in leadership. The study showed that white professionals were most interested in leadership roles in their 20's and declined from there, while BIPOC professionals' interest peaked in their 30's and 40's. Not surprisingly, these results were linked to concerns about work/life balance and the demands associated with the executive leadership roles. [A 2020 study](#) across sectors found similar results; many people feel that the risks of leading, such as getting blamed for failure, and challenging interpersonal responsibilities, outweigh the benefits.

FIGURE 1 | INTERESTED IN TAKING A TOP LEADERSHIP ROLE



[The Push and Pull Report Link - BMP_The-Push-and-Pull-Report_Final.pdf](#)

Interestingly, the BMP report also noted important differences in what motivates people to positions of leadership; push and pull factors. When people are pulled into leadership, they are inspired to lead based on positive experiences they've had in their organizations or field. When people are pushed into leadership, they are motivated by negative experiences that they feel responsible to resolve when they have more power and authority. The results of this study show that the more respondents experienced challenges, such as inadequate salaries, little attention for staff wellness, and lack of opportunities for advancement, the more likely they were to aspire to top leadership positions. This was especially true for BIPOC respondents. The report did find that there were some supportive factors, such as training, mentorship, and self-care initiatives that increased the pull to leadership roles as well; however, the results were mixed as to whether they increased aspiration for leadership among white or BIPOC professionals. BIPOC respondents were also less likely to have received support from the executive director, board of directors, or other staff and less likely to report that the board of directors and other staff support their leadership.

What Does it Mean for Our Field?

In the disability service sector, we have also been citing a growing workforce crisis for decades; though the focus has mostly been on the [desperate need to attract and retain direct support professionals](#). Recognizing that there is also a shortage of people who are supported to grow into and who are interested in attaining executive leadership positions is also important to ensure that our sector has the bench strength needed to sustain services and supports. Fortunately, efforts to promote an engaged workforce, such as addressing challenges with burnout, ensuring people have the training and support they need to succeed on the job, and other tactics are likely

Pull to leadership happens when people are inspired to move to higher positions of leadership in their organization based on positive experiences, such as connection to the mission, support and encouragement from mentors and current and previous organizational leaders, and interest in continuing and growing the work of an organization.

Push to leadership happens when people are motivated to take on higher positions of leadership in their organization because of negative experiences, such as discrimination, inadequate pay, or toxic organizational culture, ineffective structures and practices, and obstacles to growth.

to enhance the pull to leadership for professionals working in all levels of an organization. Further, essential practices where the nonprofit and government sectors tend to fall behind, such as succession planning, coaching and development, and more, benefit both the next generation of frontline and executive leaders.

These negative trends in the move to higher leadership roles are an important reminder that many of our organizations need to take a hard look at our organizational practices and operations that encourage or discourage people to lead, particularly for people of color who are still much less likely to hold executive leadership positions in the disability service sector. Adopting practices that pull people into leadership, such as showing clear opportunities for advancement within an organization, offering mentorships, and paying more than lip service to employee wellness are critical to ensuring the next generation of leaders is ready and interested in assuming positions of authority.

What Does It Mean for Me?

- If your organization is in succession planning (or will be shortly), consider the factors that may limit BIPOC leaders from attaining higher positions of leadership in your organization. According to research, the issue is clearly not lack of qualification or lack of interest; meaning leaders must examine the internal structures, biases, and (even unintentional) discriminatory practices that hold people back.
- The BMP report shows that even though BIPOC leaders report higher interest in top leadership positions, they are more likely to be pushed into those positions due to less satisfaction with current or previous leadership, operations, growth opportunities, or organizational impact. To increase the pull to leadership, adopt practices that research shows encourage people to lead, such as mentorship and coaching, establishing work/life balance for employees in all roles, and increasing a culture of support across the organization.
- Start to investigate interest in leadership in your organization now. It would help to understand who wants to eventually work in top leadership roles and why (i.e. push or pull). Knowing this can help your organization start to address issues that may get in the way of the next generation of leaders. It can also ensure that when opportunities arise, you know who is motivated to lead.
- If you interact with the board of directors, ask them to focus on succession planning, even if the executives in your organization are not nearing retirement age. Ongoing succession planning that encourages the next generation of leaders to prepare for top leadership roles can increase a pull to leadership and ensures that your organization is prepared for expected or unexpected turnover in the future.

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.



