The Death of Rehabilitation, or Lighting New Pathways to an Inclusive Working Life

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By

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Cambridge Scholars
Publishing

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This book first published 2025

Cambridge Scholars Publishing

Lady Stephenson Library, Newcastle upon Tyne, NE6 2PA, UK

British Library Cataloguing in Publication Data
A catalogue record for this book is available from the British Library

ISBN: 978-1-0364-4162-3
ISBN (Ebook): 978-1-0364-4163-0

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ACKNOWLEDGMENTS

It is impossible to recognize every individual who has contributed in a meaningful way to the evolution of my professional development over a long 51-year career. I owe a debt of gratitude to many disability researchers, policymakers, funders, advocates, co-workers and colleagues, business leaders, governmental partners, educators, family members and guardians, workforce collaborators, and, of course, self-advocates in services. Thank you all for contributing so richly to my valued understanding of what is important to advance a working, inclusive life in support of people living with disabilities.

In large measure, my inspiration and growth in the disability employment space is the end outcome of shared work with many like-minded colleagues, past and present, from the National Association of People Supporting Employment First (APSE), Minnesota APSE, and Minnesota's Employment First Coalition. In particular, thank you to the "scary guys," Jon Alexander and Bob Niemiec, for their strong leadership and building a foundation for better policies and practices in our state.

As a student of organizational change, this "old dog continues to learn new tricks." I would like to extend a heartfelt thank you to my talented colleagues at the Minnesota Transformation Initiative (MTI) Technical Assistance Center for inviting me to be a contributing member of MTI's consultation team. MTI is demonstrating that the transformation of policies, practices, and service outcomes is within the reach of any organization committed to building the best life possible for the people they support.

I would like to thank the Rehabilitation Services Administration (RSA) at the US Department of Education for having confidence in me and investing financially in my graduate education. Thank you, RSA, for equipping me with the capacity to think, evolve, and pursue outcome excellence as a professional.

I would like to express my gratitude to Elanor Harris for helping to bring my original manuscript to publication-ready copy. Many thanks, Elanor, for your excellent suggestions, edits, and overall support to make this book more accessible and readable.

Many thanks to the editorial and production teams at Cambridge Scholars Publishing (CSP) for demystifying the publication process and bringing this book to a worldwide marketplace. A special thank you to CSP's senior commissioning editor, Adam Rummens, for his helpful guidance and technical support throughout the process.

Over a long career, the journey required many transitions, riding the twists and turns, highs and lows, and navigating a road less traveled. Through it all, I was grounded in the loving support of my wife of 50 years. Colleen, thank you for being there, always.

Finally, I would like to dedicate this book to the late John J. Barrett. John, thank you for your many years of encouragement and ensuring the space for creative freedom. Together, we opened many doors of progressive change during a time when we did not have the guidance of a clear public policy vision nor the benefit of dedicated funding. We made a difference.

PREFACE

To The Reader:

It was a long, fascinating journey. My career in the disability employment space began more than 50 years ago after earning a degree in vocational rehabilitation. This journey has been rich in professional experiences, observations, revelations, and, most importantly, learning. I chose this career pathway because of my interest in guiding working-age youth and adults with disabilities to obtain employment, prosperity, and social inclusion. Over five decades, I held the titles of rehabilitation counselor, lead rehabilitation counselor, program manager, vice president, executive director, and organizational consultant. For this reason, my chosen field of work has offered opportunities to engage directly with the disability employment space through the lens of direct service, middle management, and disability advocacy, as well as executive job functions.

In addition, I have had opportunities to work directly with a wide range of allied disciplines. This includes workforce development, vocational rehabilitation, day habilitation and day services, mental health, chemical health, intellectual and developmental disabilities, serious brain injuries, deaf, deafblind and hard of hearing, secondary education and school-to-career transition, post-secondary education, social services, welfare, social security, homelessness, criminal justice, and immigrant/refugee immersion and resettlement. Without question, working-age youth and adults living with diagnosed and undiagnosed disabilities are present and actively engaged in all of these disciplines.

This wide range of job experiences has provided me with a unique framework to observe what is working and what is not working. As I enter the final stages of a lengthy career, I feel obliged to share my lessons learned and provoke discussion that might help shape the next generation of disability services, practices, and support. So, I authored this book to advance transformational changes that I believe can measurably improve competitive integrated employment and community life engagement outcomes for all.

Let me begin by saying that the route to employment, self-dependence, and economic prosperity adopted by legacy disability programs and service systems is paved with good intentions. Over the 50 years, most professionals I have had the privilege to work with are outstanding people who are dedicated to their jobs. Moreover, a majority supports, at least in principle, the goal of securing a higher quality of life for people with disabilities. So, my aim is not to discredit the work of good people but rather to offer a respectful, critical review of current business models and practices in use.

