National Leadership Consortium Bulletin

Leading Toward Authentic Language and Services

The 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: Choice and Control: Who Holds the Power?

If we've learned nothing else in the almost two decades of the National Leadership Consortium on Developmental Disabilities, it's that systems transformation is both beautiful and messy. It's not linear. There are sometimes setbacks and not all parts change at the same pace. Leaders often struggle to navigate and lead through transformational change. Many come to the Leadership Institute because there is a gap between where they want to be as leaders and as an organization and how they are currently operating. Leaders are finding that the policies are not aligning with their practices nor are shared values informing those practices.

We are seeing some of that messiness now. More leaders are using words like choice, control, self-direction, and person-centeredness that may point organizations in the direction of better supporting human dignity, quality care, and equity. However, there is always a risk that these words will not be used true to their meeting and as indicators of positive change, but instead just as meaningless catchphrases that can mislead stakeholders. There are too many organizations that use these words in their mission, but still create barriers for the people they support to have meaningful choice, control, and freedom in their lives. Our system needs to examine whether we are really walking the talk. There has also been a resurgence in congregate care models that are inherently restrictive and not person centered, but still use the "right words" in their mission and funding requests. These new congregate care settings are in part why we started the Bulletin. We wanted a platform to challenge these new models and share best practices with leaders and stakeholders in our system to ensure they are person centered in their words and actions.

In this issue of the Bulletin we explore the meaning of the words choice, control, and person and system-centered services, what the research shows is their impact on people's lives and their relationship to one another, and innovative approaches to supporting practices true to their meaning. We discuss "language creep" or how these words lose their meaning when not supported by practice. We know that there is power in language but sometimes these concepts can lose their power and intention and become distorted in their meaning. Meaning can also be misconstrued when it comes to policy and practice. Many of our well-intentioned policies can be carried out in ways that limit choice and control for people utilizing services. As you read this Issue, we hope you feel challenged to consider the ways that our society and service system limits and eliminates choice and control for people and how we may shift our thinking and our practices to change that. We hope you enjoy it and as always be in touch and lead on.

Happy reading,

Kristen Loomis

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Mean What You Say: The Importance of Language

Introduction by Steven Eidelman

Contributions by Tanya Richmond, Amanda Lay, Cody Drinkwater, and Jack Butler

Walking to the gym at the University of Delaware after a day of meetings I passed two "cool kids," 20-somethings who were high fiving each other and shouting, "Spread the Word!" (cool kid #1) "To end the word!" (cool kid #2). I didn't stop to ask them whether or not they knew the context and history of what that phrase was, but I was impressed. Soeren Palumbo, a consultant and a sibling of someone with a disability, and Timothy "Timbo" Shriver, a disability rights advocate, created the *Spread the Word to End the Word* campaign with modest goals, including, "Our belief is that the world would be better if all people were valued, respected, embraced, included. Included in the games we play and the friends we make. Included in our schools, our workplaces, and our communities." Today they are approaching *900,000 signatories.* Words matter. Attitudes matter. But people have not always been so language conscious and forward thinking as we are today.

This language consciousness is demonstrated by national disabilities organizations that are setting a positive example to the rest of the community. Speaking directly to dignity and belonging and the role terminology plays. AAIDD (*www.aaidd.org*) has retained its leadership role on assessment and terminology. Their name has changed from: Association of Medical Officers of American Institutions for Idiotic and Feebleminded Persons (1876) to, several name changes later, American Association on Intellectual and Developmental Disabilities (2007). The name changes were not a result of a scientific breakthrough, but rather the wishes of self-advocates and others. *Disable-Disrespect.org*, a project of the Indiana Governor's Council for People with Disabilities says it so well: "Your words and actions have power." They certainly do.

We have mastered the art of using language to describe programs, services, rights, and responsibilities. Unfortunately, we as a field (though certainly not alone in this practice) use new terms and new nomenclature to describe old practices. In one state, the state institutions have been rebranded State Supported Living Centers. Another state rebadged some of their institutions as Neuro-Medical Treatment Centers. This renaming sounds so benign, but it is not. This is akin to putting lipstick on a pig. Collectively we have a role that includes promoting dignity and respect. If we don't who will?

We asked self-advocates and professionals in the field to offer their experiences and perspectives on the impact of language. Here's what they shared…

The Stanford Disability Initiative released a *Disability Language Guide* in 2019 that can be a helpful resource to people concerned about language use related to disabilities.

Also check out *Disable Disrespect*, a guide on language use created by the Indiana Governor's Council for People with Disabilities

Tanya Richmond, *a Partner at Support Development Associates, LLC (SDA) and the co-chair of The International Learning Community for Person Centered Practices (TLCPCP), explains how she has seen language misused in her work:*

Person-centered care supports people to develop the knowledge, skills and confidence they need to more effectively manage and make informed decisions about their own life, health, and health care. It is intended to be coordinated and tailored to the needs of the person. The supports derived from this approach should both honor what is important to the person and keep the person central to all decisions in their life while ensuring they are healthy and safe. But, from my perspective, each of the terms "person-centered," "choice," and "control" are all used as systems-centric code words.

For example, I often see the instruction for support "give choices" written into person centered plans. This has come to be synonymous with "select from among the things offered." While at first glance this instruction seems to meet the intent of the HCBS Rule, it neglects to consider that the choices offered need to be connected to what is important to the person. Without that consideration, the locus of control is still with the offerer. I have also seen choices used as ways to teach consequences. "It's your choice" is a poor (and sometimes dangerous) substitute for the kind of exploration that is required to assist someone in making a choice. It is neither sufficient in terms of exploration nor diligent in terms of weighing options. Similarly, "giving" a person control assumes that the person has no control and will "be allowed" to be in control, instead of it being something people inherently have. I believe the original intent was to follow the person's lead and to deemphasize the support role so the person can stay in the lead.

