

National Leadership Consortium **Bulletin**

Leading Change Beyond
Your Organization

**NATIONAL
LEADERSHIP
CONSORTIUM**



ON DEVELOPMENTAL DISABILITIES

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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.

Introduction: Leading Change Beyond Your Organization

Through the many emails, meetings, and daily responsibilities, it can be so easy to exist only within our teams and organizations. We consider how we can leverage our unique strengths, skills, and interests to better our pieces of the system. But what we know about systems is that “a system is never the sum of its parts. It’s the product of their interaction” ([Russell Ackoff](#), Consultant and pioneer in the field of systems thinking). How are we creating opportunities and spaces to better understand and impact those interactions? How can we use our influence to impact the systems we live, work, and interact in?

Systems change is a long-term process that requires a balance between working within the system, changing the system, and replacing the system. What elements are working? What elements need to be eliminated? What elements need to be changed? We have had many successes in changing our system, but we have a lot of work left. We still see a disconnect between the disability service sector and others support areas, such as healthcare and mental health. If we are going to continue to make strides in systems change, we need to include a few [key elements](#). Systems change can only be successful when we include diverse voices and concentrate on building and fostering relationships. It needs to start with an exploration of the root cause of the challenges and maintain data-driven decision-making. We must recognize power-imbalance and work to support and empower those with historically less. Lastly, strategies must be flexible, leaders consistent, and short and long-term wins must be celebrated and recognized.

As Judy Heumann so perfectly put it in her book [Being Heumann: An Unrepentant Memoir of a Disability Rights Activist](#), “Change never happens at the pace we think it should. It happens over years of people joining together, strategizing, sharing, and pulling all the levers they possibly can. Gradually, excruciatingly slowly, things start to happen, and then suddenly, seemingly out of the blue, something will tip.”

In this Issue of the Bulletin, we hear from leaders across the system and look at the many ways that this work of strategizing and pulling levers is being done already. First, with Ari Ne’eman, Assistant Professor at Harvard University and disability advocate, we explore what it means to be a systems leader in this field and how advocacy is a valuable and necessary part of change. An interview with Priya Penner, activist, advocate, and disability rights/justice consultant, shares what the Disability Justice framework is and how it can be applicable to many social justice issues. At the heart of systems change is collaboration and Stacy Nonnemacher, Director of Cross System Strategies at NASDDDS, shares how collaboration is a key tool in cross-system interaction and change, such as in the creation of and work at The Link Center. Another insightful example of the impact of meaningful strategizing and collaboration is the National Center on Advancing Person-Centered Practices and Systems. In a Q&A with the Co-Directors, we investigate the work being done, what makes it successful, and the continued opportunities in this work. A final example of needed systems changes given in this issue is healthcare, highlighted in the article by Cory Gilden, Research and Evaluation Manager of the National Leadership Consortium.

In our last few articles, we move to look at how we can develop our skills and practices to be a better systems letter. Emmanuel Jenkins, owner of We Stand 4 Something and motivational speaker, shares effective practices to strategic, meaningful communication. Amanda Rich, Owner of Open Roads Inclusive Community Consulting, highlights the need for hope and trust as we look to impact and change organizations, communities, and systems.

We hope you enjoy this opportunity to consider how you can impact the systems that impact us and those we support and serve most,

Kristen Loomis Greenidge

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Expert Q&A: Disability Rights and Community Leadership

An interview with Ari Ne'eman, Assistant Professor in the Department of Health Policy and Management at the Harvard School of Public Health and longtime disability advocate

- People with disabilities bring valuable expertise that helps policymakers make better decisions about funding and services.
- All types of advocacy, including self-advocacy, advocacy on the state level, and advocacy on the national level, are necessary to make change.
- When you are making a switch from advocating for yourself to advocating for others, good questions to ask yourself are, “How can I develop the skills, and what skills am I going to invest in developing, for my advocacy to actually be effective?”

You've been a disability rights advocate for almost 20 years. What originally got you into this work?

I came into disability rights advocacy because I believed, and still do believe, that people with disabilities are unfairly and systematically excluded from society. I had some of my own experiences with that coming up in the special education system and being sent to segregated special education settings as a child. It seemed to me that in order for change to take place, there was a need for people with disabilities and those who shared our values around inclusion and integration to have more influence in public policy. So I worked for many years in disability rights advocacy; I was the executive director of the [Autistic Self Advocacy Network](#) (ASAN), one of President Obama's appointees to the [National Council on Disability](#), and then for the last five years or so transitioned into the world of research, which in some respects is very different, but in other respects is focused on the same goal of trying to ascertain how public policy impacts people with disabilities for better and for worse.

You mentioned that you founded the Autistic Self Advocacy Network in 2006. What are the goals of that organization and what were you personally trying to achieve by establishing a self-advocacy network?

ASAN's work is focused on empowering autistic people and having our voices heard in the halls of power and in doing so to promote inclusion and self-determination for people with disabilities more broadly, so that remains the organization's focus. I stepped down as ASAN's executive director in 2016 but continue to serve on the organization's board. It's a group that is very much still near and dear to my heart. ASAN's work has really played an important role in trying to meld the values framework that motivates us to a strong commitment to subject matter expertise in disability policy and that's something that's reflective of the disability rights movement in many respects, especially the developmental disability movement at its best.

It's very easy to say, 'these are our values and policy makers should do things that align with those values,' but when you take that general approach, you really abdicate power because you are relying on policymakers to translate your broad statements of values into specific and operationalizable policies. So what I've always felt was necessary, and I think this reflects the work that I did at ASAN and reflects the work I do as a researcher now, is to try and meld a commitment to values with very strong subject

matter and technical expertise as to how those values can be operationalized in public service systems. [Ed Roberts](#), the father of the independent living movement had this phrase called ‘advocat.’ He said the ideal disability rights advocate was part advocate and part bureaucrat: an ‘advocat.’ The reason he said that is that people with disabilities generally live a huge portion of our lives intertwined with public systems and public policy, so it’s not enough to be an idealist, you also have to really immerse yourself in the practical exigencies of changing public policy to have an impact. That’s very much my philosophy and it’s one I’m really pleased to have learned from other people in the movement who I’ve been fortunate to have as mentors over the years, people like Steve Eidelman, Nancy Thaler, and many others.

You served as one of President Obama’s appointees and as a consultant for the [American Civil Liberties Union \(ACLU\)](#), among many other national organizations throughout the years. How did you begin working with national organizations?

I ran ASAN for 10 years and I had a desire to do something else, to explore a new adventure after that. I actually thought that when I left ASAN that I’d go straight to grad school, but then the 2016 election happened and I was very concerned about the prospect of dramatic cuts to Medicaid and rolling back of public services that people with disabilities depended on. So, I approached the ACLU and made the case that there was a need for a larger community of liberal advocacy groups to come to the table to defend disability rights in a more comprehensive way. I ended up going to work for them from the beginning of the Trump administration to the beginning of COVID-19, where we did a lot of work to push back against the Trump administration’s efforts to slash Medicaid. We did work to reauthorize [Money Follows the Person](#). We also did some work on challenging medical discrimination against people with disabilities.

The reason I ended up leaving the ACLU was that I shifted to working as a consultant with the [Department of Health and Human Services \(HHS\)](#). I’ve had the pleasure of working with a really fantastic team over there to develop the recently issued [Section 504 regulations](#) that were just finalized by HHS which put forward a really comprehensive vision for addressing healthcare discrimination against people with disabilities, as well as discrimination against parents with disabilities by child welfare agencies and family court systems, and a whole host of other issues within HHS’s purview.

I believe we need to see the values and knowledge base that we’ve built up in the disability rights movement translated into larger organizations that stretch beyond disability, whether that comes in the form of groups like the ACLU or the [Service Employees International Union \(SEIU\)](#), which I’ve been consulting with to help them build a coalition of disability and labor organizations to challenge the exclusion of people with disabilities from the protections of the [National Labor Relations Act](#). In programs like [Ability One](#) and other “set aside” programs that predominantly hire workers with disabilities, employers have often asserted that they’re not covered by the National Labor Relations Act and basically say, ‘well, we may be hiring them and paying them, but they’re actually clients in a program rather than workers working for an employer,’ and there’s some unfortunate legal precedents that have enabled them to do that. I’m proud to have worked with SEIU and a variety of disability groups and labor groups that they brought together to try and challenge that. Just as we’re fighting for people with disabilities to have the same rights under wage law, we should also be fighting for people with disabilities to have the same rights under other aspects of labor law.