On this particular matter, I would like to quote Nobel Prize-winning economist and statistician Milton Friedman, who once said: "One of the great mistakes is to judge policies and programs by their intentions rather than their results." Many contemporary policies and programs operate with the best of intentions but miss the target by generating disappointing results for the people they support.

As I look back at the evolution of our disability services landscape, there are certainly notable achievements over the past five decades. For example, disability advocacy efforts and court-directed settlements have resulted in landmark legislative mandates and improvements in public policies. Also, disability research and employment demonstrations have led to exciting innovations in workforce strategies and practices. Further, emerging technologies such as artificial intelligence, computer software programs, and electronic devices or equipment have been introduced to support the limitations of human functionality. Finally, changes in population census and demographic data have resulted in workforce shortages, leading to unprecedented job opportunities in the labor market. Despite these converging, exciting advancements, the employment participation rate of Americans with disabilities remains abysmally low, especially for working-age adults living with complex, significant disabilities.

Let us examine the other side of the equation. It is easy to see how many disability programs and services are highly fragmented and were stitched together over time like a patchwork quilt. Despite our best efforts at modernizing legacy programs, most still lack clarity in vision, essential partnerships, shared outcome goals, a coherent division of labor, unified funding strategies, and seamless, evidence-based practices that will result in a person-centered, inclusive working life. Instead, a large percentage of adults with significant disabilities (e.g., intellectual disability) are engaged in endless programs and services that limit opportunities for real workforce participation, community inclusion, and personal expression.

National and state statistical data reveals that most adults with disabilities fall far short of quality-of-life indicators enjoyed by most of their non-disabled peers. To illustrate this point, too many are supported by sheltered workshops in jobs that pay subminimum wages. Many are employed in subcontracted jobs developed for groups of workers with little to no attention paid to their individual job interests or skills. Further, many people living with complex disabilities do not work at all. Rather, many are supported in day service programs that limit social engagement with others in their local communities by structure and service design.

To be fair, there are pockets of service and outcome excellence, and unrealized promise and opportunity. Of course, we have already demonstrated that we can advance a working, inclusive community life in support of people with disabilities. Person-centered outcome success is indeed attainable when prospective job seekers have a plan, find a willing employer, and have access to evidence-based employment and community life engagement practices. What we have *not* demonstrated is a collective will and priority to transform resources and capacities to bring employment and community life engagement outcomes to scale.

So, my burning question to the reader is this: What will it take for us to level the playing field of opportunity and outcome success for people we are privileged to support?

The underlying thesis of this book is that measurable systemic change is possible. However, it will take new ways of thinking about this work we do as well as taking bold actionable steps to change business strategies and practices. What lies ahead of us is the need to build measurable, sustainable momentum (critical mass) to break through the tipping point, the threshold of historic change. Make no mistake about it… the size and work scope of this goal I am proposing is complex and political. Whether you are a self-advocate, family member, friend, neighbor, educator, rehab counselor, case manager, business leader, direct support professional, or employment specialist, each one of us is called to agency, and each of us has an important contribution to make to the cause.

So, where do we begin? How do we begin? This is coming from a professional educated in the discipline of rehabilitation, so it will sound like heresy. However, we need a “hard reset.” We need to announce that rehabilitation is dead. Further, let us place habilitation to rest, as well. We need to discard these outdated terms and replace them with strengths-based language to codify the importance of essential workforce and community contributions from everyone.

Let me explain. Our profession, and allied fields of work are essential, but in desperate need of rebranding. This begins with rethinking our fundamental vision and purpose. Moreover, it proceeds with building greater clarity in service and outcome mapping. That is, defining what we do, how we do it, where we do it, and why we do it in the way we do to achieve a person-centered, self-determined life. Simply stated, we need to reframe how we think and communicate about the basic elements of our work.

Words matter. The principles of rehabilitation are outdated and an antithetical expression of who we are, what we do, and how we ought to be representing job seekers with disabilities to business leaders and the general public. Let us be honest here… the brand of (re)habilitation communicates in a not-so-subtle way that there is "something wrong" with the individuals we support that requires fixing or corrective action. The principles of rehabilitation reinforce pervasive attitudes of "ableism," a devaluing of individuals living with significant disabilities.

Of course, we communicate the very same message subliminally to the people we support in services, their families, community members, as well as the professional staff we hire to deliver direct services. The current brand is not only dismissive to individual job seekers but counterproductive to our stated mission. It reinforces the "soft bigotry of low expectations" and limits access to local labor force opportunities. What employer is in the business of hiring (perceived) "damaged goods?"