"Person-centered" has become a code word for anything that remotely resembles a person expressing a preference and is one of the most often-touted buzzwords or selling points for advertising services or supports. The intent of being person centered is missed when we only focus narrowly on the superficial preferences (e.g., coffee or tea) and fail to understand what a life in balance looks like from the person's perspective (e.g., living in an apartment in the city with a roommate who has some shared interests, or working at a job that pays me a fair wage and keeps me motivated to do my best). Many disparate approaches labeled as "person-centered" have come onto the scene, causing a dilution of quality, confusion for these seeking service and supports, and, frankly, cover for practices that are substandard and not person centered.

Amanda Lay, *a self-advocate, support broker, and speaker, shares her experience with language:*

"Choice" and "person centered" mean that total autonomy is with the person to the extent that is realistically possible. My family is excellent at providing me with as much choice as possible. I am currently working for many people as a support broker. Although the purpose of self-direction is that the person is in charge, it has been my experience that for any number of reasons the parents make the choices or decisions for the person with disabilities. When others make those choices, it isn't self-direction in the true sense of the word. I have always believed that all people are capable. Self-direction puts that into practice. The terms choice and self-direction are misused in my life when I experience situations where people see me in my wheelchair and automatically speak to my mom or others supporting me instead of directing their question to me. This is demeaning and insulting.

Cody Drinkwater, *a regional self-advocacy coordinator and freelance writer, gives his insights about how language has progressed:*

I have never had to live in a provider setting. For this I am grateful. I have always had the support of my family. For me, independence and autonomy is incredibly important. The ability to go where I want, to befriend who I want, to love who I want is not only essential to me, but is an important right for anyone who has a disability. Being able self-direct and self-determine my own life gives me the freedom and autonomy to live how I want to live. The Person Centered Planning Process has done wonders for me and my ability to function in this current society. I think when people hear the words "PCP" they think of paperwork and documentation, but it is so much more than that. The Person Centered Planning Process represents someone's life goals and achievements. Through the Person Centered Planning Process, an individual with disabilities can get support to help plan the life they want. I currently have support staff that help me with both budgeting and organizing my week and I have noticed the results. This is the ideal future of disability accommodation and inclusion.

Picture for a minute the absence of support systems for the disabled. Imagine how lost some of these individuals would be. If you can imagine this, then you have a good picture of what life was like for those with disabilities over a century ago. Due to my background in history and experience volunteering at the Baltimore County Historical Society, I know that most individuals with disabilities were either kept at home, put into asylums or placed into almshouses, all of which had terrible conditions. The initial goal of these institutions was to rehabilitate individuals with disabilities, but the methods used, such as being chained to the wall, were horrific and ignorant. Research from the Nabb Center at Salisbury University revealed that there were almshouses all over Maryland, including Wicomico County (located 11 miles east of Salisbury. It's no longer there.). I am certain that I would have been thrown into an almshouse because I did not fit the "normal" mold. I would have been labeled "feeble minded" or an "imbecile" despite the fact that I am college educated.

Circumstances for the disabled improved after the Lunacy Commission, written in 1898, exposed the poor conditions of the almshouses. The Lunacy Commission was the first in a long line of progressive acts, policies and programs throughout the 19th and 20th century that made life easier for the disabled. These included improved conditions in asylums, the Social Security Act in 1935 and President Truman's signing of the National Mental Health Act in 1946, Medicaid and Medicare and the Voting Rights Act in 1965, the Americans with Disabilities Act in 1990 which provided civil rights protection for the disabled and the American Education for all Handicapped Act (called the IDEA act) which was also enacted in 1990. These Acts show the march of progress and how far those with disabilities have come from the days where they were thrown into cells and treated like animals.

It's important to reiterate that even though conditions are much better in this day and age, those with disabilities must keep fighting to step out of the dark shadow of their history. They must show the world that they are important enough to stand alongside everyone else and not be relegated to the side-lines. Progress is an ever moving vehicle and those with disabilities must remain at its helm. They must fight for their voice to be heard and consistent funding for their programs and institutions is essential in order for them to succeed.

Jack Bulter, *Director of Person-Centered Supports and a DSP for Achieva, gives his perspective on the misuse of language in the field:*

Throughout my 28 years in the human service field, I have heard terms like "choice," "control," and "person-centered" presented to people with disabilities. Many times, the understanding of the terms by stakeholders (including program leaders) was reflective of the current culture, compliance standards, and personal beliefs that existed during that time. The terms, however, can have negative consequences when misused. When misused, "choice" can be presented as, "It's your choice," used as a last resort phrase used when all redirections from an undesired behavior have failed. "He chose a sheltered workshop," sounded a lot different than, "She or he was placed in a program where people with disabilities are segregated and devalued based on their eligibility." There were occurrences where I have witnessed human service workers using choice as a "natural consequence." The result leads to some type of negative outcome or service added to a plan. These examples are extreme cases of prescriptive responses, but distortion of language may be more common due to beliefs shaped by mandatory "Rights and Responsibilities" policy and training. These types of policies unintentionally neglect to eliminate the distinction between disability rights and all human rights instead of encouraging informed choice for everyone.

I've also seen the distortion of someone's control over their daily existence. I've heard an example of a person having control as, "He chose what he wanted to drink when presented with the option of Diet Pepsi or Diet Coke." How about Rum and Coke? And the statement, "I did a person-centered plan for an individual recently." YOU did the plan for the person? The divide between client versus the people who receive support and people who do not widens with every misuse. Even the use of independence can become skewed by being measured by someone's ability to achieve total independence or by the caregiver's understanding of what interdependence means.