Whether we're talking about the ACLU or the SEIU or larger agencies of government like Health and Human Services, there's a real value in taking the insights and expertise that we've incubated in the disability rights movement and bringing them into these larger contexts.

Why do you think it's important to work with national organizations?

It's important because public policy is heavily influenced at the national level, but there's also a lot of value in working with states and local organizations. In fact, I think a big problem that the disability rights movement has right now is that we're a little too top heavy. I actually think that if people are coming up in the movement now and are wondering, 'Where can I do the most good?' it's not necessarily going to D.C. or getting involved with national advocacy. We desperately need more people orienting towards state legislatures right now where there's a lot of opportunity for positive influence. The common thing for me over the last six or seven years has been to try and bring disability into non-disability spaces. There's value in both state and national advocacy. And I actually believe the movement needs to do more to be investing at the state level right now.

In terms of investing in states, I've recently been working with the [Inclusa Foundation](#), and it was really natural to recommend that we reach out to the National Leadership Consortium when it became apparent that we wanted to invest in Wisconsin's Long Term Services and Supports (LTSS) ecosystem. Because ultimately, the work the National Leadership Consortium does is so important precisely because it's building cohorts of leaders that can drive systems change, including among providers at the state and local level. In the absence of the pipeline of provider leaders that the National Leadership Consortium helps produce, public policy makers are limited in their ability to make a change. I'm excited by the investment the Inclusa Foundation is making in the National Leadership Consortium [coming to Wisconsin](#). It has the potential for a large impact. And similar programs like that should be actively considered by funders at the state level wishing to make a long-term investment in positive systems change in their communities.

You recently earned your Ph.D. in Health Policy. How do you hope this new degree will contribute to your future advocacy work?

Well, I really transitioned from a primary role as an advocate to a primary role as a researcher. Obviously, researchers inform advocacy, but my primary identity is as a disability policy and health services researcher. As of July first, I started a faculty appointment as an Assistant Professor in the Department of Health Policy and Management at the Harvard School of Public Health. Harvard is a fantastic place to make an impact and to influence the next generation policy makers. I hope to try and bring information and values from the world of disability into this new setting as well. I'm quite excited about the new role.

Can you describe something that was helpful to you in your journey as an advocate or in your journey as a public policy and health researcher?

People with disabilities don't live siloed lives. We set policy and we do research in siloed contexts, but there's a profound need to think more broadly. In one of my dissertation papers, I looked at how Medicaid expansion and expansion of health insurance impacted disability benefits enrollment. In another, I looked at how Medicaid managed care impacted employment for people with developmental disabilities. And you might say that these are connecting different areas because one is about health insurance, the other is about income support, and the other about employment, but actually in people's lives they're experiencing this as part of a holistic whole. If your health insurance is paying for

your supported employment provider, as Medicaid typically does when they are the primary payers for supported employment services, then a disruption to Medicaid impacts your likelihood of remaining employed. When we think across systems it better positions us to make an impact on people's lives.

What advice would you give to professionals that would help them support people with disabilities to become stronger as self-advocates?

The impression many people have is that self-advocacy is something that has to involve a very sophisticated approach or talking to legislators or policymakers. And while it's certainly true that we need people to talk to legislators and policymakers, self-advocacy is simply expressing one's own needs and desires. You can self-advocate without being able to talk. You can self-advocate in ways that are read as simple 'behavior' on the part of people around you. We need to do better about respecting those more everyday forms of self-advocacy rather than thinking advocacy and autonomy are only for people who can talk or who don't have an intellectual disability or anything of that nature. I would argue that self-advocacy is most important, and acknowledging and respecting self-advocacy is most important, when it comes to people with the most significant and complex impairments. So, the advice I would give to support professionals, first and foremost, is to recognize and respect the self-advocacy of the people that you're supporting, even when they are quite different from the people who tend to go to a legislator or a legislative meeting or participate in the advocacy coalition.

What advice would you give someone who is wanting to transition from self-advocacy to become involved in larger systems change efforts?

I believe in an ethic of responsibility, which is to say it's not useful or productive to be impotently railing at injustice without a practical strategy for changing it. The moment you make the switch from advocating on your own behalf to trying to advocate for a community you have to hold yourself accountable, not just for being right, although that's also quite important, but also for being effective. And the truth is that people with disabilities, especially people with developmental disabilities, face grave dangers in terms of isolation, segregation, deprivation, of autonomy and basic rights. We need to figure out ways to move the needle to try and address those dangers and to try and empower people to have the rights and inclusion that everyone deserves. So, if you are making a switch from just advocating for yourself to advocating for others, The first question you have to ask yourself is, 'How can I develop the skills, and what skills am I going to invest in developing, for my advocacy to actually be effective?' People may sometimes think that the most important thing in being an advocate is to be right about what society should do. But if you're right and you're not actually changing society, you are not doing the job.

What are some current key policy changes that you're interested in watching develop?

The transition to non-congregate service provision, which has been the major story of developmental disability services over the last several decades, remains crucial. For a very long time, we brought people out of large buildings where someone else controlled every aspect of their life and told them what to do for every hour of the day and moved them to small buildings where someone else controlled every aspect of their life and told them what to do for every hour of the day. And now we're recognizing that moving someone from an institution to a group home is really only the first step in the process. Very frequently, group homes just function as small institutions.

We don't necessarily know what the service system will look like in the next 20 or 30 years, but a big part of where we need to go is the growing separation of real estate and service provision and the growing shift to non-congregate and scattered site models that truly integrate people into the community. If you live in a group home where your provider owns the place you live in, if you want to fire your provider then you need to find a new place to live. That creates a very high bar for addressing any kind of serious quality issue, even those that are about fundamental rights and dignity or even safety. Imagine if in order to change grocery stores or dry cleaners you had to find a new house or apartment—you would put up with a lot from your grocery store and dry cleaner before doing that. All the more so when it comes to the more intimate types of service provision that people with disabilities receive for which it's often very difficult to find a replacement. Now, if you are living in independent housing, a home or apartment that either you own or that you lease through a lease rental agreement that's with you and not with your provider, and you want to fire your provider and replace them, then *they* leave. And so there's a much greater capacity to exit abusive or simply unsatisfactory provider relationships.

Some people talk about the shift away from provider owned housing as this radical concept, and in the sense that it changes the model we've relied on in developmental disability service provision for a long time, it is. But I actually see it as something quite distinct from radicalism. I see it as the opportunity to unleash the quality improvement potential of market forces in developmental disability service provision. Americans have tended to be very enthusiastic about the free market for a long time. The free market requires the ability to say, 'No, I don't like that service or that provider. I'm going to go somewhere else.'

Separating out real estate and service provision is a crucial component to allowing market forces to promote quality in some meaningful way, with respect to developmental disability service provision. If you are in a group home and you do not want to have to find a new place to live, then you are stuck with your provider; you do not have access to a market. If you are in your own home or apartment, you can fire that provider and bring in a better one and the cost of doing that is dramatically lower for you than it is for someone who has to change houses to change providers.

Ari Ne'eman is an Assistant Professor of Health Policy and Management at the Harvard T.H. Chan School of Public Health. He holds a PhD from Harvard University. He previously served as executive director of the Autistic Self Advocacy Network and as one of President Obama's appointees to the National Council on Disability. Contact Ari at aneeman@hsph.harvard.edu



Expert Q&A: Grassroots Organizing, Systems Change Advocacy, and Activism

An Interview with Priya Penner, longtime activist, advocate, and disability rights/justice consultant

- Using a Disability Justice framework can help lead to more effective and ethical organizing.
- A Disability Justice framework involves understanding and listening to the people who are most impacted by an issue and asking whose voices are missing or excluded from advocacy efforts.
- A Disability Justice framework can and should be applied to all social issues, including issues like climate change.
- Many skills are important when working towards systems change including the ability to pivot, clearly identifying the issue, and listening to those who are most impacted by an issue.

What is The Partnership for Inclusive Disaster Strategies and what is your role with the organization?

I work for the [Partnership for Inclusive Disasters Strategies](#), also known as the Partnership. We are the only U.S.-based, disability-led organization that focuses on the rights, needs and equity for people with disabilities and older adults, before, during, and after disasters. What that really means is that we serve as the nation's disability and disaster hub. I like to say that if it relates to disability in disasters in any capacity, it's up our alley and we are involved in some way. We support local communities in responding to disasters. For example, we are supporting a local Center for Independent Living in Maui after the wildfires to help them get what they need to get the job done on the ground.