Yes, I get it. The term "disability" is defined in federal, state, and local statutes and used to unlock budget resources essential to the delivery of basic (re)habilitation services. Outdated terms such as "disability" and "rehabilitation" are the bedrock foundation of business models and are used in daily practice. However, guiding policies and strategies can be changed and recrafted in new ways to better align with contemporary vision, practices, and intended outcomes of workforce participation and community inclusion.

Of course, we observed a similar, successful campaign in the removal of the objectionable use of "mental retardation" from our professional and public lexicon. So, this can be achieved within a contemporary blueprint of transformational change. What is needed now, perhaps more than ever, is a clarity of vision, consensus of purpose, and collective call to action.

The death of rehabilitation will give greater momentum and clarity to the rise of a working, inclusive life. Of course, it will take much more than updating of brand to reach the proverbial tipping point. It will take a stronger consensus in purpose, clear direction in policies and goals, actionable and accountable leadership, reinvestments in workforce capacities, and stronger access to evidence-based practices to bring authenticity to an industry-wide rebrand.

The following chapters in this book were written to offer ideas, stimulate discussion, weigh the possibilities, and inspire strategies that align better with a successful change process. My underlying goal is to build consensus and unite the collective energies of policymakers, disability advocates, service providers, professionals, and business leaders in building a system of alternative practices and support to improve quality-of-life outcomes.

Today, we need to be speaking with one voice about the urgency and importance of sweeping nationwide transformational change. I would like to propose consideration of a national campaign that unifies performance goals shared by federal, state, and local agencies working in support of the disability employment space. A nationwide campaign should be structured to rally all stakeholders around four primary objectives:

1. Significantly, measurably, and incrementally reduce long-term outcomes of segregation in publicly funded disability, habilitation, and rehabilitation services.
2. Prioritize funding investments in evidence-based practices to advance the fundamental goals of a self-determined, working and inclusive community life.
3. Eliminate 14 c of the Fair Labor Standards Act, thereby discontinuing the practice of paying subminimum wages to workers with disabilities.
4. Adopt and promote a national BHAG (Big Hairy Audacious Goal) to double the employment participation rate of Americans with disabilities working in the open labor force by 2030.

Together, we can do this!

Don Lavin

PS: RIP Rehabilitation

CHAPTER 1

LAYING THE FOUNDATION FOR SOCIAL AND ECONOMIC JUSTICE

The arc of the moral universe is long but it bends toward justice.
—Martin Luther King

Based on my five decades of experience, Dr. Martin Luther King's observation is accurate. Indeed, the wheels of progress grind slowly with many notable achievements. However, national and state statistical data clearly document that Americans living with disabilities have not fully realized the benefits of landmark legislative wins and court-directed mandates ensuring their human and civil rights.

As a newly minted counselor working for a rehabilitation facility in 1973, I remember thinking and believing we can do better than this. I was employed as a rehabilitation counselor for a large, sheltered workshop that paid subminimum wages to a majority of its participants. However, I am forever grateful that this employer assigned me to supervise a new track of program services introduced to deliver job skills training in partnership with local employers. The strategies used by these job skills training programs were highly unique during this period when institutional care was still considered an acceptable mode of treatment for people with significant disabilities, and sheltered workshops and adult day habilitation centers were emerging throughout the country as innovative "community-based services."

The practices of these business-based services were measurably better in securing competitive integrated employment (CIE) outcomes in contrast to the predominant sheltered workshop services provided by my employer. The training experiences, skills development, social inclusion, and job outcomes of people participating in this business-based training model were superior in every way. The participants were building skills and obtaining jobs that paid equitable wages and benefits. Moreover, employers were pleased to hire and support a majority of the individuals trained.

Speaking candidly, we did not have clear or universal language to describe what we were doing. Concepts like job coaching, supported employment, customized employment, and person-centered planning were not as yet a part of our professional lexicon. Furthermore, none of us were trained or certified in the knowledge, skills, and competencies needed as a gateway to delivering these services. With this said, we were introducing, albeit crudely, service strategies that closely resemble some of today's researched principles and practices.

As a young, inexperienced professional, I could not unsee what I was learning. Despite my youthful inexperience, direct engagement with these programs changed my career trajectory. I was offered the opportunity to become the lead counselor for these business-based programs and worked for three years to expand employer partnerships so others could benefit. In 1976, I left my lead counseling position to become the program director of a smaller, struggling community rehabilitation organization. There, I worked as a middle manager to transform its program services and prioritize CIE as the preferred outcome.

In the early 1970s, my colleagues and I were working outside the vision and guidelines of existing public policies. Further, many of our industry's pioneers, such as Justin Dart (a disability rights advocate), Dr. Wolf Wolfensberger (author/lecturer, the principal of normalization), Dr. Lou Brown (professor/lecturer, special education), Dr. Marc Gold (researcher/trainer, systematic instruction), Madeline Will (public policy champion, supported employment), Dr. Paul Wehman (researcher/author, supported employment), Michael Callahan and Cary Griffin (national training consultants, customized employment) and others had not as yet made their impact on shaping a better understanding of what is possible. Indeed, I learned a lot from each of these industry icons, and we all owe them a debt of gratitude for the significant contributions they have made to advancing the possibilities of an inclusive, working life.