The infusion of person-centered language into systems, mission statements, and provider values intended as a north star has also led to misuse and unintended action-related associations. I can recall reading a person-centered plan that stated a person's goal was to gain competitive employment. The plan was well written and executed and signed off by all team members. Ten years later, the person who the plan was written for was still wasting days in a workshop being paid sub-minimum wages. If person-centered or self-directed action had occurred, work towards the person's vision would have continued and only ended when the goal was accomplished. The essence of person-centeredness is for the planning and action to live and breathe. That plan existed for ten years, and ten years of a person's life wasted where they did not want to be with no action taken. But the human service worker did their job; they created a person-centered plan on paper. And the system continued to fund a ten-year and counting "pre-employment" choice.

Words matter. The campaign to end the "R" word and using the word "people" instead of "client" may help facilitate change. However, the change is not sustainable if real action is not taken to correct and prevent devaluing systems and beliefs. The problem that leads to the misuse of terms seems to lie within the true understanding of the person a human service provider is assisting and the system that funds the support. One term and one approach will not meet everyone's expectations. And funding programs that devalue people will only create new terms and goals that are never fully realized.

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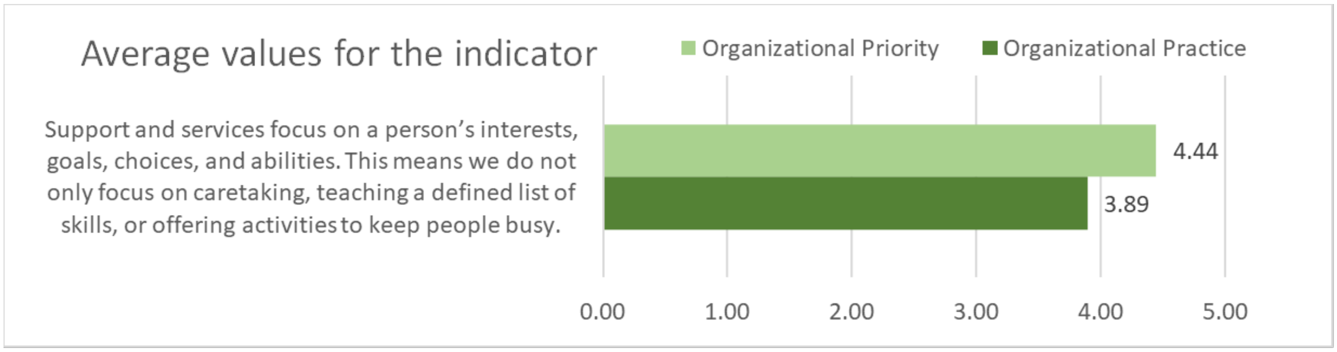
Program and Systems Centered vs. Person-Centered: How Do We Know?

By Caitlin Bailey

So many of our organizations have adopted principles of person-centered practices in our missions, visions, philosophies, training, and even policies. A few years ago, the National Leadership Consortium conducted a study showing that the adoption of language in our organizational structures is an important step in implementation. We have also worked with many leaders across the globe who have recognized that there can be a wide gap between calling something person-centered and actually implementing person-centered practices. A recent tool that we have developed, the Organizational Priorities and Practices Inventory (OPPI) tool shows just that. The OPPI combines the principles of person-directed services, self-determination, participatory management, diversity, equity and inclusion, effective and transparent leadership, and stakeholder input into organizational governance with daily workplace practices to evaluate organizational performance. When asked about the degree to which their organization prioritizes principles related to autonomy, choice, and control[1] for people with disabilities vs. the degree to which they practice it on the OPPI, there is an 11% difference, with respondents on average rating their priorities .50 points higher than their practices (on a scale from one to five). What these organizations are actually doing is falling short of how much they prioritize and value it.



Often with good intentions, leaders make decisions in the name of person-centeredness for the people supported, but that are really for the benefit of the programs and systems.

In her short film for Open Future Learning, *Person Centered vs. System Centered,* Beth Mount describes some central tenants of what it means to be person-centered vs. system centered that are useful to help us determine whether we are making program/system or person-centered decisions.

Programs and Systems Centered Approaches	Person-Centered Approaches
Assumes that people belong to the system, and it's the system's job to fix them	Assuming that people belong to themselves, their families, and their communities, and it's the system's job to support them
Defines people in terms of their deficiencies and what is "wrong" with them	Defines people as whole and by their capacities
Designs service plans to fix people so that they become 'whole people' who are 'ready' to engage in the real world	Designs service plans assuming people already are or have something to contribute to their communities
People get services based on what is available in the system rather than what people want and expect	People take what they need from services and systems that are designed to be responsive to their interests, expectations, and wants

Another way we've recently seen leaders in the field differentiate program and systems centered vs. person-centered is during a statewide Visioning and Planning Summit, sponsored by the Oregon Council on Developmental Disabilities. During the Summit, stakeholders from across the state developed guiding questions to help inform decision-making for systems and organizational leaders that ensure person-centered approaches. The questions include:

- Does this decision/action support **self-determination**[2]?
- Does this decision/action support people to **move toward a community life rather than a service life**?
- Does this decision/action move us toward a **more equitable approach**?
- Does this decision/action **simplify rather than create unnecessary complexity**?
- **Who benefits** from this decision/action?

Finally, and most importantly, as the Autistic Self Advocacy Network describes in its letter to the Administration for Community Living, for something to be person-centered instead of systems or program-centered, it must include the leadership of people with disabilities as key contributors and decision-makers. They wrote:

> "In order to embody the values of person-centered planning, it is imperative that people with disabilities be deeply involved in any discussion on this topic ... Any project that claims to focus on person-centered planning yet does not center the voices of people with disabilities, violates the core principles of person-centered planning."

Their powerful words remind us that if our organizations are making decisions that impact people with disabilities without including them in the decision-making process, we are, by default, making systems or program-centered decisions.

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[1] OPPI Indicators for Autonomy, Decision Making, and Control for People with Disabilities: Choice and control for people with disabilities are basic human rights. All people with disabilities should have control over all aspects of their lives, including which services they use, who works for them, where and with whom they live, how they spend their days, who they love, and with whom they spend their time.

