



Reach Out e-Diversity News

An Electronic Publication of the Ohio Developmental Disabilities Council

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April 2015 Edition | Volume 9, Issue 2

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Read, Pass on to Friends, Family Members, Colleagues & Constituents



Ohio at a Crossroads: The Developmental Disabilities System

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Diversity Leaders: 6 Things NEVER to Say About Disabilities



Differing abilities are a part of healthy diversity. It's our business to promote inclusiveness throughout our organizations and to advocate for policies and programs that support it.



Where Are the CEOs and Executive Managers with Disabilities?

As we prepare to celebrate the 25th anniversary of the passage of the 1990 Americans with Disabilities Act (ADA) on July 26, I cannot help but ask, how many corporate CEOs, presidents or high-level executives with disabilities easily come to mind?

Why April is Important to Me



Four years ago, April would come and go without much fanfare. I call this "the before", which is a time when the most exciting event would be Easter dinner and the occasional egg hunt.

Then December 6, 2011 happened.

Take our Survey! [Take the ODDC Survey](#)

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Ohio at a Crossroads: The Developmental Disabilities System

By Rose Frech, Fellow, Applied Research; Jon Honeck, Ph.D, Director of Public Policy and Advocacy; Kate Warren, Graduate Assistant, Cleveland State University, Maxine Goodman Levin College of Urban Affairs

This report was prepared with support from The Cleveland Foundation

An Overview of the Developmental Disabilities System in Ohio

The Ohio Department of Developmental Disabilities (DODD) provides general oversight to the state's system of supports and services for individuals with developmental disabilities. Locally, County Boards of DD are responsible for facilitating these services. County Boards serve nearly 90,000 individuals each year; about half are adults. While historically service provision has favored institutional settings, the pendulum has swung toward a preference for community-based services and independent living, which decrease isolation and increase integration for individuals with developmental disabilities. Finding the proper balance is an ongoing discussion across the state and country.

ICFs and Developmental Centers

A range of services and supports are available for individuals with developmental disabilities, including various residential



options. Intermediate Care Facilities (ICFs) include both privately operated facilities, Board-operated facilities, and 10 state-run Developmental Centers (DCs). In 2014, these residential options accounted for about 6,700 beds. The size of these facilities varies; while many are smaller and more "home-like," others are large and deemed by many to be "institution-like." In total in 2014, almost 3,000 individuals lived in facilities with more than 16 beds, while only 529 were living in six-bed or smaller facilities.

The advocacy group Disability Rights Ohio recently called into question the state's heavy reliance on ICFs, which many believe promote segregation, impede the rights of those with

developmental disabilities, and may violate federal law. 2,500 individuals currently living in ICFs are on waiting lists to leave and receive services in the community. The state is currently working to convert ICF beds to Medicaid Waivers, which allow individuals to waive their right to institutional care in favor of receiving services in a home- or community-based setting. Relatedly, efforts are underway to decrease the size of large-bed facilities. To date, these efforts have been slow. And, because the state pays the nonfederal Medicaid match for ICFs, Boards may have a financial incentive to direct individuals into ICFs rather than onto Waivers, where county Boards are responsible for the nonfederal Medicaid match.

Medicaid Waivers

Waiver programs include services such as non-medical transportation, employment and day services, nutrition assistance, respite for caregivers, certain therapies, accessibility modifications, and personal care assistance. These services

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allow individuals to live in the community. Ohio currently has four DD waiver programs that serve people with different types and levels of need, including the Individual Options (IO) Waiver, the SELF (Self Empowered Life Funding) Waiver, Transitions (TDD) Waiver, and the Level One Waiver. As of February, 2015, over 35,000 people were receiving services through DD waivers across the state. Since 2002, Waiver growth has quadrupled. DD waiver reimbursement in Ohio totaled approximately \$1.5 billion in 2014.

As of October, 2014, there were over 45,000 people on the waiver waiting list across the state. The median wait time is about 6.4 years. A 2014 study suggests that approximately 22,000 individuals on waiting lists had current unmet needs for services. The number of individuals on waiting lists varies significantly by county, but overall, DODD reports that the statewide list grows by 100 to 200 individuals each month. Several counties only remove individuals from the waiting list on an emergency basis or as other individuals with waivers no longer

require these services, due to death or relocation.