We also have our [Disability and Disaster Hotline](#) to support disabled disaster survivors directly. Our hotline is for people with disabilities or family members to call in (or email) with any sort of issues. We get a lot of folks who are struggling with housing after disasters strike. Other needs in the short term include things like food and water. Then, in the longer term we support them with FEMA applications and things of the like.

We also do systems advocacy and work with our federal partners, like FEMA, the Department of Homeland Security, Civil Rights and Civil Liberties, and the Administration for Community Living. So, we work with our federal and local partners to support system change advocacy. You can find an example of that work on the [heat.gov](#) website. Originally, it had a section on who is most impacted by heat related occurrences but people with disabilities were left off entirely. We advocated, created a letter around that and with the support from our community, it was resolved quickly. Other larger things, for example, include FEMA individual assistance reforms; but the list goes on and on.

My current role does a little of almost everything. I do hotline support when needed. I do a lot of administrative support, training, and technical assistance in any capacity. The training and technical assistance involves us working with other organizations, for instance Independent Living Centers, to build their capacity in responding to disasters and disaster preparedness. We do a lot of intersectionality-based work and focus on the intersections of disability and disaster for multiple marginalized folks. I do content creation for the training and websites and help with language access and ensuring with have ASL interpreters.

Is this your first role working with grassroots organizing around disability justice issues?

No, this is not my first foray into disability rights-based organizing. I started organizing when I was 14 or 15 and got involved in grassroots organizing with [ADAPT](#), a national grassroots, civil disobedience organization. That was where I got my crash course in disability rights and grassroots organizing. There I did a lot of media messaging work and was involved in logistics. From there I got involved in the local Center for Independent Living and organizing on the local level. When I got into college, I did a significant amount of organizing in college on campuses with other disabled disability justice-oriented folks. That's really where I shifted from disability rights to disability justice. That would be my real first foray into organizing a Disability Justice framework.

How do you define Disability Justice?

Oh wow. I don't know if I have a clear succinct definition. I, of course, go back to [Sin's Invalid's principles](#) on their website. They really talk about what disability justice means, but they don't say, 'Disability justice is this—period.' They don't say how they describe disability justice as the end all be all. They talk about disability justice as a framework. No one person or entity is going to have all the answers but using the framework of the [10 principles](#) to understand what is disability justice is going to continue the movement of disability justice. Something a Disability Justice framework does that disability rights frameworks don't always do is prioritize the experiences and expertise of folks who are most impacted. That, of course, is one of the principles. The focus is centering the experiences of multi-marginalized disabled folks. It really shifts our understanding of disability rights and organizing in any capacity whether it's racial justice, whether it's prison reform, whether it's climate justice, etc. By having this Disability Justice framework, it really changes the lens in which we do all our work around any issue.

When we talk about disability justice versus disability rights, we're really talking about that shift from perhaps people who are more privileged to those who are most impacted. When we talk about Disability Justice, it's a framework, it's a strategy, it's a continuation of disability rights in a way to meaningfully focus our efforts so that no one is falling through those cracks. It's not an end point. I mean, for crying out loud, the Disability Justice framework principles include collective liberation, right? It's an end goal, but also how are we going to get there from here? Currently there is a lot of space between where we are and collective liberation.

What do you see as some of the current most pressing policy issues or opportunities related to disability justice at this current moment in time?

I want to shift the framework of this question because that implies that there are specific policy issues or topics that disability justice is involved in and therefore there are other topics and issues that disability justice isn't. The Disability Justice framework needs to be applied to every policy issue. If a Disability Justice framework is not applied to a policy issue, any policy issue, we are inherently excluding a significant portion of our communities. I think this also then begs the question of who is setting these policy issues. I don't think that's really for one person to say. I think it's the community and again we as a community are involved in all pieces of the pie and all aspects of society.

What do you see as some of the most important skills needed to effectively and ethically work for community and systems change and/or engage in grassroots organizing?

The first thing is one that comes sort of naturally to a lot of disabled folks given how we just must interact with the world the ability to pivot to problem solve. You need to understand that this is the goal, but a lot may have to change in the chain to get to the goal. To get from A to Z a lot may need to change from A to B. So being able to recognize when something isn't working, then realize we need to change it up. I think that is a core skill set for any organizer in general.

I think another important skill set for organizing effectively is to really be able to get to the heart of the issue. I think a lot of times in any organizing people will say, 'This is the issue...' but the issue is slightly different. That slight difference is important to how you get at and develop strategies to solve the problem. The strategies may be dependent on how you are framing the issue and if that frame is accurate, it will also impact how you are communicating the issue.

Speaking of effectively and ethically, at its core and at its best, disability justice gets at some of those ethical concerns. Using a Disability Justice framework in your work and really using it as opposed to just saying you are using it means you are engaging in those principles which are necessary for ethical work. We are all human and part of doing systems change work ethically, is being real.

What are some challenges that leaders of disability service organizations who may or may not have disabilities themselves should consider when they become more engaged in system or community change efforts?

I think this goes back to a question of allyship, especially when talking about folks who may not identify as disabled themselves. Speaking specifically to folks who are non-disabled, who are service providers in some capacity, taking that step back is important. This is what I would say to anyone looking to be an ally and involved in any space where they're not necessarily directly part of the community: you're new to this space. There are folks who have been doing the work. Taking that step back will allow you to listen to what's happening around you and learn from the marginalized community members, the disabled person or the multi-marginalized disabled person.

When you are coming into a new space, you need to recognize that you're not as experienced in this area and need to learn from others first. Disabled folks are subject matter experts. We are community organizers. We are leaders.

I think some pitfalls and challenges I've experienced from folks coming into organizing spaces who may be providers who aren't familiar and aren't committed to learning can derail the messaging sometimes. If you're not advocating for the for the right needs, you could actively be harming our community because you're advocating for something that's not truly helpful. I think just taking that step back and listening, especially to disabled folks who are multi-marginalized. For example, looking for non-White leaders to uplift, looking for non-cis leaders to uplift, and looking for non-speaking leaders. It's important to always ask, 'Who isn't in this space?'

What brings you hope as you continue your advocacy work, especially in relation to disability justice or with the organization that you're working with now?

I think that's a question that we all need to be asking ourselves regularly: 'What brings us joy when we do this work?' because this work is so thankless sometimes, if we are being real about it. I think what brings me joy and hope for this work is working with who I can work with. I mean that in a few different ways. One is my immediate team at the Partnership. Being able to do the work that we do, the way that we do it, and being funded for it as my job is just astounding to me. I don't know if this would have been able to happen 10 years ago. As devastating as it is as we keep learning about what is happening in Gaza and the Congo and around the world, we're in this moment where the problems are not going to be fixed, but people are recognizing the need. That is unique and very important.

Also being able to work with the amazing humans that are doing disability justice work nationally and globally who are these incredible thought leaders, who constantly challenge me every single day to continue to be better is just amazing. I am inspired so much by my colleagues, my comrades, my siblings, and to be able to say I can share space with them brings me so much joy.

As an almost second generation of folks brought up with the ADA, recognizing how far we have come, in addition to being able to work with the people that I work with, to be alongside the thought leaders I've been able to be alongside of, is also recognizing that we are making progress. It feels so small, and it feels so scary because it can all come collapsing down on top of us, but we're making progress. The work that we're doing is meaningful and we as individuals have an impact. Even if it is that day-to-day impact. I think it's tough to stay positive. I would never tell anyone that they have to be positive about these things because the world is on fire. But the amount of caring and love and strategy and brilliance and all of it is there too. We are and we will continue to be better.

Is there any advice that you would give to people who are just becoming more involved in grass grassroots organizing or systems change work?

I think it's being ready to mess up and willing to learn how are you going to fix that. This work is messy, and we are not going to be perfect. It's an ideal we can all work towards. Be real and be intentional with that process and be transparent about it.

Priya Penner is a longtime activist, advocate, and disability rights/justice consultant. She joined [The Partnership for Inclusive Disaster Strategies](#) as their Executive Assistant in 2020 to help ensure multiply marginalized communities are heard within the disaster response and recovery field. Contact Priya at priya@disasterstrategies.org.



A Career Searching for Sustainable Practices for Cross-System Collaboration

By Stacy Nonnemacher

- Collaboration across people and systems is required to ensure that people with co-occurring conditions get what they need when they need it.
- The Link Center is an example of organizations working together towards a common goal.
- It is critical to plan for collaboration to make sure people are supported holistically.