[2] Defined by Wehmeyer as 'acting as the primary causal agent in one's life and making choices and decisions regarding one's quality of life free form undue influence or interference.'

Innovative Initiatives:
Expectations Matter: My Life, My Choice, My Plan

By Amanda Rich

Conversations with Crystal Brockington, Pamela Ford, Gail Godwin, Nicole Leblanc, Babette Smith, Melanie Smith, Leonard Stevens

What is the "Expectations Matter: My Life, My Choice, My Plan" Training Program?

Leading with integrity, or "walking-the-talk" is an on-going journey within the disability service field and beyond. The ideas that people with disabilities with varied support needs are capable of meaningful and untold contributions within their community, have the right to control their own destiny, have the right to participate fully in the economy, and that services should be built around the person to support their goals are not new. Finding programs that truly model and reflect these values can be difficult though.

The Expectations Matter: My Life, My Choice, My Plan training program is built upon the idea that people with disabilities are the experts on their own lives and in the best position to teach other Disabled people, their families, and service providers about life-planning and support. It is a training program run by the Expectations Matter cohort at Shared Support Maryland on person-centered planning that was developed by and for people with developmental disabilities and their families.

Crystal Brockington of the Image Center of Maryland and one of the trainers for the Expectations Matter program put it this way, "All of our program was developed by people with developmental disability, and we train others with developmental disability on person-centered planning and self-direct services." Pamela Ford, Deputy Executive Director at the Southern Maryland Center for Independent Living and a trainer for the Expectations Matter program, said that the core of what makes this program special is that, "We embody the purpose of 'nothing about us without us,' and that's what the whole person-centered planning is all about. It is making sure that the plan is centered around the person, and that nothing happened without them from the beginning of the plan to the ending of the plan." Nicole Leblanc, a consultant and trainer for Liberty Health Care of Maryland, TASH, Human Service Research Institute and Expectations Matter, shared that one of the main goals of the project is to transform the disability service field to "make services move from system centered to person centered."

The program was initially funded by the Maryland Developmental Disabilities Council and offered to Maryland residents with disabilities, their families, and support staff they choose. However, the program has since expanded to West Virginia through their Developmental Disabilities Council, the modules trained at Virginia and Kentucky Partners in Policymaking, ANCOR membership, training a cohort of trainers at a local provider agency in Maryland, and opened its audiences to provider organizations and other business leaders.

What Topics are Covered in The Training Program?

Crystal shared that the program is individualized and tailored to each audience. She said, “Each group and training unfold as its own little flower because all the participants are different, are coming from different perspectives and different experiences. We find that it’s really empowering, not only for the participants, but also for the trainers because the trainers are sharing their growth with others. It’s one of my favorite projects to work with, and it really is truly innovative.”

Babette Smith and her daughter Melanie, both master trainers for the Expectations Matter program, said, “The training takes it from the history of person-centered planning all the way up to what you can do before your meeting, during your meeting, and after your meeting.”

Nicole added that the trainings center on “human dignity and rights. For example, the right to vote and the right communication. Your plan is private. You have a right to understand your plan to have it in plain language. We talk about paths to funding and how to choose and change your team. We talk about tools and other resources, both at the meeting and in your life, possible agenda items for meetings, and who is in charge. We also talk about employment and employment accountability. We talk about the importance of you being in control.”

Babette and Mel added that in each training they highlight “how important it is for every person to receive information in a way that they can best understand it, whether it be verbal or written. We talk about the best way to communicate, whether they prefer telephone or email.” Babette said, “Melanie shares examples of how she and her team started developing her plan, which used an integrated star which is a tool [out of the LifeCourse Framework]. She gets to talk about who’s important in her life, and why that’s important to her. Her nephew is very important to her. So, we share pictures because when she’s working on her person-centered plan, we use a lot of pictures.”

How is this different/innovative?

From the perspectives of the many trainers we talked to, the Expectations Matter program is unique and innovative in several different but related ways. For one, it is designed and delivered by and for people with disabilities and the important people in their lives. People who learn from the training are learning from other people with disabilities and seeing them in a position of power and authority. For many, seeing people with disabilities, especially those who have intensive support needs and/or who communicate in nontraditional ways, in paid, valued positions of power (training others) is new. That experience can change what they think is possible for their lives and may change what family members, support providers, and potential employer’s think is possible as well.

Babette and Mell said, “We found it to be just an amazing opportunity both for the trainers and for the participant and realized that this was innovative, because who better to train about person center planning than those who are developing their own person-centered plan? Where else can you receive a training by people with disabilities? In most traditional trainings, organizations want to present their most educated person with the master’s degree as the presenter. Expectations Matter has true presenters that know what they’re talking about, based on their lived experience. It’s just amazing to learn from people who have the experience based on their life, not based on their formal education.”

People learn what is at the heart of a person-centered plan. Crystal shared, “People get so happy when they realize that, ‘Well, the plan is supposed to be about me.’ It’s not just an administrative formality.”

The participants learn not only from the content of what is being delivered but the method of how it is being delivered and by who. Nicole shared that, "The trainings model peer mentorship and demonstrate presuming competence. We get to get the word out about dignity of risk. You know our society needs to move away from over protecting us, sheltering us. The system needs to be person centered, not system centered. No more of the top down. There should be no more 'you're the provider, you know what's best for me.' This training not only models how to do planning and support but models the value of presuming competence, dignity and risk, mutual support, and having high expectations in the delivery."

Pamela shared how the trainings often happen in teams and that each team member contributes based off their knowledge, interests, and strengths while other team members offer support for parts of the training (for instance technology use) that may be challenging.

The trainers use multiple modes of presenting information. For instance, Babette and Mel said, "She [Mel] gets to share, via pictures, what is most important in her life and what makes her life centered around her. When we started the project, it was more that she was an assistant. She was going to advance the slides and it morphed into that she could be part of the training and she does a very good job presenting and telling people about the specific parts of your plan that are important to her, and visually that shows individuals that no matter your ability level, you can still be involved in person centered planning."