Many factors contribute to long waiver waiting lists, including a lack of adequate local funds to make the match. However, data demonstrate that funding alone does not determine waiver accessibility. County Boards may elect to divert available funds to other programming. Given the many restrictions and requirements tied to waiver services, counties may be reluctant to expand their Waiver programs for fear of losing local control. The IO Waiver, the most frequently utilized waiver, has no monetary cap, and boards may be cautious to offer new waivers without knowing what their contribution will be in future years.

Day and Employment Services

Ohio's developmental disability system also includes services that offer support for social and employment needs. Medicaid is the primary payer for most day and employment supports, though County Boards often heavily supplement this funding. Adult day programs engage individuals, teach life skills, help with social interaction,

and provide opportunities for community integration. Adult programs may also be vocational in nature, including facility-based sheltered workshops. Another more independent and integrated option is community employment, with support services such as job coaching or aides as needed. Many advocates argue that sheltered workshops and adult day programs segregate individuals with developmental disabilities from the community, do not provide adequate employment training, and often pay less than a minimum wage. Others praise the benefits of sheltered work, maintaining that many individuals with developmental disabilities cannot fully adjust to community employment, and will face harassment or bullying, and that local communities are not ready and willing to accept integrated employment.

Ohio's Employment First Initiative emphasizes the importance of integrated employment for all persons with developmental disabilities and consequently is working to design a funding system to shift resources to accommodate that vision.

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However, since its inception, Employment First has not led to significant change in the employment landscape throughout the state.

System Funding

Ohio's funding structure is unique in that a large percent of its funding for services for persons with developmental disabilities comes from local revenue streams, primarily property tax levies. Due to this reliance on local money, discrepancies in funding across the state are vast. On average, Boards spend about \$14,500 per individual served, ranging widely from less than \$5,000 in several Ohio counties to over \$20,000 in many others. In some cases, this means that Ohioans with developmental disabilities can't access equitable services. However, increased funding doesn't always lead to increased access to community-based services. Counties may elect to spend money on less-integrated services.

CMS Rule Change

Ohio is preparing to implement changes to Medicaid rules that have narrowed the types

of settings in which Medicaid reimbursable services can take place, with a greater emphasis on integrated, community-based settings and outcomes. This will have a significant impact on services.

- Sheltered work and day services, as they have traditionally been delivered in Ohio, will no longer meet the requirements outlined in the new rules, as these settings largely isolate individuals and don't allow for full access to the community.
- The CMS rule calls for "conflict-free" case management. Boards directly employ Service and Support Administrators who complete eligibility determinations, develop service plans, and connect people to recommended services. In addition to this case management service, many County Boards also provide services *directly* to individuals, including Medicaid waiver home-and community-based services. According to CMS, there is an inherent conflict of interest in this structure.

States will have as many as five years to come into full compliance on the new rule; Ohio is requesting 10 years for certain provisions, including those described above. Transition plans were submitted to CMS in mid-March, 2015.

The Governor's Budget

In February, 2015, Governor John Kasich announced his 2016-2017 biennial budget, which requires approval by the Ohio legislature. The Budget included substantial investments in developmental disability services: \$112 million above 2015 levels over the course of the two years. DODD has announced that, if approved, spending would target ICF downsizing efforts, increased funding for community employment, and most notably, the addition of 3,000 HCBS Waivers.

Key Recommendations for System Change

As a result of our research, we recommend the following changes to improve the Ohio developmental disabilities system.

- Develop a long-term solution

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to the state's complex Waiver problem. The current system is not sustainable. This should include examining options to increase the financial capacity of counties and additional state-funded waivers.

- Increase funding for Employment First. Improve the partnership with Opportunities for Ohioans with Disabilities (OOD) and streamline access to employment services.
- Implement changes to accelerate ICF downsizing and conversion, including decreasing rates for beds serving those with lesser

levels of acuity.

- Add additional housing supports to fully support community integration.
- Undertake an examination of the SELF Waiver to remediate barriers to use.
- Assess waiting lists to identify who has the greatest levels of unmet need and assure that these individuals are targeted for enrollment in the most appropriate Waiver.
- Increase collaboration among Boards to lead to cost savings and increased efficiency.