Reflections on Barriers to Collaboration

Over 25 years ago, I started my career supporting people with disabilities as a job coach. Although I was certified as a Special Education teacher, I realized quickly that supporting adults was important and was my purpose. As I continued to support adults in their homes, their communities, and their places of employment, I understood that to support someone holistically, it required many people and many systems to engage and collaborate. When the opportunity to take this experience to state government presented itself, I enthusiastically accepted. As a clinical director in a state intellectual/developmental disabilities (IDD) agency, many barriers threatened our ability to bring people and systems together that was desperately needed especially for people who presented with complex support needs including:

- 1 Systems focus on determining “primary diagnoses” and not viewing the person as a multi-dimensional human being.
- 2 Systems are not willing to build relationships, resulting in mistrusting the intentions of any attempts to engage and collaborate.
- 3 Policies and systems that did not support practices that are effective in supporting people with complex support needs.
- 4 Systems not understanding other system’s eligibility requirements, waivers, services, and supports.
- 5 Biases and misunderstandings that some people cannot have mental health needs and/or would not benefit from mental health treatment.

These barriers not only frustrated me and those who were seeking to get someone the support they needed but also perpetuated the cycle of diagnostic overshadowing or not seeing potential co-occurring conditions or diagnoses, thus pushing people into one system instead of supporting the whole person.

A Federal Example of Cross-System Collaboration

Fast forward years later and [The Administration for Community Living](#) (ACL) responded to what was not only my frustration but also the frustrations of so many others trying their best to navigate cross-system strategies to support people with complex support needs. ACL brought together associations and organizations to achieve a common goal: to bridge IDD, brain injury (BI), and other cognitive disabilities systems with mental health systems. The National Association of State Directors of Developmental Disabilities Services (NASDDDS), the Association for Persons with Intellectual Disabilities and Mental Health Conditions (NADD), the National Association of State Mental Health Program Directors (NASMHPD), and the National Association of State Head Injury Administrators (NASHIA) were charged with creating [The Link Center](#), a national resource and technical assistance hub designed to address the disparity in access to

comprehensive, community-based, mental health services for persons with IDD, BI, and other cognitive and communication differences. Guided by a steering committee of 14 people with lived experience, the partnership of these four key organizations and other advocacy and university allies has created:

- 1 A commitment to common goals of systems changes, capacity building, and increasing service access.
- 2 A collaboration of pooling respective expertise towards common goals.
- 3 Opportunities for learning and expanding our collective understanding of how best to support people with co-occurring conditions.
- 4 Most importantly, a process by which people with lived experience and thought leaders guide the work and activities to achieve the goals of The Link Center.

The Map to Finding Sustainable Practices for Cross-System Collaboration

Through examples of partnerships like those created through The Link Center, others who are searching for ways to better collaborate across systems should feel encouraged and motivated. As a former clinical director and direct supporter, I know that seeing federal entities engage towards common goals that directly impact people would be incredibly inspiring to persevere at the local level despite any current barriers. But, beyond motivation and inspiration, we need to make concerted efforts to collaborate to get people what they need and not just what is available from one system that may be willing to support them. We can take a lesson from the business field to purposefully endorse “[collaboration-friendly environments](#)” by ensuring:

- 1 **Diversity:** make certain the table isn’t filled with only like-minded people, but people who represent different perspectives and opinions that should be considered and heard.
- 2 **Equality:** give each idea, opinion, or perspective equal weight and refrain from autocratic decision-making.
- 3 **Energy:** maintain a high level of engagement and interaction where emotional engagement drives the team.
- 4 **Mobilization:** develop an action plan that is grounded in questions and expected outcomes identifying accountable persons.

Collaboration is required to ensure people with co-occurring conditions get what they need when they need it. Examining what effective partnerships look like and how they accomplish their goals is critical. Furthermore, systematically structuring what collaboration-friendly decision-making should look like to ensure that people get what they need should be a priority for systems that support people with IDD, BI, other cognitive disabilities, and co-occurring mental health conditions. We have proven, and I have experienced, that no one system can do this alone.

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How the National Center on Advancing Person-Centered Practices and Systems (NCAPPS) Promotes Systems Change

A Q&A with Bevin Croft and Saska Rajcevic, Co-Directors of the National Center on Advancing Person-Centered Practices and Systems at the Human Services Research Institute

- NCAPPS is an initiative that helps government agencies make their systems more person-centered.
- NCAPPS brings together teams of people who care about person-centered practices to collaborate and learn from each other.
- Meaningful systems change takes time and commitment. We still have a long way to go to make systems more person-centered.

Can you describe NCAPPS and the work you do?

The [National Center on Advancing Person-Centered Practices and Systems \(NCAPPS\)](#) is an initiative supported by the [Administration for Community Living \(ACL\)](#) and the [Centers for Medicare & Medicaid Services \(CMS\)](#). NCAPPS helps states, tribes, and territories implement person-centered thinking, planning, and practices. It is administered and staffed by the [Human Services Research Institute \(HSRI\)](#).

The goal of NCAPPS is to promote systems change that makes person-centered principles not just an aspiration but a reality for people with disabilities and older adults who use long-term services and supports. At NCAPPS, we work to promote person-centered thinking, planning, and practice:

- **Person-centered thinking** focuses language, values, and actions toward respecting the views of the person and their loved ones. It emphasizes quality of life, well-being, and informed choice.
- **Person-centered planning** is directed by the person with helpers they choose. It is a way to learn about the choices and interests that make up a good life and identify the supports (paid and unpaid) needed to achieve it.
- **Person-centered practices** are present when people have the full benefit of community living and supports are designed to assist people as they work toward their desired life goals.



We operationalize and help implement these ideas through a few different activities. We convene Learning Collaboratives (more about those later), provide in-depth technical assistance, conduct webinars open to the public, and develop many different kinds of resources. You can access these resources and webinars on our website at: <https://ncapps.acl.gov/>

Can you describe the NCAPPS Learning Collaboratives and the goals of that initiative?

One of the greatest strengths of NCAPPS is our wonderful network of people with disabilities and their allies, advocates, providers, and government agency staff who share a passion for person-centered practices. Since 2020, we have hosted Learning Collaboratives that bring teams of people together along with national experts to learn from one another about specific topics. Topics have included:

- **Person-centered services for people with brain injury.** 16 teams from 15 states came together to explore strategies to make community-based services for people with brain injury more person-centered. The strategies were: 1) Engaging people with lived experience in self-advocacy and systems change, 2) Incorporating and improving person-centered needs identification, 3) Establishing person-centered planning best practice, 4) Improving and expanding person-centered services and supports.
- **Self-direction.** 22 teams from 16 states explored specific systems change efforts focused on the global aim of enhancing the availability, quality, and access to self-direction. Each team chose one or more focus areas to pursue including: disseminating information regarding self-direction, its benefits and how it works; developing self-direction policies and procedures that are equitable, transparent, flexible, and easily understood and implemented; enhancing infrastructure to support self-direction; and recruiting and training Direct Support Professionals, support brokers, and peer mentors to support self-direction.
- **Racial equity (two cohorts).** We partnered with colleagues at the Georgetown University National Center for Cultural Competence (NCCC) to foster space for those interested in understanding and implementing antiracist principles and practices in human service systems. The first round had 30 participants, and the second round had 48 participants. Participants engaged in self-reflection to develop a deep understanding of how each of us can promote racial equity within human service systems. Activities included a shared reading of Ibram X. Kendi's book [How to Be an AntiRacist](#), and self-reflection experiences designed to apply antiracist concepts to our roles in human service systems.
- **"Beyond Compliance" for leadership.** In partnership with colleagues at Support Development Associates (SDA), NCAPPS created a learning opportunity for 39 human service administrators and leaders in advocacy and provider organizations across 16 states to build capacity to lead change towards more person-centered approaches. In more than 10 sessions, participants were introduced to the [9 Elements of a Person-Centered System](#).

Currently we are facilitating two new Learning Collaboratives. One is focused on minimizing rights restrictions in home and community-based service settings, and another explores person-centered practices for older adult nutrition services.

What makes NCAPPS innovative?

Members of the NCAPPS team received training from the [Institute for Healthcare Improvement](#) on the [Breakthrough Series Collaborative](#), a model that incorporates quality improvement and data measurement. We adapted this model to meet the needs of the NCAPPS network. One adaptation is the incorporation of time and space for Learning Collaborative members with lived experience to come together to share experiences, provide support, and advocate for their priorities within the Learning Collaborative structure.