What I am trying to communicate in this chapter is the importance of engaging in clear, progressive public policies. Sound, well-written public policies are essential to protecting the rights of people living with disabilities. However, they also galvanize a shared vision, create common definitions, encourage alliances, establish legislative goals, and prioritize public investment in best practices that will increase desired outcomes. Further, good public policy encourages innovation and better methods to increase the employability, workforce participation, and community life engagement (CLE) of individuals who are underrepresented in our labor force and community.

Not only did I witness how incremental improvements in public policy can advance better job outcomes, but I also observed firsthand how a lack of progressive disability policy impacts quality of life. This is not only true in the United States but in six other countries and four continents where I had the privilege to consult. In my experience, securing good jobs is a worldwide struggle in the disability advocacy space. However, countries with the strongest public policies lay down an essential blueprint for social and economic change. Public policies cannot transform the disability landscape alone. Also, it will require the teaming of public and business investments in service practices to explore, plan, find, maintain, and grow in person-centered employment and community life outcomes.

The late public policy champion, Bobby Silverstein, once shared that the underlying goals of effective disability public policy are to 1. Protect human and civil rights; 2. Promote equality of opportunity in education, employment and community living; 3. Increase full access to community participation; 4. Foster self-dependence and independent living, and 5. Improve access to employment, prosperity, and economic self-sufficiency. (Silverstein 2003) Credited as the principal architect of The Americans with Disabilities Act (ADA), Silverstein understood the power of public policy as a sustainable force for social and economic change.

While it is beyond the purpose of this book to create a network of public policy “wonks,” it is important to understand and celebrate landmark achievements that drive social and economic justice today in support of youth and adults with disabilities. What follows is a short but noteworthy list of landmark legislation, court mandates, and disability initiatives impacting the rights of individuals with disabilities to self-determination and enjoying fuller access to the competitive labor force, earning equitable wages, and participating in inclusive community life engagements.

Section 504 of the Rehabilitation Act 1973

Section 504 of the Rehabilitation Act of 1973 was the first disability civil rights law to be enacted in the United States. It prohibits discrimination against people with disabilities in programs that receive federal financial assistance. The Rehab Act, as it is known, established an important foundation for the future enactment of the ADA in 1990.

(https://www.hhs.gov/sites/default/files/ocr/civilrights/resources/factsheets/504.pdf).

Individuals with Disabilities Education Act (IDEA) 1975

The Individuals with Disabilities Education Act, also known as IDEA, is a national law that replaced the Education for All Handicapped Children Act, signed by President Ford in 1975. The IDEA ensures eligible students with disabilities are provided with a free and appropriate education (FAPE). IDEA ensures eligible youth are provided with the development of an Individual Education Plan (IEP) customized to each student's learning needs. Also, IDEA addresses the need to develop transition plans, ensuring youth are connected with the adult services and resources they need to secure appropriate post-secondary education and training, employment, and community living outcomes.
(US Department of Education, https://sites.ed.gov/idea/)

Developmental Disabilities Assistance and Bill of Rights Act, 1984, 2000

The Developmental Disabilities Assistance and Bill of Rights Act, also known as the DD Act of 1984, was authorized to provide federal funding to states and territories to "empower individuals with developmental disabilities and their families to help shape policies and services that impact them." The DD Act funds a wide range of activities to research and invest in innovative practices that improve the quality of life in support of youth and adults with intellectual and developmental disabilities (IDD). To illustrate, the DD Act funds: 1. State Developmental Disability Councils, 2. Disability Advocacy and Protection Agencies, 3. University Centers for Excellence in Developmental Disabilities Education, Research, and Service, and 4. Projects of National Significance. Key stakeholders impacted by the DD Act are major contributors to building new capacities for individuals with IDD to live their best lives. This includes collaborative efforts with local coalitions supporting best practices in person-centered planning, education, employment, and CLEs.
https://acl.gov/about-acl/authorizing-statutes/developmental-disabilities-assistance-and-bill-rights-act-2000.