The trainers shared that the program changes how the participants think about people with disabilities and themselves, in part by showing that there are many paths and possibilities in life. Leonard Stevens, another master training for the Expectations Matter program, describes the power of other people with disabilities and their families seeing him train and hear the story of his life. He said, "I get to tell my life story. You just have the expertise that you never know who you're going to meet, and who you're going to become in later life. It's powerful for everyone."

Crystal shared, "All of our audiences are learning from people with developmental disabilities. In a setting where it's peers teaching peers, the peers get confidence and say, 'I never thought about approaching this problem this way.' When it's in a setting of families and caregivers, They're just like, 'Oh, my gosh! I'm going to go home and speak to my daughter this way. I didn't understand that hurt her, from her perspective.' And then businesses are like, 'Wow! I didn't realize you could do all this. I have space where someone could do this and this and that, and we could accommodate this.' So, it's just definitely a big unwrapping of experiences that really benefits each audience."

Babette and Melanie added, "Most people who meet Mel would think that she's probably not able to hold down a job. We started with this, and Shared Support Maryland was like, 'Lets see what else Mel's capable of…' We really thought outside of the box, and it has developed into a job that Melanie does well. I think it's an opportunity for individuals to step outside of their comfort zone and outside of their normal and for others to see what is possible when you think outside the box. Agencies and family members see people with disabilities in a new light. It shows that they do have the capability to make decisions and to plan their life, and to live a good life. It shouldn't be determined by another person, how an individual lives their life just because they have a disability. And I think, seeing that, and seeing these great trainers with disabilities, sharing their expertise, and sharing what a person being able to plan their own life has done for them is just eye opening."

All the trainers also noted the trainings benefit the trainers as well. The trainers are paid for their time, labor and expertise and are supported in developing their skills. Leonard shared, "I learn how to do a lot of things and just get out my comfort zone and just talk about my experiences and share my expertise with everyone." Pamela added, "We work according to the abilities that we have, and we get to see a lot. We got to learn a lot. We are still learning throughout the entire process. And that's the beauty of it all is that we never stop learning." Babette and Mel said, "It's been amazing for us personally, because Mel has a job that she loves. She knows that feeling of getting ready for work, getting dressed, doing the hair, do the make-up, do the everything. She knows the value of it. So, personally it's been a life changing experience for her to have a fulfilling job that she loves, and that she's excelling at."

What is Next for the Expectations Matter Program?

The trainers for the Expectations Matter program would like the see more agencies investing in the program for it to continue and to reach wider audiences. Nicole said, "I'd like to see it go national. For us to set our rates and state agencies, DD councils, and others pay us to do this training, not only for people with disabilities but for agencies as well." Leonard added, "It should go internationally as well. Everyone who uses services should have this."

They hope that this model becomes available to all of those who use services and is introduced during transition planning in school. The Expectations Matter team would like to see this become a standard of practice across layers of service delivery system, from colleges and universities to potential employers, to family members, to support service agencies. It should also be available to all whom use services and should become part of the transition planning process as people with disabilities are transitioning out of school and possibly into adult services. Pamela said it this way, "They must know and we must know that expectations matter. We'll make it happen. We can. I know we can make it happen."

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Babette Smith is a Master Trainer for Expectations Matter

Melanie Smith is a Master Trainer for Expectations Matter

Leonard Stevens is a Trainer for Expectations Matter

Congregate Care: Lessons Learned

By Cory Gilden

What does the Research Say?

During the 1700s and 1800s, many people with intellectual or developmental disabilities (IDD) were placed in hospitals, almshouses, and asylums for their care. These early institutional settings generally began with good intentions. They often offered education, work skills training, safety, and medical care in welcoming environments ran by professionals like doctors and educators. These facilities were intentionally moved to the country to protect the mental health and emotional wellbeing of people with intellectual and developmental IDD, since doctors at in the 1800s believed urban areas worsened mental health. Lack of understanding about or acceptance of people with disabilities in broader society at the time coupled with uncertain economic conditions caused families to struggle to care for their loved ones with IDD at home. Congregate institutions offered them hope and a place that promised to care for their family member better than they could.

Into the 1900s, there was a dramatic decline in the expectations and conditions of these congregate settings for people with IDD. Many institutions were unregulated, overcrowded, and lacked the funding and staffing they needed to educate or even provide humane treatment of the people residing in them. A documentary by Geraldo Rivera in 1972 titled "Willowbrook: The Last Great Disgrace" displayed the horrific neglect and filth of a state supported institution for children with intellectual disabilities in New York. Similar circumstances were featured in "Christmas in Purgatory: A Photographic Essay on Mental Retardation" by Burton Blatt and Fred Kaplan, published in 1974, which documented conditions at five state institutions for those with intellectual disabilities in four eastern states. The book shows children in locked cells, crowded dormitories with beds end-to-end across the room, and understaffed and abusive facilities.

Although there are still about 17,000 people living in state-run institutions today, the isolation of people with IDD in custodial congregate settings began to decrease as policy and funding shifted to support the medical and educational wellbeing of children and adults with intellectual and developmental disabilities outside of institutions, which increased the quality of life for many. A review of deinstitutionalization and post-deinstitutionalization research of the experiences of people with IDD in English-speaking countries found that people with IDD experience greater choice and self-determination, more participation in social networks, relationships, and community-based activities and are more satisfied with community-based settings. Another review of literature from the past few decades also found that deinstitutionalization improved the quality of life for people with disabilities, increasing their sense of wellbeing and independent decision making. When people with disabilities are included in community settings, they are more likely to experience increased agency, independence, and financial autonomy. Research repeatedly shows that community-based living brings about many more positive outcomes for people with IDD than congregate settings.

What does it mean for our field?