Another innovative feature of the NCAPPS Learning Collaboratives is our strong focus on quality improvement. All team members learn about the [Model for Improvement](#) to test out new ideas. They begin with a global aim and a framework developed by a panel of experts based on the topic. The aim is the main idea that everyone is committed to. The framework then includes detailed strategies to help reach that goal. Teams learn the framework and then develop their own local aim based on the global aim. They select specific strategies from the framework to implement and test, along with measures that will help them to know if what they're doing is leading to the desired results. Between the Learning Sessions, the teams conduct 'tests' using [Plan-Do-Study-Act](#). Teams report data on their progress back to NCAPPS to support ongoing learning and understanding. In later Learning Sessions, teams identify strategies for longer-term sustainability of systems change efforts. The Learning Collaboratives culminate in a summit where teams share what they've accomplished with one another.



How did the idea for NCAPPS come to be?

In the past 30-plus years, the support systems for older adults and people with disabilities have changed dramatically. The delivery of support has shifted increasingly to community-based supports options. At the same time, policy, financing, and the interplay between clinical, acute care, and long-term support and service often creates a complex and sometimes incomplete array of available services for those who need support. In the design and implementation of systems of support, leaders have struggled to consistently put person-centered values and practices at the foundation. NCAPPS was established to be a resource for systems to make the shift from being system-centered to being person-centered. NCAPPS was designed to address these needs by supporting broader development of best practices and conceptualization of person-centered systems designs in state programs. This is not an easy process, but we are glad to have built a community of people who are working toward this goal every day.

If NCAPPS reaches its goals, what will the impact be on the lives of people with disabilities and the community?

It's our goal that person-centered practices will be the standard across all government agencies that oversee services and supports for older adults and people with disabilities. If systems are truly person-centered, then people will have the services and supports that they need to live the lives they want to live. We're a long way from reaching that goal, but we're proud to provide space for champions of person-centered practice to come together to share, learn, and keep one another motivated.

What else should professionals in the disability field know about NCAPPS or getting involved in cross-systems efforts in general?

We are always glad to grow our network! You can sign up for the NCAPPS newsletter which goes out about twice per month by sending an email with "subscribe" in the subject line to ncapps@hsri.org.

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Answering the Call to Action: Systemic Change Toward Developing a Disability Competent Health Care Workforce

By Cory Gilden

- Systemic change is needed in the health care field to ensure that people with disabilities get quality health care.
- More training about disabilities needs to be added to current training and accreditation programs to create systemic change in the way health care professionals deliver services.
- All professionals supporting people with disabilities, even those not in health care, should know what defines quality health care so they can make sure the people they support are treated well.

System change is more likely to be successful with a concrete structure and when key stakeholders are involved. One example of this can be found in recent efforts to update health care education and training programs to include disability content and experiences to improve the quality of health care for people with disabilities.

What Does the Research Say?

[An article](#) published in *Disability and Health Journal* in 2020 asserts that because people with disabilities have higher rates of chronic health conditions and poorer access to health care than the general population, the health care field needs to become better prepared to handle their needs. The article discusses gaps in health education, continuing education curricula, and document barriers to progress. Authors suggest that the competency of health care professionals can be increased by strengthening their knowledge, skills, and behaviors through more training, more robust evaluation protocols, and with different delivery models and incentive structures. Authors propose that training be centered on the [Core Competencies on Disability for Health Care Education](#) developed by the [Alliance for Disability in Health Care Education](#), which explains six competencies related to health care for people with disabilities:

- 1 **Contextual and Conceptual Frameworks on Disability:** Acquire a conceptual framework of disability in the context of human diversity, the lifespan, wellness, injury, and social and cultural environments
- 2 **Professionalism and Patient-Centered Care:** Demonstrate mastery of general principles of professionalism, communication, respect for patients, and recognizing optimal health and quality of life from the patient's perspective
- 3 **Legal Obligations and Responsibilities for Caring for Patients with Disabilities:** Understand and identify legal requirements for providing health care in a manner that is, at minimum, consistent with federal laws such as the Americans with Disabilities Act (ADA), Rehabilitation Act, and Social Security Act to meet the individual needs of people with disabilities

- 4 **Teams and Systems-Based Practice:** Engage and collaborate with team members within and outside their own discipline to provide high-quality, interprofessional team-based health care to people with disabilities
- 5 **Competency:** Collect and interpret relevant information about the health and function of patients with disabilities to engage patients in creating a plan of care that includes essential and optimal services and supports
- 6 **Clinical Care Over the Lifespan and During Transitions:** Knowledgeable about effective strategies to engage patients with disabilities in creating a coordinated plan of care with needed services and supports.

The authors suggest that combining these [Core Competencies](#) with the [Disability-Competent Care model](#) developed by the [Centers for Medicare & Medicaid Services' Medicare-Medicaid Coordination Office](#) offers an organizing structure to inform health care training programs. The Disability-Competent Care model has three core values:

- 1 **Participant-Centered Approach:** Recognizes the participants' preferences, goals, and choices that provide the foundation for their individualized plan of care
- 2 **Respect for the Participant's Choice and the Dignity of Risk:** Honors and respects the participant's choices even if they are inconsistent with health care recommendations
- 3 **Elimination of Medical or Institutional Bias:** Bias may impede providers and plans from addressing the individual as a whole. Biases may include unique disabilities, limitations, and preferences for social and community participation

Together, the article argues, new disability content being required for accreditation of all health care training programs, evaluating disability competence as a criterion for promotion and graduation of health care training programs, licensure boards requiring disability competency for attaining and maintaining professional license, and innovative incentive structures and integrated care can bring about systemic change toward quality health care for people with disabilities.

What Does It Mean for Our Field?

While this article issues a call to action focused on improving health care education, practices, and research to strengthen the competency of health care workforce, there are many ways non-medical professionals supporting people with disabilities can contribute. Systems change often takes time to grow roots. Even after new training, accreditation, and incentives are set in place, it will take a lot of work to undo medical, institutional, and personal bias in professionals, and it will take a lot of working with people with disabilities for medical professionals to develop their comfort levels and competencies.

To help medical professionals strengthen their disability competency, service providers in the disability field can serve as examples in the Core Competencies, since they are already doing things like centering goals around the person, working collaboratively with other team members, and thinking of the person's care across their lifespan in their daily support of people with disabilities. Additionally, frontline staff know the person they support well and



have knowledge about their cultures, preferences, social capabilities, health status, and other useful information that will be critical to health care professionals to provide competent and respectful care. The communication and interactions between frontline service providers and health care professionals is essential to quality health care.

What Can I Do? What Does It Mean for Me?

[Resources for Integrated Care](#) is a website that provides technical assistance products and webinars for health providers and health plans. While the site is primarily designed for the integration of services for those who utilize both Medicare and Medicaid, the resources and tools on this site can help all service providers, medical or otherwise, ensure that appropriate services and supports are being provided.

The [Disability-Competent Care Self-Assessment Tool](#) and the [Disability-Competent Care Self-Paced Training Assessment Review Tool](#) are designed to help health care organizations evaluate their current ability to meet the needs of participants and identify strategic opportunities for improvement. It is also important for service providers assisting people with disabilities at their medical appointments to be familiar with these standards so they can help safeguard the rights of the people they are supporting to receive quality health care. If something in the self-assessment tool is not being done, then a DSP or service provider staff may step in and suggest a change. For example, the assessment has questions related to participant engagement such as, “Do participants play an active role in their own assessment and care planning?” and “Does the care management staff develop an individualized, professional relationships with the participant, showing respect for the participant’s preferences and choices?” If the person they support is not engaged in the process appropriately, then the DSP can help redirect the medical professional to encourage engagement with the person with disabilities.

For systemic change toward more person-centered processes, including health care, it will take the combination of a solid structure and plan and the involvement of key stakeholders, including people with disabilities and the people who support them, to make it a success.

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.



Strategic Communication in Systems Change Advocacy: A Guide to Effective Practices

By Emmanuel Jenkins

- Clear and effective communication is important in advocacy work.
- Communicating a vision and message involves knowing the core message, defining the long-term goals you are aiming for, tailoring the message for different people, and using stories and data to argue your points.
- Strong communication involves knowing how to get a message across using stories and data, using different ways of communicating to bring groups together for a common goal, and knowing different communication styles.

Effective communication is the cornerstone of successful systems change advocacy, particularly when advocating for people with disabilities. This process involves articulating a clear vision, uniting diverse groups, and ensuring that all stakeholders, including individuals with disabilities and their families, understand and support the cause. Strategic communication requires a blend of specific skills and an understanding of various communication styles, making it vital for advocates aiming to create meaningful and lasting change.