Americans with Disabilities Act of 1990 (ADA)

ADA is a civil rights law that prohibits discrimination based on disability. It affords similar protections against discrimination to Americans with disabilities as the Civil Rights Act of 1964. The ADA is sweeping legislation that protects against discrimination in basic areas of community living, including Title I: Employment, Title II: Public Services, Title III: Public Accommodations, Title IV: Telecommunications, and Title V: Miscellaneous Provisions.
https://www.ada.gov/

Olmstead Supreme Court Settlement 1999

In 1999, the US Supreme Court issued a landmark decision in the case referred to as Olmstead vs. LC. The court ruled that unjustified segregation of people with disabilities constitutes discrimination under Title II of the ADA. "The Court held that public entities must provide community-based services to persons with disabilities when (1) such services are appropriate; (2) the affected persons do not oppose community-based treatment; and (3) community-based services can be reasonably accommodated, taking into account the resources available to the public entity and the needs of others who are receiving disability services from the entity."
(Archive.ADA.gov, https://archive.ada.gov/olmstead/olmstead_about.htm).

Workforce Innovation and Opportunity Act (WIOA) 2014

The Workforce Innovation and Opportunity Act, also known as WIOA, replaced the previous Workforce Investment Act (WIA) and was signed into law in 2014. WIOA aims to increase coordination among federal workforce programs to assist employers in connecting with skilled workers and to support job seekers with education, training and assistance to secure high-demand, competitive jobs. Under Title IV of WIOA, the Rehabilitation Act of 1973 was amended and authorized payment of vocational rehabilitation services to states in support of job seekers with disabilities. New priorities established under WIOA include the following: 1. Increasing access to CIE for vulnerable, working-age youth with disabilities under state vocational rehabilitation agencies; and 2. Setting limits and conditions on payment of subminimum wages to workers with significant disabilities under 14 c of the Fair Labor Standards Act, 3. Section 188 of WIOA prohibits discrimination under the law and mandates equal access to all services provided by state

vocational rehabilitation (VR) agencies, American Job Centers, and associated programs.
(PACER’s National Parent Center on Transition and Employment, https://www.pacer.org/transition/learning-center/laws/workforce-innovation.asp).

In my view, one of the most important contributions to the passage of WIOA is the development of universal language and standards for measuring employment outcome success. The historical evolution of outcomes in the disability employment space has led to multiple definitions used to describe employment. To illustrate, terms such as sheltered employment, extended employment, center-based employment, community-based employment, work enclaves, mobile work crews, as well as others have emerged over time.

The good news is that WIOA clarified and defined **CIE** with nationally accepted standards and conditions to galvanize a formal definition. CIE is defined in WIOA as the preferred, optimal outcome of services as measured by the following conditions:

- the employee works full-time or part-time in the competitive labor force
- on the payroll of the hiring company or business
- earns at least the federal minimum wage or higher
- all wages and benefits earned are equitable to those paid to workers without disabilities doing the same or similar work
- the worker has the same opportunities for job contribution and advancement as other employees
- the worker is socially integrated into the company with co-workers who do not have disabilities.

Another provision of WIOA is an important clarification that customized employment and supported employment are valued practices that advance CIE. The law defines both customized employment and supported employment and further clarifies that CIE is strengths-based employment that can be customized and negotiated in ways that meet the needs and expectations of both the employer and employee.

Customized employment and supported employment have evolved in the disability employment space as disruptive innovations to services and practices used historically by legacy rehabilitation and habilitation

programs. We will discuss these practices and strategies in more detail throughout the chapters of this book.
https://www.dol.gov/agencies/eta/wioa.

Home and Community-Based Services, Final Settings Rule 2014

The federal Home and Community-Based Services program, also called HCBS, provides opportunities for eligible Medicaid beneficiaries to receive services in their home or community instead of institutions or other program settings that isolate people with disabilities. In 2014, the Center for Medicare and Medicaid Services (CMS), the federal agency that oversees HCBS, issued updated guidance to states concerning new “settings criteria” that must be associated with the delivery of HCBS.

HCBS programs operate under the umbrella of the Medicaid Waiver and are, therefore, a major source of funding for community services delivered in support of eligible adults with IDD, complex physical disabilities, and behavioral concerns. Often referred to as the “Final Settings Rule,” the new guidance by CMS clarifies that HCBS participants must have access to the full benefits of community living, including their right to receive services in integrated, non-institutional settings. This new guidance strengthens the rights of individuals to make informed choices about their desired community living outcomes. This includes aligning where HCBS services and support must be provided in support of these outcomes.
(Center for Medicaid and Medicare Services,
https://www.cms.gov/newsroom/press-releases/cms-issues-new-guidance-state-implementation-home-and-community-based-services-regulation).

For many decades, the federal HCBS program has been grounded in a medical model of policy, treatment, and therapeutic services. For this reason, it has never been an ideal fit for planning and engaging services leading to vocational or employment outcomes. With this said, CMS has updated Medicaid Waiver regulations to make CIE an accessible goal. The HCBS Final Settings Rule is another step in the right direction to guiding the possibility of a self-determined life.