New privately-run "intentional communities" are currently being built and presented as a solution to the shortage of safe, accessible, and affordable housing and lack of community supports for people with disabilities. Intentional communities are voluntary residential communities of people who work together toward a common purpose and a shared lifestyle; but in the disabilities world, communal living can have negative implications. While the emerging intentional communities for people with disabilities are described as "safe, supportive, and fun" and offer appealing features like community centers, work skills training, and employment opportunities on the property or in the community, they still segregate people with disabilities from the general public for much of their day and limit their potential for building diverse authentic social networks and developing self-determination. They are called charming names like "enclaves," "pods," "mini communities," and "farmsteads" to distract from the reality that they are self-contained, isolated campuses. On the surface, the beautiful properties with manicured lawns and luxury amenities are a far cry from the squalor of the traditional large, state run, hospital-styles settings that institutions used to be, but they are still segregated and exclusionary, often designed for people with low support needs and the financial means to pay the high rents and fees. Many advocates believe that "'intentional community' has become a sanitized word for a well-marketed institution."

What does it mean for me?

States first had the option to receive a waiver of Medicaid rules for governing institutional care in 1983, with Home and Community Based Services (HCBS) becoming a formal Medicaid State plan option in 2005. People with disabilities have experienced the benefits of HCBS support and research has documented the related increase in their quality-of-life outcomes. The HCBS Final Settings Rule is in place to "enhance the quality of HCBS and provide additional protections to individuals that receive services," compelling service providers to support the settings that have been shown to bring about the best outcomes for people with disabilities, not what has been recognized as harmful.

Evaluate. Some supporters of the intentional communities refer to them as "beyond inclusion" and put a positive spin on intentional communities as diversifying housing opportunities for people with disabilities, but history has shown that "separate but equal" strategies and segregating anyone from the general public brings negative consequences like promoting "otherness" and stigma. It is up to leaders in the field to research and evaluate the pros and cons of intentional communities.

Educate. Leaders in the disabilities field should not only educate themselves about disabilities history and current best practices in services, but also their employees, the people they support, and their families. Some of these intentional communities are being launched by families of people with IDD who want their loved ones safe, cared for, and included somewhere, but maybe they would think differently if they knew the history of segregation for people with disabilities. Being educated is a strong defense against repeating historical mistakes.

Advocate. If your organization is working toward self-direction and self-determination, then support legislation and movements that are best aligned with these goals (e.g., advocating against the institutional bias in Medicaid programs and reducing waitlists for HCBS services). Supporting inclusion in the community in all aspects of a person's life will help advance self-determination.

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.*

Intentional Communities: We Know How This Ends

By Janet Price-Ferrell

I have been a proponent of inclusion since my son, Autin's, earliest days. At almost five months, he was diagnosed with hydrocephalus and at 18 months he had a grand mal seizure, which is when we were thrust into the disability world. While visiting various preschool classrooms when transitioning from early intervention to school services, it was clear that this was a whole new world compared to school for our "typical" son. Why was this world so different, so separate? When Austin was starting kindergarten, the school wanted him in a separate classroom all day but the kindergarten teacher who had just gotten her master's degree in Special Education had other plans. This started our journey of true inclusion!

Of course, we had some bumps along the way, but having Austin in general education classrooms and in the community has given him his life. People need reminders that risk, for everyone including Austin, is a part of life. For example, when Austin had a seizure at school and fell off the slide on the playground, I had to remind the teacher and principal that, yes, Austin was allowed to be on the slide again, just like all the other children. In school, the general education students knew him, shared jokes, supported him at state chorus competitions and in foods class, asked him to the prom, and gave him a standing ovation at graduation. As he got older, Austin being part of his community has given him even more experiences than most. Austin has the ability to give to his community as well. In the ROTC program, he got medals alongside students without disabilities, even though he has a high level of need due to his seizures and intellectual disability. Currently Austin lives in his own condo with the support he needs to live in his own place. He picked the colors he wanted and helps plan his meals. His neighbors know him at the pool, and we know he is safe in the community.

My experience making sure my son has continued access to all the world has to offer is why I do not believe in congregate settings, no matter how comfortable they are or what the current buzzword is this generation.

The current buzzword or euphemism for congregate settings is "intentional communities." Parents in every state are coming together to create intentional communities for their adult children with disabilities. Many use the language of today: "person-centered service model," "inclusive residential," or "neighborhood with a purpose" and not the oblivious language associated with segregation and isolation in our history. Also common with these new communities are the promises that residents with a variety of needs will have access to individualized services such as life skills training and employment assistance as well as recreation and social opportunities in a safe and attractive setting.

Here is a bit of description about a training school that was open in the 1950s and the language is eerily similar to the promises of intentional communities today:

> *"In 1852 a school for "feeble-minded youth" opened in Germantown, Pennsylvania; another opened in Albany, New York in 1855; and another in Columbus, Ohio in 1857. Training schools were considered an educational success, offering hope to many families with children with disabilities."*

While these training schools originally met the needs of persons with mild to moderate disabilities by 1857, with the economics after the Civil War and increase of immigrants, many people couldn't get the jobs they had trained for anymore and ended up in jails or poor houses.

History shows that it was difficult to maintain the quality and intention of these schools and they transformed into a model of care that was far from ideal. As enrollment grew, schools in the 1870s and 1880s became asylums instead of training schools, with students becoming "inmates." These schools became less about education and training and transformed into custodial institutions where higher functioning inmates were used as laborers to reduce costs. This was also around the time of the photographer Burton Blatt's famous "Christmas in Purgatory," a photo essay that revealed the horrors of institutional life.

Even the worst institutions were created with good intentions but devolved over time due to changing leadership, economics, and politics. This change can happen very gradually. For example, someone has a food allergy, so then no one living there can eat this food. Or maybe a new administrator decides that common kitchens are too dangerous so they are removed for additional housing space that can lead to more income. Or the new administrator is concerned about safety and does not allow visitors after 10pm. Or the training classes are too expensive to offer. When the bottom line is more important than the people, it is no longer an intentional community but only a place to house our loved ones. It is a slippery slope and history has shown us that congregate settings are not the answer.