Communicating a Vision and Message Effectively

To advocate for systems change, it is crucial to start with a well-defined core message and vision. This message should encapsulate the goals and values of the advocacy efforts, providing a clear and compelling narrative that resonates with a broad audience. Here are some steps to develop and communicate your message effectively:

- 1 **Identify the Core Message:** Determine the key points that you want to convey. This message should be concise, memorable, and reflect the essence of your advocacy. For example, if advocating for better accessibility in public spaces, your core message might be, “Equal Access for All.”
- 2 **Define the Vision:** Your vision should outline the long-term goals and the positive changes you aim to achieve. It should inspire and motivate stakeholders by presenting a hopeful and achievable future.
- 3 **Tailor the Message:** Adapt your core message to suit different audiences without diluting its essence. This ensures that the message is relevant and impactful for each group you address.
- 4 **Use Stories and Data:** Combine emotional stories with statistical evidence to create a compelling argument. Personal stories can humanize the issue, while data provides credibility.

Using Communication to Unite People and Groups

Building a coalition of supporters is essential for successful advocacy. Effective communication can bridge gaps and foster a sense of shared purpose among diverse groups. Here's how to do it:

- **Engage in Active Listening:** Show genuine interest in the perspectives and concerns of different groups. This builds trust and demonstrates that their input is valued.
- **Facilitate Open Dialogue:** Create platforms for open discussion where all voices can be heard. This could be through town hall meetings, social media forums, or workshops.
- **Highlight Common Goals:** Focus on shared objectives and values to unite groups. Even if they have different primary interests, identifying common ground can help forge a stronger coalition.
- **Communicate Regularly:** Keep stakeholders informed and engaged with consistent updates on progress and setbacks. Transparency fosters trust and a sense of collective ownership.



The Vital Role of Communication in Systems Advocacy for People with Disabilities

In the realm of disability advocacy, clear and effective communication is paramount. It ensures that individuals with disabilities and their families are fully informed and can actively participate in advocacy efforts. Here's why it is critical:

- **Accessibility:** Information must be accessible to people with different disabilities. This includes providing materials in various formats such as braille, large print, audio, and easy-to-read versions.
- **Clarity and Simplicity:** Use straightforward language and avoid jargon. Complex information should be broken down into manageable parts to ensure understanding.
- **Cultural Competence:** Understanding and respecting the cultural backgrounds of your audience enhances communication. Tailor messages to reflect cultural sensitivities and preferences.

Communication Styles and Their Importance

Understanding different communication styles is essential for effective advocacy. Here are several types:

- **Assertive Communication:** This style is clear, direct, and respectful. It's effective for making your needs and opinions known without alienating others.
- **Empathetic Communication:** This involves active listening and showing understanding and compassion. It's crucial when dealing with sensitive issues, as it builds trust and rapport.
- **Nonverbal Communication:** Body language, facial expressions, and gestures can reinforce or undermine your message. Ensure your nonverbal cues align with your spoken words.
- **Collaborative Communication:** This encourages input and feedback from all stakeholders, fostering a sense of inclusion and shared responsibility.

The Role of Leadership in Advocacy

Effective leadership is vital in systems change advocacy, particularly when working with individuals with disabilities. Leaders must be mindful of:

- **Inclusivity:** Ensuring that people with disabilities are included in decision-making processes. Their insights and experiences are invaluable for shaping effective advocacy strategies.
- **Empathy:** Demonstrating genuine understanding and concern for the challenges faced by people with disabilities. This builds credibility and trust.
- **Adaptability:** Being willing to adjust strategies based on feedback and changing circumstances. Flexibility is key to overcoming obstacles as they arise and achieving goals.

Strategic communication in systems change advocacy is a multifaceted skill that requires clarity, inclusivity, and cultural competence. By effectively communicating a clear vision, uniting diverse groups, and ensuring accessibility and understanding, advocates can drive meaningful change for people with disabilities. Emphasizing different communication styles and strong leadership further enhances these efforts, making the advocacy process more robust and impactful.

Emmanuel Jenkins is the Founder of *We Stand 4 Something* and a motivational speaker. Contact Emmanuel at ejenkins@westand4something.org.



Hope and Trust: Essential Skills in Systems Change Leadership

By Amanda Rich

- Hope and trust are important for community and systems advocacy.
- Hope and trust building are teachable and learnable skills.
- Developing skills in hope and trust is good for the wellbeing of individuals, organizations, and communities.

Engaging in systems or community change efforts requires leaders to draw upon many skills and can seem (and be) complex and challenging. A lack of acknowledgement or willingness to engage in that complexity puts systems change, like other important ideas in our field, at risk of becoming another buzz word. [The World Resources Institute](#) defines systems change as “shifting component parts of a system—and the patterns of interactions between these parts—to ultimately form a new system that behaves in a qualitatively different way.” Though it may seem like a contradiction, becoming more skilled in engaging with this complexity involves “up-skilling” in two simpler, yet important, areas: hope and trust building.

Changing systems, like those of our disability support systems, involves the reimagining of parts of our society that have deeply entrenched patterns, shaped by many different belief systems, players, and policies. It involves not only creating a vision and plan for a better future, developing a deep understanding of both the issue of focus and the intersecting environments that shape the issue, but also requires leaders to work ethically, effectively, and collaboratively with different stakeholder groups who may hold different priorities and points of view. A 2022 article from the [Stanford Social Innovation Review](#) highlights that systems change efforts require leaders to understand the root cause of the issue, engage with institutional policies, cultural awareness efforts, programmatic operations, and work collaboratively with cross-sector groups. At the heart of all these leadership tasks are two fundamental skills that are often taken for granted, the skills of *hope* and *trust*.

What does the research say?

Often, trust and hope are discussed as things that are “nice” to have if you are lucky enough to have them. Both, however, are skills that can be honed, cultivated, and employed to help leaders build stronger teams and engage in systems change efforts more effectively to build a better world. Advocating for change requires working with others to develop a vision for a better future, plans to help move the world closer to that vision, and the belief that you aren’t just running on a hamster wheel. In other words, engaging in systems change efforts is a practice of *hope*. Hope can be defined in many different ways, but one of the most useful for leaders comes from psychologist [Charles Snyder](#) who said hope is made up of at least 3 parts that are teachable and learnable skills:

- 1 **Goals/Vision Crafting:** A goal, or a vision, is a clear articulation of a direction to strive towards.



- ② **Paths/Way-power:** The development and articulation of a plan, routes, or steps one could take to move closer to the goal or vision. Additionally, it involves innovating alternative paths if unexpected roadblocks get in the way.
- ③ **Agency/Willpower:** The belief that you, your team, and community can stay on the path/s to achieve the goal.

This theory of hope provides a bridge between human thoughts, emotions, and actions. Developing hope is associated with positive personal outcomes like [greater health and wellbeing](#), positive workplace outcomes like [lower rates of burnout and greater job satisfaction](#), and improved outcomes for the community in terms of greater [community engagement](#).

Hope is not about just thinking happy thoughts. It requires action and practice. In the book [Hope Rising](#), the author's describe hope as a minivan. The people loading into the car have a destination in mind (the goal/vision), a road to follow (the path), and gas in the tank (agency). Hope helps to propel individual and collective actors into action to build a better future.

[Trust and hope](#) are related but distinct concepts. There is no universal definition of [trust](#) but definitions of trust often involve concepts of risks, dependability, and integrity. In his book, [The Thin Book of Trust](#), Charles Feltman defines trust as "choosing to risk making something you value vulnerable to another person's actions." Whereas hope might be the minivan, trust is what gets people into the van.



When leaders understand how trust develops, they can become more effective at fostering it. Advocacy and systems change efforts rest on collaborative relationships with others. [Trust](#) may be the most important "ingredient" to successful relationships. In their book, [The Trusted Advisor](#), authors David Maister, Charles Green, and Robert Galdford present a useful equation or model for understanding the "anatomy" of trust. They say that trustworthiness is determined by the sum of a person's perceived credibility (transparency with relevant experience, skills, knowledge, and background), reliability (consistency over time), and intimacy (the level of emotional safety people feel with them), minus their perceived selfishness or misalignment between goals.

Like hope, high levels of trust are associated with greater [wellbeing, improved physical and mental health, and community engagement](#). Additionally [high trust teams are more effective](#). Leaders play an [important role](#) in predicting trust on their team.

What does this mean for the field?

As a field it is important to remember that building safer, kinder, more sustainable, and effective systems of support services require the efforts of many groups. Progress is not possible without hope and trust.