National and State Employment First Policies and Initiatives

One of the most exciting developments in the disability employment space in the past decade has been the rapid growth of our nation’s Employment First movement. According to APSE, there is evidence of Employment First efforts taking place in every state. As of this writing, 31 states have passed Employment First legislation, 16 states have Employment First Executive Orders, and 32 states have administrative policies or regulations in place in support of Employment First practices. Also, it is common for states to have combinations of legislation, Executive Orders, and/or State Agency administrative policies prioritizing Employment First efforts.
(National APSE, https://apse.org/about-2/employment-first-copy/)

What is Employment First? National APSE defines Employment First as follows:

> Employment First means that employment in the general workforce should be the first and preferred option for individuals with disabilities receiving assistance from publicly funded systems. Simply put, Employment First means real jobs, real wages. (APSE Employment First Fact Sheet)

While Employment First policies contain variations in their provisions and directives state by state, there is unmistakable evidence that the national landscape is shifting due to local grassroots efforts. These efforts are resulting in stronger alliances by a cross-section of state and local governmental agencies, as well as partnerships with disability advocacy agencies and private service providers to help translate Employment First policies into direct service practices. The goal is for national and state Employment First efforts to measurably increase CIE outcomes by investing financial resources and focusing energies on evidence-based practices that will result in workforce participation.

In addition, it is a goal that Employment First policies will elevate expectations among all stakeholders that CIE is an attainable goal for many marginalized people due to the complexities of their disabilities. Employment First Champions aspire to impact the learning of business leaders as well, so they recognize it makes good business sense to hire workers with a wide range of abilities to meet their goals. Finally, Employment First advocates hold out hope that people with disabilities will come to recognize that their best life is one that includes working in a well-matched job in the labor force.

As a professional who was actively involved in the Employment First movement, I can attest to its strong impact in laying a new foundation for social and economic justice. However, social and economic change is challenging work. Slow, incremental gains have characterized the historical evolution of disability services in the past 50 years. We have moved from business models of institutional care to smaller models of community care that retained many of the same elements of institutional care, albeit more humanely. Today, we have reached the precipice of what is possible by recognizing that people living with disabilities are individuals, not members of a disability group. They have unique interests, abilities, and gifts to share, and we must move forward with this understanding in both policy and practice.

What is stopping us? Let us move ahead to Chapter 2 to discuss these concerns.

CHAPTER 2

THE AXIS OF INERTIA

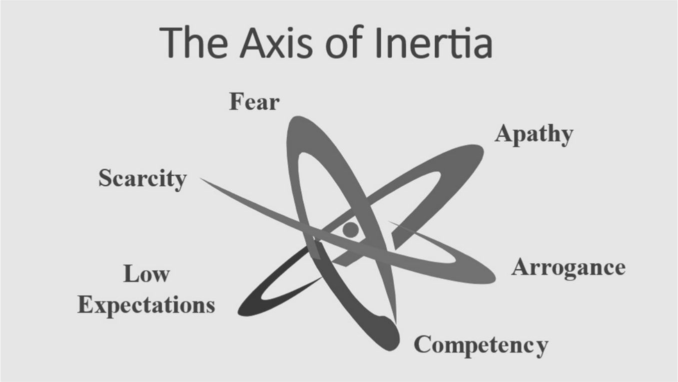
Vision without Action is just daydreaming,
Action without Vision is merely biding time,
But vision plus action can change the world.
—Joel Barker, Futurist

I learned early on in my work in the disability employment space that it was going to take much more than landmark legislation or court mandates and directives to move the needle in the direction of an inclusive, working life for people living with disabilities. Words do matter and the vision of social and economic policy change must be articulated in clear, written words. However, true transformational change is grounded in action.

In 2007, my colleague Dale DiLeo authored a seminal book in the disability employment space entitled *Raymond's Room: Ending the Segregation of People with Disabilities*. In this publication, DiLeo used the term "disability industrial complex" and called out the stubborn resistance to transformational change by disability service providers that deliver legacy services despite growing evidence of more effective practices. (DiLeo 2007).

For five decades, I observed this strong resistance to change by policymakers, service providers, professionals, family members, and even people with disabilities. We are often told to "follow the money" to understand better why transformational change is so strongly resisted. There is no question that money is a central element in this equation. However, changing the current state of the disability service and support systems to achieve better outcomes is far more complex than simply reinvesting public financial resources.

So, what happens when the unstoppable force meets with the immovable object? I refer to this phenomenon in the disability employment space as 'The Axis of Inertia: the Six Enemies of Transformational Change.' These 'enemies' are fear, apathy, arrogance, competency, tokenism, and scarcity. They operate both independently and collectively to immobilize required actions and maintain the status quo of disability support systems, organizations, programs, services, and outcomes.



Let us take a closer look at each of these ‘speed bumps’ slowing down our progress.