The Benefits of Positive Organizational Culture for People with Disabilities

By Cory Gilden

- Having a positive organizational culture (the shared values and norms of an organization) is important to keep employees from leaving and to having good organizational performance.
- Treating employees at service provider organizations with dignity, respect, and fairness has a positive impact on the people with disabilities that those employees support.
- Leaders can treat their employees with dignity, respect, and fairness by creating a place where everyone has input, training people appropriately, and showing appreciation by rewarding their employees for good work.

What Does the Research Say?

It takes more than simply getting the job done and keeping the doors open to be a strong leader. Leaders are also responsible for building positive organizational culture, something that has been shown to contribute to [employee engagement, satisfaction](#), and [retention](#), and [organizational performance, productivity](#), and [resilience](#). Organizational culture includes the “[shared values, beliefs, behaviors, and norms that influence the way an organization’s employees interact with each other and approach their work](#).” Gallup has identified [five significant drivers of company culture](#):

1) *leadership and communication*, with leaders conveying consistent messaging about organizational values and modeling those values with employees; 2) *values and rituals*, where organizational values and expectations are reinforced frequently; 3) *human capital*, with processes from onboarding to development and promotion reinforcing organizational purpose, brand, and culture; 4) *work teams and structures*, promoting structures and processes that support the desired organizational culture; and 5) *performance management*, such as accountability, reward systems, and goal setting that align with an organization’s purpose and reinforce its desired culture. This article highlights research related to the first driver of leadership and modeling organizational values.

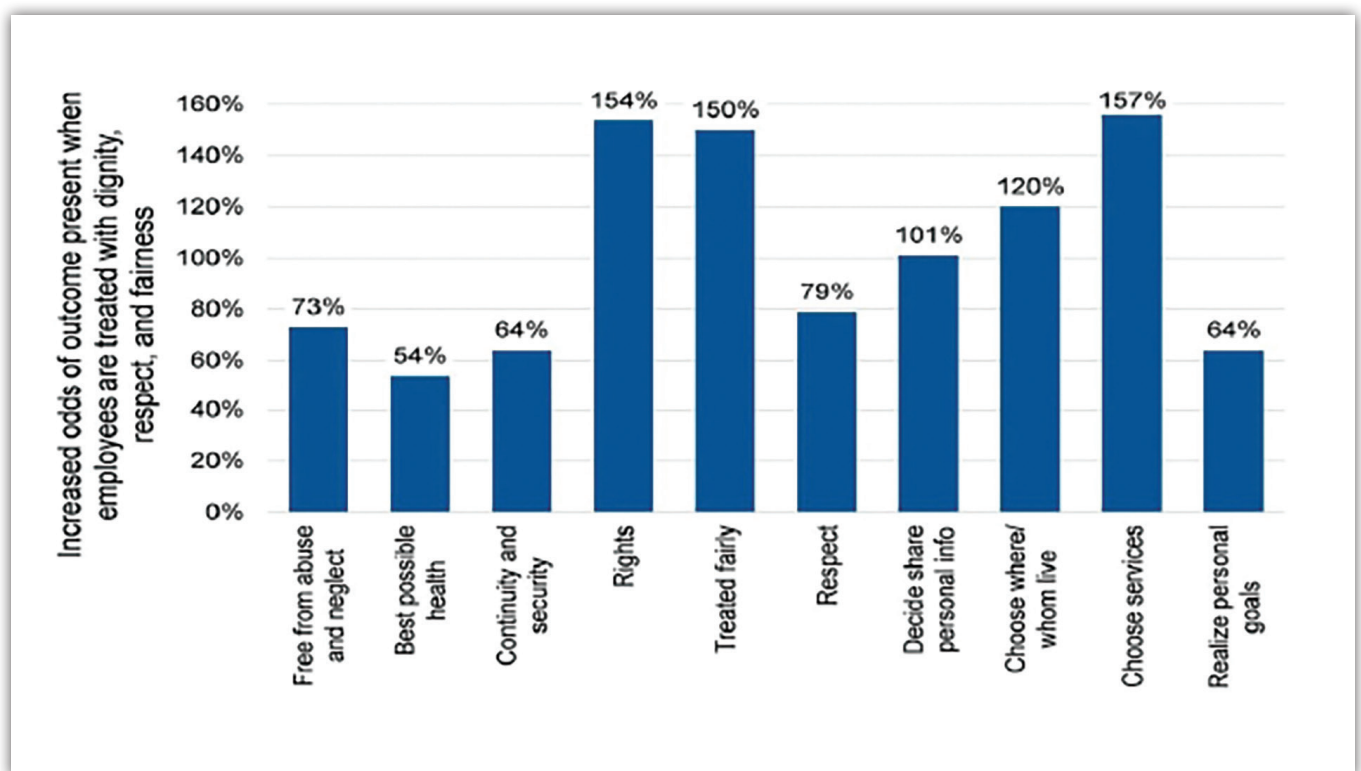
Five Significant Drivers of Company Culture according to Gallup