Intentional communities can not only be segregating and not inclusive, but also very exclusive in nature. Many are built in isolated areas with plans for a complete community full of amenities. Some families bought in early and the promised movie theaters and bowling alleys were never built, leaving people more isolated than before. The cost of many of these intentional communities are limited to wealthy families with monthly costs of $3,000 a month or more, out of the reach of many families. Other intentional communities require skills or abilities tests to apply.

The desire for inclusive communities was renewed, in part, as a response to the lack of community-based services to suit the needs of people with disabilities. For people with disabilities with higher needs, many programs have become out of reach. College programs were an exciting possibility when our son was in school but by the time he left high school, these programs now ruled him ineligible due to his support needs. Job training programs that were created for people like our son, now required higher skills to apply. Even if he were admitted into these programs, they are often not individualized, but instead everyone goes to the same classes or training to do the same jobs. Instead of investing renewed effort and resources into intentional communities that segregate people with disabilities, which has been shown to reduce quality of life outcomes, that energy should be directed to transforming and building community services to better support people to meaningfully belong.

Congregate settings may be appealing with their promises of beautiful properties and safety from the dangers of the outside world, but they are not inclusive or person centered and do not offer the opportunity for our loved ones with disabilities to live their best lives. We have seen throughout history how this ends. Instead of regressing into the mistakes of the past, we must continue to move forward and demand progress toward better life outcomes for people with disabilities through self-direction and self-determination in the community where we all belong.

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Dignity of Risk, Safety & Autonomy

By Amanda Rich

In 1972 Perske wrote, "There can be such a thing as human dignity in risk, and there can be a dehumanizing indignity in safety!" (p. 200). Those who support people with psychiatric and cognitive disability often grapple with the question of how to support people in living full, dignified, self-determined lives with all the risk that involves, while helping people stay safe and healthy. As human beings, we are inherently vulnerable to harm. As the old cliché goes, "no one gets out of this world alive." The history of disability services, especially those that serve people with intellectual and psychiatric disabilities, have been shaped by assumptions that dignity of risk must come second to the need for safety, that the greater choice, control, and freedom people with disabilities have in their life then the less safe they are, and that presumably non-disabled people will make inherently safer choices than people with disabilities. The rise of and re-emergence of congregate care and systems of conservatorship are based, at least in part, on these assumptions. The "right" to care has often come with the sacrifice of one's right to freedom, autonomy and dignity (See the book On the Margins of Citizenship: Intellectual Disability and Civil Rights in Twentieth-Century America for more).

The belief that people with disabilities cannot choose what they want for their life, that dignity of risk is not compatible with supporting safety, and that autonomy makes people with disabilities less safe are changing, but they persist. Although more organizations are making efforts to honor dignity of risk, the legacy of these beliefs profoundly shapes the service sector and people with disabilities' experiences within it. Research has found that not only do these beliefs oversimplify the concepts of autonomy and safety, but they are also false. Autonomy, in many ways, supports safety.

What Does the Research Say?

Autonomy and safety are simple concepts yet at the same time show up in our lives in messy and complicated ways. Safety, for instance can have an objective component, the observable risk of harm in a particular context, and a subjective component, how safe we *feel*. Both play a role in our overall wellbeing, including our physical health. Additionally, each individual, family, and organization differs in how much risk they can tolerate before feeling unsafe. These differences are shaped by context, culture, past experiences, personality, and perceived levels of support.

Self-determination theory holds that autonomy, or the ability to choose and shape one's own life and behavior is one of three fundamental human needs, along with competence (i.e., effectiveness in what one does) and relatedness (i.e., connectedness to and sense of belonging with others). Researchers have found that the greater people's perceived autonomy, the greater their perceived life-satisfaction, happiness, feelings of trust and connection to others, and hopefulness. Greater autonomy may also protect against depressive symptoms. Autonomy is not primarily shaped by one's levels of functioning or skill, but by our relationships, expectations, and opportunities.

What Does This Mean for Our Field?

Though all people have the capacity and need for autonomy, the context people live in and the relationships people have shape their opportunities to exert control on their lives. Many people with intellectual and developmental disabilities experience less opportunities for decision making and have less freedom to control their lives than people without disabilities. Additionally, the ability to direct one's life is shaped by laws and policies, accesses to resources, the important others in our life learning to listen to, understand, and support our choices. People with more intensive support needs and those who communicate using non-traditional often face greater limits on their autonomy due to policies such as guardianship, limited financial resources, a lack of access to a functional system of communication, and the biases, beliefs and constraints of support providers.

Both safety and autonomy need to be supported in the pursuit of "good life." Autonomy in the sense of control is an important factor for activating the part of our nervous system associated with feeling safe. People with intellectual, developmental, and psychiatric disabilities are at greater risk for particular types of harm including accidental injury, some illnesses, and physical, sexual, psychological and financial harm than people without. It is not however the absence of threat that makes people feel safe. Instead, it is the presence of meaningful, trusting human connection and autonomy. A recent study found that people with intellectual and developmental disabilities perceive greater access to care, connectedness, safety, and perceived respect for their dignity in care in community-based vs institutional settings. They also perceived more support for autonomy in community-based residential settings. Another study found that even after controlling from severity of impairment and dual diagnosis, the greater the presence of HCBS related outcomes people had, the fewer their emergency room visits, instances of abuse, neglect, and injuries. Greater perceived autonomy is associated with a richer sense of trust and connection, which serve as the strongest protectors against harm. Autonomy, meaningful inclusion, and connectedness support safety.