Our first enemy of change is fear. Fear says: “We can’t do this because __fill in the blank__.” Enter your selected worry or concern in the space provided. There are so many! Here is a short sample of fears I often hear expressed:

- People do not want to work.
- People do not work fast enough.
- People do not have the abilities or skills to work competitively.
- People are not flexible enough to work competitively.
- People do not respond well to change.
- People have maladaptive behaviors.
- People do not have the tolerance to work a full-time job.
- Employers or co-workers will not accept people.
- Companies do not have the time to support employees with complex disabilities.
- Companies do not have the knowledge or skills to supervise employees with disabilities.
- People will miss their friends and co-workers in the sheltered workshop.
- People are vulnerable and could be exploited by others.
- People will lose their disability and healthcare benefits.
- People who go to work in the open labor force will be unable to access other rehabilitative or therapeutic services.

- It will cost too much money to support individuals in the open labor force.
- People do not have access to transportation.
- Direct Service Professionals (DSPs) working in sheltered workshops or center-based programs will be left behind if we adopt new service practices.

Does any of this sound familiar? Have I missed any? The range of expressed fears or concerns is voluminous. Moreover, if you examine closely, a majority of perceived fears are cloaked in elements of truth.

To illustrate this point, consider just a few examples. “People don’t work fast enough” is highly circumstantial. This might be true in jobs that are poorly matched or in job conditions where work speed is an essential requirement. Another example is “people don’t have access to transportation.” This is only true until alternative transportation options are developed in support of a job seeker. Finally, “people will lose their friends in the sheltered workshop.” This concern is shortsighted as friendships can certainly be maintained in other ways once people transition to new jobs. Also, it does not consider the possibility that new friendships are waiting to be developed in the open labor force.

When I hear about these fears, both real and unfounded, I am reminded of a quote attributed to the late civil rights advocate, Nelson Mandela. He once said: “It always seems impossible until it is done.”

The second enemy of change is apathy. Apathy says: “If it ain’t broke, then don’t fix it.” It is common to hear positive expressions such as “People are very happy here.” Or “people like the jobs they have and don’t want to change.” I have even encountered assertive pushback, such as “people can leave the workshop if they want to.” And a more aggressive “no one is chaining people to their chairs to work here.”

Once again, some points of view are embedded in half-truths. People with disabilities may respond positively to their present-day circumstances because “they don’t know what they don’t know.” It is important to remember that many people participating in sheltered workshops or center-based day services were not guided to their outcomes through a contemporary process of person-centered planning. Further, many have a limited fund of education, life experiences, and work histories to outweigh the benefits of alternative pathways and opportunities.

Apathy is often embedded in false arguments. When we drill down to granularity, would people push away opportunities to work in real jobs better matched or customized to their unique interests and skills? Would people object to leaving subminimum wages to earn equitable wages and benefits? Would people reject opportunities to work alongside co-workers who do not have disabilities? Would people be disappointed by having more disposable income, attaining higher levels of social inclusion, or being empowered to live a self-determined life?

The third enemy of change is arrogance. Arrogance says: “How dare you question my professionalism, credentials, knowledge, motives, values, or many years of experience!” Arrogance is an end product of ego and may be expressed by defensiveness. Attitudes about transformational change are sometimes shaped by a stubborn “determination to be right” rather than being open to ongoing learning to better skills and practices.

Arrogance is sometimes observed in well-meaning family members who believe they are acting in the best interests of a loved one. Moreover, it can certainly flow from leaders, managers, and DSPs who are highly invested in legacy disability programs and services.

To illustrate this point, I recall launching a school-to-career transition program that was secured with federal funding to introduce the emerging concepts of Discovery and Customized Employment in support of youth with disabilities. Among our project partners was a large secondary education program very set in its ways in the delivery of school to adult transition services. This school system employed a tenured team of special educators, many of whom had decades of teaching experience. The truth is that several were very offended by proposals to adopt innovative ideas. The new employment consultants hired represented threats and innovative disruptions to the daily routines of these educators. This project was a documented success over a five-year demonstration period. However, the challenge was winning over the support of a few educators in accepting “there may be better practices” in support of students who were not benefiting from standard transition services.

The fourth enemy of change is competency**.** Competency (the lack thereof) says: “I want to get better employment outcomes for the people I support, but I do not know what to do or how to do it.”

Success in workforce recruitment, skills development, and staff retention are fundamental to achieving transformational change. However, a majority of DSPs supporting people with disabilities are lacking in the essential fund of knowledge and competencies to deliver on the promise of achieving CIE outcomes.

Why is this so?

In my consulting work, I have observed a lack of alignment among the stated vision, performance goals, staffing pattern, and service practices of sheltered workshops and center-based programs, hoping to transform their outcomes to CIE.