For more on the Governor's budget, a complete set of



recommendations, and much more information on the DD system in Ohio, read the [full report](#).

Questions? Contact Jon Honeck at [jhoneyck@CommunitySolutions.com](mailto:jhoneck@CommunitySolutions.com) or Rose Frech atrfrech@CommunitySolutions.com.

Did You Know?

Federal education officials are fielding an increasing number of complaints related to disability discrimination in the nation's schools. More than 3,900 complaints based on disability were filed with the U.S. Department of Education's Office for Civil Rights during the 2014 fiscal year, the most recent period for which statistics are available.

"It does not matter what sixty-six percent of people do in any particular situation. All that matters is what you do."

—John Elder Robison, author of Look Me In the Eye

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Diversity Leaders: 6 Things NEVER to Say About Disabilities

By Lori Golden

Ernst & Young AccessAbilities™ Leader

“The difference between the right word and the almost-right word is the difference between lightning and the lightning bug.”
—Mark Twain



As diversity leaders, we understand that disability is just another kind of difference, like culture, ethnicity, gender or sexual orientation. We recognize that diversity is a valuable source of insight and adaptability, generating better business ideas and high-quality service. Differing abilities are a part of that healthy diversity. It’s our business to promote inclusiveness throughout our organizations and to advocate for policies and programs that support it.

In building an inclusive culture, we’re on the front lines and need to be visibly living our organizations’ values every day. It’s important that we set the tone not only in what we do and say, but *how* we say it—in formal messaging as well as everyday conversation. This is where even

diversity leaders can get stuck.

Sometimes inclusive language can seem a bit cumbersome, but with a few simple changes each of us can make a significant difference—helping to promote an inclusive culture while setting an example both inside and outside our organizations. Here are six ways never to talk about disabilities:

1. Never say “a disabled person” or “the disabled.” Say a person or people “with disabilities.”

Put the person first. A disability is what someone has, not what someone is. For instance, “mentally ill” is less respectful than “person with mental-health issues.” “Retarded” is never an appropriate term. Say “intellectual disabilities” or “cognitive disabilities.”

2. Never use the term “handicapped parking.” Use “accessible parking” instead. Handicapped parking is still in use (e.g., when referring to

parking placards), though the word “handicapped” is offensive and has been virtually eliminated in most other contexts. Remove it from your organization’s vocabulary completely by using the term “accessible parking.” (It’s also more accurate, as accessible describes the parking and handicapped does not.)

3. Never use the term “impaired.” Use terms such as “low vision,” “hard of hearing” or “uses a wheelchair” instead. Though it may be used in legal contexts, the word “impaired” can be offensive, as it implies damage. Many people with disabilities do not see themselves as damaged, but simply as different.

4. Never say “hidden” disabilities. Say “non-visible” or “non-apparent.” Many disabilities are not apparent, such as serious illnesses or chronic health conditions, sensory limitations, or mental-health and learning disabilities. When referring to these disabilities,

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avoid using hidden, as it has negative connotations, implying purposeful concealment or shame.

5. Whenever possible, don't say "accommodations." Say "adjustments" or "modifications." This can be tricky, as accommodation has a specific legal meaning and must be used in certain contexts, like policy or government communications. However, accommodation suggests doing a favor for the person who has a disability. An accommodation is a workplace or work-process modification made to enable an employee to be more productive. It is necessary and not a preference or privilege. The terms adjustment and modification capture this idea without suggesting a favor or special treatment, so are preferable whenever specific legal terminology is not required.

6. Never use victim or hero language; describe situations in a straightforward way.

Don't use language that portrays people with disabilities as victims, such as "suffers from," "challenged by," or "struggles with." Say "someone who uses a wheelchair" or "wheelchair user," not "wheelchair-bound" or "confined to a wheelchair." On the flip side, don't use heroic language when people with disabilities complete everyday tasks and responsibilities. People with disabilities don't see themselves as inspiring simply because they're going about their daily lives. We all have challenges—working around those challenges is not heroic, it's just human.

What Terminology Should I Use?