A report by the Vera Institute found that a primary reason people with disabilities do not disclose abuse or other crime victimization is a fear that service providers or loved ones, will restrict their autonomy as result of the harm committed against them in an attempt to offer protection. The fear of loss of autonomy may also prevent people with disabilities from engaging their support providers in their decision making or problem-solving processes. Additionally isolation and loneliness dramatically increase the risk of harm for both people with and without disabilities. Higher levels of autonomy are associated with lower levels of loneliness. Treating people as if they have no agency also increases the risk that people will experience violence.

What does this mean for me?

There are many opportunities for professionals to advance autonomy for people with disabilities in their roles and across the field, such as:

- Recognize your role in supporting autonomy. Many people with intellectual and disabilities need support services to promote their autonomy. Support providers play an important role in respecting and promoting the dignity and autonomy of the people they support. Supporting the autonomy of people with disabilities requires providers to learn how each person they support communicates, to remove barriers to choice, and to respect the choices people make.
- See autonomy as relational. Though autonomy means the freedom to make choices and control one's life, all of us at times need support to make decisions and pursue our goals. Relational autonomy looks at the impact of advocacy, support, policy, and relationships on the agency we exert in our lives. Increasing the autonomy of people with intellectual and developmental disabilities, especially those with more intensive support needs and who communicate using nontraditional means, will require support providers to recognize their power and engage in ongoing processes to learn about the goals of people they support, how they communicate, and how to build support around their goals.

- Question assumptions. A common response to risk and harm within the disability service system is to restrict people's freedom, which can feel punishing. When people make mistakes or experience harm, challenge these reactions. People with disabilities face to having dignity of risk in their lives are their provider's lack of awareness about the importance of dignity of risk, false assumptions about safety and a lack of practice and opportunity to learn to assess risk and make choices. Some of the barriers people with disabilities face to having dignity of risk in their lives are their provider's lack of awareness about the importance of dignity of risk, false assumptions about safety and a lack of practice and opportunity to learn to assess risk and make choices.
- Challenge systems and policies. As a field we must examine the legacy of the myth that less freedom makes people safer and change policies and practices that stem from it. This means challenging systems like guardianship and investing research and practices to explore and promote expanding guardianship alternatives such as supported decision making.
- Challenge congregate care. Challenge narratives that new models of congregate care will be inherently safer than self-directed and/or community-based supports. One of the primary reactions to psychological trauma is feeling unsafe. When people feel unsafe, they are more likely to try to control others and are less likely to fully participate in their environment even if it is counterproductive. The history of the field of disability services is steeped in trauma and past harm. Supporting dignity of risk must involve and acknowledgment of and intentional efforts to heal that trauma.
- Invest in training and support for the direct support workforce. Autonomy is relational and support providers play a vital role in helping people develop skills around decision making and ensuring opportunities to exert control in their life. That will require addressing issues of workforce turnover since good, trusting relationships take time.

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What We're Reading, Viewing, and Listening To

Title: Belonging: The Science of Creating Connection and Bridging Divides

Author: *Geoffrey Cohen (2022)*

This rich and beautifully written book weaves together research and personal stories to discuss how to address the epidemic of loneliness and polarization. It discusses how we have become so isolated and polarized and how to expand empathy and create meaningful and lasting connections.

Title: The Burnout Challenge: Managing People's Relationship with Their Jobs

Author: *Christina Maslach and Michael Leiter (2022)*

In this thought-provoking book, two of the leading scholars on burnout discuss the root causes of burnout, its relevance, and what leaders can do to increase worker health, wellbeing, and productivity. This book provides practical, actionable, and evidence-based strategies for managing burnout.

Title: How Great Leaders Take on Uncertainty

Author: *Anjali Sud & Stephanie Mehta (2022)*

In this interview style TedTalk, Anjali Sud discusses the importance of leading with humanity and flexibility especially as workplaces change to meet the needs of a new generation of employees.

Title: Can You Punish A Child's Mental Health Problems Away?

Author: *Alexander Stockton (2022).*

This heart-felt, multi-media opinion piece focuses on the challenges of, problems with, and abuses by youth residential treatment programs for young people with disabilities and other mental and behavioral health issues.

Title: Employment Helps Adults with Intellectual Disabilities See What They Are Capable Of

Author: *Hunter Lacey (2022).*

This beautiful National Public Radio (NPR) photo series features employees with intellectual and developmental disabilities and their perspective on how work impacts their lives.

Upcoming Events

Leadership Institutes

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

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

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

Upcoming Training Sessions

May 2023

The Midwest Leadership Institute will be held in Kansas City, MO, May 7-12, 2023. Applications are open now and will close on March 31st. Click here for more information or to apply. This Institute is open to all Disability Sector Leaders in the Midwest

Spring 2023

The Spring 2023 Virtual Leadership Institute for Developmental Services will be held via Zoom March - April 2023. Applications are open now and will close on March 1st. Click here for more information or to apply. This Institute is open to all Disability Sector Leaders.

July 2023

The Summer Leadership Institute will be held in the Greater Philadelphia Area, PA, July 16-21, 2023. Applications are open now. Click here for more information or to apply. This Institute is open to all Disability Sector Leaders.

National Leadership Consortium Workshops

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

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

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

Spring 2023

Accelerator for Champions of Equity (ACE) Workshop

In the last few years, the demand for nonprofit professionals to be change makers in advancing diverse, equity, and inclusion (DEI) has exponentially increased. After reflecting on these demands and listening to its members, The National Leadership Consortium on Developmental Disabilities has contracted with national trainer and DEI consultant, Jonathan Meagher-Zayas, to create the **Accelerator for Champions of Equity (ACE)**. ACE will be a comprehensive cohort style coaching and training program designed to provide dedicated organizational leaders with the tools, support, and information to advance DEI at their organization. Build the network you need to make change happen at your organization. This Workshop will run from March – June 2023 and will include seven sessions. To learn more about this Workshop, add your name to the list here.

Contact Us

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If you have any trouble accessing the referenced material,
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