- 1 Leadership and Communication
- 2 Values and Rituals
- 3 Human Capital
- 4 Work Teams and Structures
- 5 Performance Management

What Does It Mean for Our Field?

The National Leadership Consortium recently collaborated with Carli Friedman, Director of Research at CQL, to investigate how leadership can influence organizational culture and impact the quality of life of the people with IDD supported by those organizations. The [study](#) analyzed [Personal Outcome Measures](#)[®] and [Basic Assurances](#)[®] data from 3,898 people with IDD served by 387 different providers and found that providers who treated their employees with dignity, respect, and fairness had positive effects on the people with IDD they supported. When frontline employees felt supported and appreciated by leadership, they share that positivity with the people with IDD they support, resulting in people with IDD being 154% more likely to exercise their rights, 74% more likely to be free from abuse and neglect, 64% more likely to experience continuity and security in their lives, 150% more likely to be treated fairly, 79% more likely to be respected, 54% more likely to have the best possible health, 101% more likely to decide when to share their personal information, 120% more likely to choose where and with whom to live, 157% more likely to choose their services, and 64% more likely to realize their personal goals, regardless of their demographics (see table below). It's clear that treating employees with dignity, respect, and fairness has cascading effects that benefit employees and organizational culture but also goes on to positively impact people with disabilities receiving services.

The Impact of Treating Employees with Dignity and Respect on People with IDD's Outcomes



What Can I Do?

Because establishing a culture of dignity, respect, and fairness has a dramatic impact on employees and the quality of life for the people with disabilities they support, leaders should work toward promoting these values in their organizations. Here are some methods supported by research to advance those values:

- **Create a culture of inclusivity** by encouraging the views of traditionally marginalized voices, different perspectives, and uncomfortable conversations when making organizational decisions. Allowing for space for “[authentic otherness](#)” helps create inclusivity and respect in the workplace.
- **Train employees appropriately for their jobs** to help [build competence and confidence](#) and deter burnout. Appropriate training and “upskilling” give employees a fair shot at being successful in their roles and [staying at their organizations](#). Also, providing opportunities for growth and future leadership positions shows respect by considering all employees as emerging leaders.
- **Develop mentorship opportunities** for new employees to be paired with experienced employees for additional support, which will prevent failure, give a safe forum for questions and feedback, connect socially with coworkers, feel less isolated, and learn about workplace culture and norms.
- **Recognize success and show appreciation** through awards, incentives, and tangible ways of encouraging exceptional work. Things like recognition at organizational events, items like pins or jackets, extra paid time off, or [other ways](#) to recognize experience and successes can increase employee [motivation](#) and [retention](#).
- **Promoting self-care for employees** at an organizational level by providing opportunities to integrate self-care daily or weekly routines, such as taking breaks, consulting with managers, and mental health support, and into training for employees, for example, about mindfulness meditation and local mental health resources and supports. Self-care contributes to professional quality of life and [may help promote retention and longevity of employees](#).

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.



Resources to Learn More about Business Acumen

- Leading disability service provider organizations is hard.
- Leading an organization involves many business-related skills such as strategic planning, fundraising, marketing, stakeholder engagement, building and working with a board of directors.
- Many leaders in the disability service sector have a strong background in providing support but less confidence with other parts of running a business.
- There are many tools and resources to help you build your business skills to keep your organization operating well.