- **Invest in breaking down silos.** For reasons of policy, funding, training structures, and tradition, the disability service field has often worked in siloes from other related groups and fields. Intentionally breaking down these siloes requires time and funding for cross-organization and cross-sector relationships building, trust-building, vision crafting and strategic planning. The field has much to learn from and to share with other groups such as those involved in cross-

disability organizing, labor movements, housing equity, aging, and health care. Building trust across groups may require the investment in [cultural or trust brokers](#) or people who specifically work to build trust across different social groups.

- **Listen to and amplify the voices of other groups.** The field of disability support services must also recognize that though they and the people who work for them will be impacted by policy changes affecting systems of care, most often people with disabilities themselves are the ones most impacted by these policies. Some people who work for and lead disability support provider organizations have disabilities themselves, but many do not. The priorities of people who lead and people who use disability support services are not always the same (See Alison Carey’s book, [On the Margins of Citizenship: Intellectual Disability and Civil Rights in Twentieth-Century America](#)). On many issues it is vital those representing groups of disability professionals become comfortable taking a step back and following the lead of disabled professionals and advocates.
- **Acknowledge harder parts of our history.** Though it is human beings who build and break trusting relationships it is important to remember that when people work for systems (like disability service systems) the system’s history as well as its current policies and practices play a role in shaping people’s trust in it. Though the disability service system has played an important role in advocating for the advancement of the rights of people with disabilities, many parts of the disability service system have also caused harm. Acknowledging past harm may be important in helping others build trust in the future.
- **Look at how far we have come.** Despite historical pitfalls the field has come a long way. Using platforms such as conferences to celebrate progress while painting a shared vision for the future will help to bake hope into the foundation of the work. Systems change can be slow and when we are in the weeds, it can feel like it is moving at a sloth’s pace. Taking a step back and being intentional about noticing progress is vital.

What does this mean for me and my organization?

Engaging in systems change often requires [cross-sector collaboration](#) with people who you do not yet know and who do not yet know you. Taking steps to build trusting relationships is vital to ensure groups are working towards similar ends, ensuring integrity in change efforts, and walking the talk of creating more humane and fair communities. Whether engaging in systems change efforts or not, taking the time to build trusting relationships with people you are working with or building something with and fostering hope is an essential aspect of effective leadership.

[The University of Minnesota Cooperative Extension](#) shares several tips or strategies for building trust within communities that may be able to be applied to cross-sector collaborations.

- Build “**contractual trust**” meaning make expectations, roles, and boundaries clear, follow through on commitments, and respect the boundaries of others.
- Build “**communication trust**” by committing to transparency through clear and frequent communication. Seek different ideas before deciding and be transparent about how it was made.
- Build “**competency trust**” by performing your role well and ensuring your organization performs its role well. This involves being honest about your area of expertise and what you bring to the table. Develop the resources your team needs to do their job well, including clarity about their roles. Remember that those who are most impacted by an issue are the experts on their experience and competence often does not mean formal training.

- Show that you **care**. Take the time to show that you see the humanity in the people who you work with and for by being curious about them. Demonstrate that you will act with their wishes and best interest in mind. This can be done in both big and small ways. Show up for the communities you are working alongside. Ask people about their lives, learn, and remember what you can. Respect people’s identities and backgrounds using approaches such as [cultural humility](#). Sometimes groups working in systems or community change efforts do not have the same priorities. That can be okay, as long as there is a sense of caring, mutual support, and an effort to find points that intersect across priorities.

An article in [The Harvard Business Review](#) outlines several strategies leaders can use to foster hope, especially during hard times.

- **Work with your teams and others within your coalition to collaboratively create a clear vision for a positive and achievable future.** Visual facilitation tools like [MAPS and PATHS](#) used for person-centered planning may also be useful for creating a shared vision in teams, organizations and advocacy coalitions. Within your organization, offer many opportunities and provide the support and autonomy for your team to practice identifying and articulating their personal goals.
- **For any goal you set, practice with your team identifying several “next best steps” to get closer to the goal.** Developing steps or a path to achieve your vision is easier when the goals you articulate are [SMART](#) (Specific, Measurable, Attainable, Relevant and Time-Bound). This allows you to break them down more easily into smaller steps and keep track of progress. Additionally work with others to identify possible “plan b’s and plan c’s” when needed. There are a lot of unknown variables when engaging in community/systems change work and having alternative routes that get you to the same vision for a better tomorrow is important.
- **Let past wins propel your future action.** Create habits around recognizing and celebrating wins, even small ones as they add up over time. Make it a practice in your organization to engage in regular, constructive individual, team, and community self-assessments, and celebrate progress. Taking stock of the past helps to build agency for future action.

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Getting Involved in Systems Leadership: Resources and Actions

By Caitlin Bailey

- Getting involved in systems leadership is important for leaders in our field. It can help leaders feel more excited about their work. Systems leadership is also important to make sure the field keeps improving.
- Three ways to get involved in systems leadership are through advocacy, building professional connections, and contributing to organizations and systems work.
- Becoming a systems leader can be hard. There are many helpful resources and tools. They are linked throughout this article.

The work that we do every day has a profound impact on the individual and collective lives and wellbeing of people with disabilities. But sometimes, work can feel a bit monotonous or even disconnected from our purpose as disability sector leaders. Research consistently shows that [no matter where we are in our careers or lives](#), having the opportunity to do meaningful work is crucial to [engagement](#) and satisfaction. Getting involved in systems collaboration, change, and advocacy beyond the scope of our day-to-day roles is one way that we can stay consistently connected to our contribution to the field.

If you're like many leaders, getting involved in systems leadership beyond your current role may seem intimidating. However, in a field where so much change is needed, there are many opportunities to connect, advocate, and contribute. Below are some practical tools and techniques that may be helpful.



Get Involved in Advocacy

Reach out to elected officials on issues that matter.

Many elected officials have a little bit of information about a lot of issues but don't know the needs or impact of upcoming legislative or policy decisions as intimately as you do as a leader in your field. Reaching out to share the impact of current and potential decisions is an important way to inform them of the priorities of their communities.

Contact information for elected officials in your area can be found [here](#).

Calling elected officials can feel intimidating and awkward; many leaders don't know where to start. [Here is a resource](#) from the Autistic Self Advocacy Network that shares the best ways to contact elected officials and provides a fill-in script that you can use. This [article from UC Berkeley](#) provides tips to write a letter to elected officials in your area.

Fact Sheet: How to Call Your Elected Officials

The best way to contact your elected officials is by phone. Phone calls work better than written forms of communication like letters or email. This is because the person on the other line has to listen to what you have to say. They can't just skim the words like they could with something written.

Phone calls also take more time for an elected official's staff to respond to. This means that if you can get a lot of people to call about a certain bill or law at the same time, it will make it hard for people in that government office to do anything else but answer calls. This shows elected officials that the public really cares about a problem. That could affect how they choose to vote for the law.

Elected officials keep track of how many people call about each problem. So if one problem is getting a lot of calls, it may make them think more about that problem.

Remember that members of Congress have both national and district offices. And, members of the State Legislature may have more than one office. The best thing to do is call all their offices. But if you can only call one, that is also okay. If you have to choose one office to call, you should call the district office closest to where you live. The person you talk to will not be your elected official; instead, it will be someone who works for them. This person's job is to let the elected official know what you said.

UC Berkeley | Library Guides | Government Policy & Information | Contacting Elected Officials | Tips for Contacting Elected Officials

Contacting Elected Officials: Tips for Contacting Elected Officials

Provides information and tips when contacting elected federal officials.

Introduction | President and Vice President | Congressional Members | **Tips for Contacting Elected Officials**

Tracking Congressional Issues | Comment on Pending Regulations

10 Tips

Letters, emails, and faxes are effective ways to communicate with your elected officials. Below are some tips on contacting and communicating with your elected official.

1. **Be Original.** Consider writing your own original correspondence. While many organizations can provide you a pre-written letter you simply sign, many legislators still consider a thoughtful, original letter from a constituent worth 1000 of the pre-written letter use a pre-written letter as a base and expand on it with your own words.
2. **Stay Brief.** The maximum length of a letter/email should be 1 page. Keep in mind that the letter will most likely be read by a legislator summarized for the legislator, so a brief letter is best.

Stay informed of important issues in our field by connecting with local and national organizations leading advocacy in our system.

If your primary job isn't advocacy, it can feel daunting. Lean on organizations that do this work to guide you about the issues and opportunities for advocacy in your state and nationally.

Want to know where to focus your advocacy? Getting on the mailing lists of your state's DD Councils, protection and advocacy agencies, provider associations, and advocacy groups is a great way to stay informed. National groups such as ASAN and the National Disability Rights Network also provide up-to-date information about important [issues](#) and [legislation](#).