First, the staffing structures are commonly siloed with wide separation in job functions between the employment and day habilitation service staff. Also, it is a widespread practice to employ just one or two professionals assigned to duties of job placement or employment development. In addition, the organization might employ one or two staff with the core duties of job coaching or ongoing employment support. In most circumstances, organizations have few, if any, DSPs trained and certified in the delivery of Discovery and Customized Employment. Therefore, the remaining balance of DSPs and the largest share of budget resources are allocated to the service space of sheltered work or day habilitation services.

Of course, the genuine solution lies in “the math.” No organization will reach critical mass in obtaining CIE outcomes until its budget and staff competencies are realigned to deliver practices that will lead to the desired change. Organizations do not advance by chance. There is no evidence that DSPs hired to deliver legacy disability services will deliver on the promise of CIE without retraining and refocusing on evidence-based practices.

A widescale transformation will remain an elusive goal unless there is a corresponding, incremental overhaul of an organization’s current workforce. Simply stated, the professional competencies needed today to achieve measurable systems change will not be realized by skill sets learned in the past.

The fifth enemy of change is tokenism**.** Tokenism says: “Of course, we believe in the importance of CIE. Our agency does help ‘*some*’ participants obtain CIE.”

Tokenism is a form of narrative shielding. While it protects organizations from criticism, it reveals an underlying current of bifurcation in vision, values, and strategy. It communicates that some people with disabilities are able to work in the open labor force, but others need the protection and support of a controlled, sheltered work or non-work environment.

Tokenism often leads to mixed messaging and confusion. On one hand, we persuade key stakeholders, such as business leaders, that hiring people with disabilities, including those with significant disabilities, makes good business sense. Nevertheless, we operate and sustain workshops and centers we control that communicate a completely different message.

Sometimes, tokenism is cloaked in the message that disability program services are much like a buffet. People can choose from the service options available to them based on their unique interests and needs. This sounds very appealing until we realize that 80% of people at the buffet are choosing the same meals… that is, disability programs serving outcomes of segregation and jobs at subminimum wages.

Of course, people do have a large appetite for options and opportunity, but these are in far greater abundance in the open labor force and local community.

Finally, the sixth enemy of change is scarcity. Scarcity says: "Transformation sounds great but we do not have the staff capacities to introduce change. We can barely staff the program we are running now! If we only had more money, staff, transportation, or __fill in the blank__, we would be better able to meet the CIE goals of the people we support."

Let us begin this discussion by acknowledging that there is a full-blown national crisis in the availability of skilled workers to support all human services fields in the United States. Moreover, this workforce shortage definitely impacts the quality of job applicants and the ability of organizations in the disability employment space to deliver service excellence. There is little question that we need to work collectively to increase public financial investments in disability support systems to build a stable, trained, competent, and sustainable workforce to achieve the stated goals of public policies and the promise of attaining a working, inclusive community life.

Public investment in disability services and support systems at both the federal and state levels has grown exponentially over the past 50 years. Billions of dollars are spent annually in support of Americans with disabilities through Medicaid waivers, social security, VR, and a wide array of community living and support services.

The point being made is that we already have a significant level of public investment in support of people with disabilities. Furthermore, the basic concern is not how much is being spent but how it is being spent. Of course, it will cost money to transform existing disability support systems, but we cannot assume the public cost of transformational change will be borne out of new money alone. We need to work more effectively to reallocate how money is spent so the money follows the person.

In a country blessed with great abundance, our disability support systems remain mired in the concept of scarcity. In my view, we not only need to rebuild the internal capacities of services and support systems but also rethink new ways to leverage these capacities from outside our internal support systems. Our public policies embrace a vision of full inclusion, but this is not measured only by a person's physical presence; it is best measured by genuine membership and belonging. To me, this means working to build natural supervision, supports, and friendships on the job as well as in the community.

This may not be popular to say but some stakeholders in our field cannot envision a future state where disability support professionals are not only in it but controlling it. The result is that we have unnecessary obligations to individuals who are 'overserved.' This is true both in facility-based services as well as in the competitive labor force. Until we work to reallocate customary time commitments to business leaders, we will struggle to extend the necessary support to individuals with the highest service needs.

When public policy and organizational leaders in the disability employment space tell me we cannot afford to pursue transformational change right now because of staff shortages, I try to tell them, "We can't afford not to."

The Axis of Inertia presents formidable challenges to organizations seeking transformational change. Are there known antidotes to address these challenges? Let us examine some ideas.

1. Calming Fears

One of the best ways to address unfounded fears is to tackle them head-on. I recommend that Employment First leaders and practitioners take time to consider and answer the challenging questions before they are asked. This should include developing a FAQ document to share facts, correct misinformation, and cultivate a level of trust. Employment First leaders do not shrink from their obligation to address expressed concerns, and they stay