As champions of diversity, we have the opportunity—and the responsibility—to set standards for how our people, organizations and society speak and think about

people with disabilities. By shifting our language, we can help shift perceptions and promote the culture of inclusion that is the backbone of healthy diversity in all aspects of life.

Golden leads Ernst & Young's internal initiatives in the Americas to create an enabling environment and inclusive culture for people working with disabilities. She works with Ernst & Young AccessAbilities™, the firm's disabilities-focused Professional Network; consults on work adjustments and career development; drives efforts to enhance ergonomics and accessibility in offices, communications, meetings, trainings and technology; and educates Ernst & Young's people on disabilities-related issues. (reprint from Diversity Inc.)



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Where Are the CEOs and Executive Managers with Disabilities?

By John D. Kemp

President and CEO of The Viscardi Center

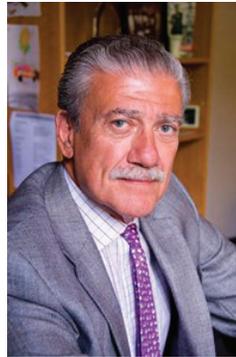
As we prepare to celebrate the 25th anniversary of the passage of the 1990 Americans with Disabilities Act (ADA) on July 26, I cannot help but ask, how many corporate CEOs, presidents or high-level executives with disabilities easily come to mind? Although I use four prostheses and steer a large not-for-profit in the New York metro area, I can only rattle off a few CEOs with a disability. While we're seeing broadened gender and ethnic diversity at the top of the ladder, people with disabilities are still lagging when it comes to making it to the C-suite.

The lack of individuals in leadership roles is reflective of the employment woes people with disabilities are still experiencing. While the road towards this landmark anniversary includes many accomplishments, the employment of people with disabilities continues to be an area where we've barely moved the needle. We're still seeing an outrageously low labor force participation rate, the percentage

of people who are working or actively looking for work, by individuals with disabilities. The February 2015 labor force participation

rate for people with disabilities, according to the Bureau of Labor Statistics (BLS), was 19.8 percent, compared to 68.2 percent for people without disabilities. If well-educated, qualified individuals aren't even in the workforce, how could they possibly climb the corporate ladder, or shall I say 'ramp'?

Let's look at ADA25 as a means of drawing attention to this continued challenge. If you are an employer, we need your "buy in." You hold the keys to unlocking employment opportunities at all levels for people with disabilities. There is more untapped, educated talent out there than



John D. Kemp

ever before. Embrace it. Recruit and hire people with disabilities. Advance those already within your organization and diversify your thought leadership.

Seek resources to assist you. There is a plethora of free resources available to employers such as the [Employer TA Center](#)— short for the *National Employer Policy, Research and Technical Assistance Center for Employers on the Employment of People with Disabilities*. The Employer TA Center is a free resource for employers seeking to foster a workplace culture inclusive of people with disabilities. Funded by the U.S. Department of Labor's Office of Disability Employment Policy (ODEP) under a cooperative agreement with The Viscardi Center, the Employer TA Center delivers technical assistance to employers seeking to recruit, hire, retain and promote qualified employees with disabilities through publications, training, webinars, a workforce recruitment program (WRP) and the Employer

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Assistance and Resource Network (EARN) website, AskEARN.org.

Putting more people with disabilities to work is beneficial to all. There is much to be said about the power of work. The confidence and self-worth, the way in which others view us and we view ourselves, and the independence that comes along with earning a paycheck. All of which translate into active participants in our communities who have the financial resources to care for themselves, and their families, and reduces the need for services and supports from governmental and human services organizations.

If you are a working individual with a disability, you, too, have an important role to play. I implore you to stand up and be counted.

Take pride in your disability and the value you bring to the workplace each and every day. If you haven't already done so, I encourage you to choose to disclose your disability. As long as you're qualified, push for advancement. You rightfully belong in C-level and executive management positions.

Remember, you serve as a mentor, a role model and instill disability pride in our younger generations.

I want to see every individual with a disability who wants to work have the chance to be employed.

I want to be able to name many CEOs and high-level business professionals with a disability. I can only hope it doesn't take another 25 years to come to fruition.