Several organizations have scheduled advocacy days and events that provide leaders with information about issues, consistent messaging, and direct connections to elected officials and systems decision-makers. Participating in these advocacy events is a great way to stay informed and collaborate with others to advocate. NADSP hosts an [annual advocacy event](#) to advance policy priorities critical to Direct Support Professionals. The [annual Disability Policy Seminar](#) is a multi-day event that provides attendees with critical information about field trends, policy, and legislation and arranges advocacy opportunities on Capitol Hill.

Build Your Network

Get yourself out there by attending events, conferences, and other opportunities to build your connections.

You can find conferences and field-specific events that align with, inform, and help you get more connected with your purpose as a leader in this field.

There are so many great conferences hosted by local and national organizations in our field; doing some research to get a sense of the topics, speakers, and focus of different conferences and events can help you narrow down the resource that best matches your interests. For instance, if you are passionate about research, you may want to look at the AAIDD or AUCD conferences. If you are interested in understanding national and state policies that impact people with disabilities, you may consider attending the NASDDDS annual conference or the annual HCBS Conference. Many [National Leadership Consortium partners](#) host conferences and events if you want to learn more.

When you are at conferences and events, avoid the temptation to sit in your hotel room or be on your phone. Many conferences hold networking events for early career professionals and receptions. Poster sessions can also be a great way to build connections as they allow you to walk around and start conversations with people who are doing work related to your interests.

Build a professional community tied to your purpose.

Some career development experts call professional networks and community connections [identity workspaces](#) because they give us a chance to build relationships and have a meaningful impact with people who have similar or complementary interests, goals, and talents. Building a professional network takes a lot of intention, but it's well worth the effort.

Become a member or join affiliates or work groups of organizations in our field that align with your interests and purpose. Many national and international organizations offer membership benefits such as reduced rates for accessing materials and conferences, opportunities to connect in person and virtually with other members, and work groups focused on addressing specific issues in the field. For instance, [members of Inclusion International](#) can join work groups with people around the world who are advancing deinstitutionalization.

Get a mentor with field experience who can help you become more connected. Many of the more experienced leaders in the field are not only willing but are also eager to mentor up-and-coming leaders. Because of their experience, they often have relationships with other field leaders who share your interests and passions. To learn more about how to choose a mentor, check out this [Forbes article](#).

Grow Your Contribution

Get connected with organizations and initiatives you care about.

Sometimes contributing to organizations that are not our own can reinvigorate passion and engagement in our own work since it gives us a new perspective while reminding us how important our role is.

Join a board of directors or advisory committee where you can provide strategic input and guidance to an organization you care about. If you have not been on a board of directors or don't know where to start, [experts recommend](#) beginning with smaller or more local organizations, many of which are consistently looking to grow their boards of directors.

Volunteer for a cause you care about. Many organizations in our field are resource-short and rely on the time, effort, and expertise of volunteers to advance their mission. Volunteering is a great way to contribute and grow your knowledge about different aspects of the field. If you don't have an organization in mind but have some specific skills to offer, you can also consider signing up as a volunteer for [Catchafire](#) or another entity that can connect you with agencies in need.

Participate in state initiatives and work groups to provide input, insights, and guidance on issues that are important to you. You can browse the websites of your state agency or DD Council to learn more about opportunities to contribute. If you have fewer systems connections, you can also let a supervisor, executive leader, or board member know that you're interested in getting involved.

Become a better change agent to maximize your contribution efforts.

Leading and contributing to systems change requires significant and often nuanced skills. Understanding and intentionality while building those skills can make you more effective and build your reputation as a systems leader.

Prioritize developing skills such as strong facilitation, political savvy, conflict management, and strategic thinking. Make them part of your annual development goals or choose one skill at a time to hone on your own. There are many free resources, including a [tool kit](#) from the National Association of State Mental Health Services, this article from [LinkedIn](#), or a guide from [Medium](#) to help you identify and build essential skills.

Get a coach or an accountability partner. Leadership coaches are an excellent resource to help identify strengths and opportunities for growth, support skill building, and build connections with resources and people. As we move through our careers, our responsibilities increase while our access to colleagues who can provide guidance decreases. Coaches help leaders stay committed to their own growth and development. You can access field experts and executive coaches through [the Consortium](#). If you do not have support or a budget for a leadership coach, consider pairing with a colleague as an accountability partner. Accountability partners offer mutual support and encouragement toward individual goals and can enhance the impact of your personal development efforts.

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.



What We're Reading, Viewing, and Listening To

Title: Systematic Thinking for Social Action

Author/Editor: Alice M. Rivlin (2015)

This newer edition to a classic book describes in straight forward terms the central questions needed to guide social change efforts. It takes the reader through processes of systems thinking that help to address the decision guiding questions like: Who wins and who loses? What will do the most good and for whom? What do we know about effective services? How do we find out what works? and What does accountability look like?

Title: The Danger of Silence

Presenter: Clint Smith Ted Talk (July 2014)

In this brief talk, poet and teacher Clint Smith discusses finding the courage to speak up against injustice and work towards change.

Title: Hope Rising: The Science of Hope Can Change Your Life

Authors: Casey Gwinn & Chan Hellman (2018)

Hope Rising describes how hope is measurable, teachable and malleable across the lifespan. It discusses the scientific evidence of hope as a practice both in people's personal lives and workplaces.

Title: KFF Health Policy 101

Author/Editor: Drew Altman

This open access, online "textbook" provides an important primary on health policy. Much of the policy work in the field is related to issues with Medicaid, Medicare and other health policies. Deepening our understanding of these policy issues will lead to more effective action.

Title: Neurodiversity as Politics

Authors: Ari Ne'eman & Elizabeth Pellicano (2023)

This article highlights important current debates and divergent viewpoints on neurodiversity and offers insightful ideas on resolving conflicts.

Title: 3 Lessons on Starting a Movement From a Self-Defense Trailblazer

Presenter: Rana Abdelhamid Ted Talk (January 2019)

This powerful talk provides three actionable insights on starting a grassroots movement.

Title: The Improvement Guide: A Practical Approach to Enhancing Organizational Performance

Authors: Gerald J. Langley, Ronald D. Moen, Kevin M. Nolan, Thomas W. Nolan, Clifford L. Norman, and Lloyd P. Provost (2009)

This practical book guides the reader through three questions that can support any effort to advance person-centered practices: 1. What are we trying to accomplish? 2. How will we know a change is an improvement? 3. What change can we make that will result in an improvement?

Title: Person-Centered Systems Change: Reflections from the First NCAPPS Technical Assistance Cohort

Presenters: Mary Bishop, Patricia Richardson, Jonas Schwartz, Thom Snyder, Michaela I. Fissel, and Saska Rajcevic

In this webinar, representatives from four states receiving technical assistance from NCAPPS showcase their achievements and share what they've learned and what they plan to do next regarding enhancing staff competencies, engaging stakeholders, strengthening quality improvement, and building cross-system consistency for person-centered thinking, planning, and practice. The webinar includes a panel discussion facilitated by people with lived experience as to why engaging people who use services is essential for person-centered systems change.

Upcoming Events

The Leadership Institute

This intensive leadership development program is designed for seasoned and emerging leaders. Applicants may work in areas of executive leadership, management, or program leadership in organizations that provide, advocate for, or fund support for people with intellectual and developmental disabilities and their families. 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.

Colorado 2024

The Colorado Leadership Institute will be held **September 8th – 13th** in-person in Lakewood, CO. Applications are open now. [Click here for more information or to apply.](#) This Institute is open to Disability Sector Leaders located in Colorado. If you are a leader with a disability, or a Direct Support Professional, you can apply for scholarship support to cover tuition and some travel and hotel costs!

Fall 2024

The Fall Leadership Institute will be held **September 22nd – 27th** in-person in Stockton, CA. 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, or a Direct Support Professional, you can apply for scholarship support to cover tuition and some travel and hotel costs!

Wisconsin 2024

The Wisconsin Leadership Institute will be held **October 13th – 18th** in-person in Madison, WI. Applications are open now. This Institute is being offered in partnership with the Includa Foundation as part of the Wisconsin Leadership Development Program. [Click here for more information or to apply.](#) Check out a [recent post by the Includa Foundation](#) about the Program. This Institute is open to all Disability Sector Leaders located in Wisconsin.

Virtual 2025

The Virtual Leadership Institute will be held virtually **January & February 2025** via Zoom. The class will 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. If you are a leader with a disability, or a Direct Support Professional, you can apply for scholarship support to cover tuition and some travel and hotel costs!



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

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