Resource	Paywall	Resource Type				Description
	Yes/Some/No	Courses & Training	Toolkits/Guides/Research	Webinars/Podcasts/Videos	Community & Consultation	
Nonprofit Learning Lab	Some	x	x	x		The nonprofit learning lab is nonprofit organization that is dedicated to training leaders in the nonprofit sector. They offer extensive training on topics such as facilitation, fundraising, strategic planning, and communication. Though many of their trainings are behind a paywall they also have a wide variety of free webinars, resource guides and tool kits.
Board Source	Some	x	x		x	BoardSource is a great resource for building, assessing, collaborating with, and supporting your board of directors. Board Sources’ stated mission is “to inspire and support nonprofit boards and executives to lead justly and with purpose.” They offer support to individual nonprofit leadership in the social sector, as well as conduct and publish a host of research and best practice guides for effective and ethical organizational leadership and governance. They have many freely accessible tools to help strengthen your board of directors through self-assessment, planning and reflection. Though some material is behind a pay wall they also offer a wide variety of cost-free resources.

Resource	Paywall	Resource Type				Description
	Yes/ Some/ No	Courses & Training	Toolkits/Guides/ Research	Webinars/ Podcasts/Videos	Community & Consultation	
Nonprofit Leadership Lab	Some	x			x	Though there is a membership feel to join the Nonprofit Learning Lab community, the site offers connections with other nonprofit leaders, training, and support for all elements of nonprofit leadership including fundraising. Additionally, they have a rotating offering of free training and resources.
National Council of Nonprofits	No		x		x	The National Council on Nonprofit offers free tools and resources to nonprofit leaders. Their resources have a range of topics including financial management, DEI, Employment and HR, Ethics, and Marketing and Communication. They are the largest network of nonprofit leaders.
Scaling Pathways Research Series	No		x			Unlike the other resources listed here, this research series published by Duke University Fuqua’s CASE center is not itself an organization. Instead, it is a series of accessible research articles that describe lessons on how organizations working for a social good can scale-up their impact. The series covers the topics of scaling through financing, scaling through leveraging government partnership, scaling through people and talent, and scaling through data use.
Strategic Planning in Nonprofits Guide	No		x			The Strategic Planning in Nonprofits (SPiN) Guide offers a step-by-step guide with activities, planning guides, and videos to walk you through each step of strategic planning.
Association of Fundraising Professionals	Some		x	x		AFP offers tools, resources, research, advocacy, and networking opportunities to empower organizations to practice ethical fundraising. Though membership in their professional organization has a cost, as do their templates, they do offer some free resource guides on a variety of fundraising topics.

Resource	Paywall	Resource Type				Description
	Yes/ Some/ No	Courses & Training	Tool-Kits/Guides/ Research	Webinars/Pod- casts/Videos	Community & Consultation	
CatchaFire	No				x	CatchaFire is a skill-based volunteering platform that connects nonprofit organizations with highly skilled professionals to complete describe, time-limited projects. Most volunteers are master's level business professionals who offer support in many areas including board development, marketing, web development, operations, and more.
Nonprofit Hub	Some	x	x	x	x	The Nonprofit Hub has an extensive free library of resources that include podcasts, webinars, articles, resource guides and more. Additionally, they have some training and resources available to paid members that provide additional resources and courses including some that count for CFRE continuing education credits.
Candid	Some		x	x		Candid offers both free and membership only trainings and resources specifically to strengthen your skills in grant finding and grant writing.
The National Leadership Consortium on Developmental Disabilities	Some	x	x	x	x	And of course we are also here for you! The NLC is predominately known for our variety of leadership training and development programs. We also conduct and publish research relevant to the field, offer individual coaching and consultation to leaders, offer an organizational assessment tool, and connect leaders in the disability field from across the globe. Join our listserv to stay up to date on our offerings and connect with other leaders here!

What We're Reading, Viewing, and Listening to

Title: [The Smart Nonprofit: Staying Human-Centered in an Automated World](#)

Author/Editor: Beth Kanter & Allison H. Fine (2022)

Description: This book offers a road map for nonprofit leaders to think about how their organization can accelerate positive social change during a time of rapid technological change. The book discusses how to use AI and other smart technology effectively and ethically.

Title: [Effective Fundraising for Nonprofits: Real-World Strategies That Work](#)

Author: Ilona Bray (2022)

Description: Bray highlights how nonprofit leaders can amplify their organization's voice to increase donations. It offers real life examples and insights from nonprofit leaders and walks readers through the fundraising steps including planning, working with donors, soliciting grants and more. A new edition will be released in February of 2025.