John D. Kemp is the president and CEO of The Viscardi Center, a network of nonprofit organizations that provides a lifespan of services that educate, employ and empower children and adults with disabilities. He is widely respected for his achievements in the corporate and nonprofit worlds. As a person with a disability who uses four prostheses, Kemp inspires others to achieve the impossible through knowledge, experience, vision, personality and persistence.

Did You Know?

Three books are being honored for their portrayal of the disability experience through a special set of awards given alongside the well-known Caldecott and Newbery Medals.

The winners of this year's Schneider Family Book Awards include tales of a boy who stutters, a girl with autism and young adults with intellectual disabilities during transition.

The Schneider awards are presented annually by the American Library Association to authors or illustrators for the "artistic expression of the disability experience."



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Why April is Important to Me

by Melissa Solares

Autism Speaks' Grassroots Advocacy Co-Chair



Why is April so important to me?

Four years ago, April would come

and go without much fanfare. I call this "the before", which is a time when the most exciting event would be Easter dinner and the occasional egg hunt.

Then December 6, 2011 happened.

It was my son's 4th birthday. All I wanted to do was celebrate and eat some cupcakes. My sweet little boy was diagnosed with autism. So we had the cupcakes and the balloons and presents but I didn't enjoy any of it.

His big, beautiful hazel eyes were no different than they were the day before, and his sweet voice sang the same 82 stanzas of the wheels on the bus the exact same way but that day changed a lot of things. We realized why I couldn't potty train him after two laborious

years of trying. What we thought was once just a significant speech delay, was so much more.

In all the haze of pregnancy jitters, I never once thought there may be a possibility that I may never hear my child call me "Mommy" or tell me that he loves me or be able to choose between Brussels sprouts and pizza. I never even thought of it. But there it hung like the birthday balloons all the around the room - the reality that my son does not speak and may never speak.

Thinking about that day three years later still gives me pause. What I realized after his diagnosis was how ill prepared I was for it. I had read all of the baby books and magazines. I was up to date on medical literature and recommendations. We didn't use a bumper in his crib. I breast fed exclusively. We did no expose him to TV or electronic devices. Despite all of my rigorous research I had no idea

what autism really was or what I could do to help my precious little boy! We went home that day and let him open his presents and sat feeling lost and alone. We had no idea who to call or what to say.

So we got online. We researched. We read. We fumbled through the first six months trying different treatments and providers until we found one that seemed to work. And my son started making dramatic improvements. He started speaking. At four and a half he was finally saying words!!!! So we continued providing treatment, draining all of our savings. But in exchange my child found his voice, which was more meaningful than any bank account balance.



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I am so thankful for that treatment and that we were able to mitigate some of the more disabling symptoms of autism for my son. I believe very strongly that everyone that would like to have access to resources or support should have it. We, as a society, would be absolutely horrified if a person had to do without needed treatment in any other scenario. So why do people with autism have to do without?

Having gone through my own experience, I am committed to changing some of the harder issues to navigate for others experiencing a new diagnosis. The first place to start is still with awareness. I come across people daily that have only a vague-Rainman-like understanding of autism. So we light it up blue, as blue as we can make it, and we ask all our friends and neighbors to light it up as well in honor of all of the people living with autism across the world. We also ask for

politicians to make proclamations like the one Mayor Hardie Davis just presented to the autism community in Augusta, Ga. I would like to personally thank Mayor Davis for always listening and supporting autism legislation and, more importantly, people in our community!

As a parent, showing up and asking for awareness is important, asking our neighbors and our leaders at every level. We have to keep showing up and keep asking for awareness even when it isn't comfortable. We must continue until we are heard! Someone once told me that we need so much awareness that we get acceptance and that is my goal. I will continue to light it up, and engage my politicians locally and nationally, and talk about autism until we have a world that understands that neurology can be different and those differences need to be understood, accepted and supported.

So, please join me and light it up blue this April! Wear blue and start the conversation with people you come in contact with in daily life at the grocery store, the dry cleaners, that pest control guy, the bank tellers, our neighbors, coworkers, college friends.

Raise awareness and then spur them into action. Register for the Autism Votes program. Raise your hand in your community to answer the call for volunteer grassroots leadership positions.



**Light it up. Get involved.
Change the world.**

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