Title: [The Way We Think About Charity is Dead Wrong](#)

Author: Dan Pollatta (2013)

Description: Though Pollatta's Ted Talk is now a classic, his message of rethinking the belief systems that limit the growth of nonprofits is still highly relevant. He encourages the listener to challenge the belief systems that hold investing in marketing and other tools for growth as diverting funds "away from the cause" and offers tips for reimagining our nonprofit sector in a way that allows us to more effectively address social problems.

Title: [The Nonprofit Dilemma: Insight & Strategies for Purpose-Driven Leaders](#)

Author: DC Armijo (2024)

Description: This book helps nonprofit leaders gain clarity around their priorities to advance their organization's mission while sustaining the organization's financial wellbeing. A portion of the net sales from this book are donated to nonprofit organizations selected from the author's [Notable Nonprofits](#).

Title: [How to Measure the Impact of Your Programs](#)

Author: Dana Francois on the Nonprofit Leadership Podcast (2024)

Description: In this episode of the Nonprofit Leadership Podcast, Dana Francois, Program Officer for Family Economic Security at the Kellogg Foundation, discusses strategies to measure program impact and the importance of measuring a program's impact.

Title: [Management in a Changing World: How to Manage for Equity, Sustainability, and Results](#)

Author: Jakada Imai, Monna Wong, & Bex Ahuja (2023)

Description: The authors in this book discuss how leaders in nonprofit organizations can expand their impact through practical strategies for things like goal setting, team culture building, and delegating. The book is engaging and useful for leaders aiming to build effective processes at their organizations.

Title: [The Way We Work](#)

Author: Various Leaders in a Ted Talk Series (2018-2024)

Description: In this series from Ted.com, leaders from a range of industries discuss how to adapt and help your team adapt to a changing work environment.

Upcoming Events

March 25 - May 13, 2025

The Leadership, Empowerment, Advancement & Development (LEAD) for Delaware Direct Support Professionals Training will be held as a hybrid program from March 25 - May 13, 2025. Applications are now open. To see exact dates and for more information, [click here](#). This 9-week program focused on the growth and development of Delaware Direct Support Professionals is open to DSPs currently working in Delaware.

April 27 - May 2, 2025

The Wisconsin Leadership Institute will be held April 27 – May 2, 2025 in person in Milwaukee, WI. Applications are open now, [click here](#) for more information or to apply. This Institute is open to disability sector leaders located in Wisconsin.

May & June 2025

The Canadian Virtual Leadership Institute, funded by the Canadian Centre for Caregiving Excellence, an initiative of the Azrieli Foundation, will be held virtually May & June 2025 via Zoom. The class will begin with two pre-sessions at the end of May and full sessions throughout June (we will then meet twice a week for four weeks). Applications are open now, [click here](#) for more information or to apply. This Institute is open to all disability sector leaders living and working in Canada.

July 13-18, 2025

The Summer Leadership Institute will be held July 13-18, 2025 in-person in Newark, Delaware, at the University of Delaware. Applications are open now, [click here](#) for more information or to apply. This Institute is open to all disability sector leaders. If you are a leader with a disability, a Direct Support Professional, or a leader who works for a state department of developmental disabilities within the United States (Gary Smith Scholarship funded by NASDDDS) you can apply for scholarship support to cover tuition and some travel and hotel costs!

April 2025 - September 2025

The Keys to Leadership: A Five Part, Virtual Workshop Series

We know that there are leaders at every level of organizations and systems, and at each level there are unique challenges and opportunities that exist for leaders in the positions. Throughout this series, we will explore some of the key areas of leadership success including:

- The Human Side of Leadership (April 2025)
- The Challenging Side of Leadership (May 2025)
- The Relational Side of Leadership (June 2025)
- The Business Side of Leadership (August 2025)
- The Data Side of Leadership (September 2025)

For this Five Part Workshop Series, attend one or all (or any combination) of the workshops. Sign Up To Receive More Information Today!

Applications will be opening soon for the following Programs:

- **The Spring Leadership Institute** (May 2025 in the Midwest United States)
- **The Workforce Innovations Leadership Institute** in partnership with NADSP (July 20-23, 2025 in Newark Delaware, at the University of Delaware)
- **The Fall Leadership Institute** (October 2025 in San Diego, CA)

If you'd like to be notified when we open registration or applications for future trainings including the Institutes listed above, please add your name to the list [here](#).



Contact Us: <https://natleadership.org/bulletin> • bulletin@natleadership.org

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