Webinar title: The Disability Integration Act & Why it Matters to You

Presenter: Stephanie Woodward, JD, Director of Advocacy, Center for Disability Rights
Sunday June 11:
Arrival and Welcome Reception

Monday June 12:
Education Sessions, Speaker Panels and Presentations, Advocacy Training, Sponsor Expo

Tuesday June 13:
Capitol Hill Meetings, Congressional Awards Reception

Wednesday June 14:
Advocate Recognition Breakfast

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THE DISABILITY INTEGRATION ACT

Creating an absolute right for all people with disabilities to live in the community
DISABILITY INTEGRATION ACT: BASICS

- Major Disability Rights Legislation

- Senate Bill S. 910
  - Minority Leader Schumer (D-NY)

- House Bill H.R. 2472
  - Congressman Sensenbrenner (R-WI)
CURRENT DISABILITY ORGANIZATION SUPPORT OF DIA, 1 OF 3

- ADAPT
- adaptive adventures
- Advance CLASS
- Advocates for Justice
- American Association of People with Disabilities (AAPD)
- Association of Programs for Rural Independent Living (APRIL)
- Association of University Centers on Disabilities (AUCD)
- Autistic Self Advocacy Network (ASAN)
- Bazelon Center for Mental Health Law
- Brain Injury Association of America
- Center for the Human Rights of Users and Survivors of Psychiatry
- Disability Rights Education & Defense Funds (DREDF)
- DREAM - Disability Rights, Education, Activism, & Mentoring
- Everyday Psych Victims Project
- Griffin-Hammis Associates, Inc.
CURRENT DISABILITY ORGANIZATION SUPPORT OF DIA, 2 OF 3

- Law Project for Psychiatric Rights
- Leadership Conference on Civil and Human Rights
- Little People of America
- Medicare Rights Center (MRC)
- MindFreedom International
- National Academy of Elder Law Attorneys (NAELA)
- National Coalition for Mental Health Recovery
- National Council on Aging (NCOA)
- National Council on Independent Living (NCIL)
- National Disability Leadership Alliance (NDLA)
- National Disability Mentoring Coalition
- National Disability Rights Network
- National Down Syndrome Congress
- National Organization of Nurses with Disabilities (NOND)
CURRENT DISABILITY ORGANIZATION SUPPORT OF DIA, 3 OF 3

- Not Dead Yet (NDY)
- Paraprofessional Healthcare Institute (PHI)
- Parent to Parent USA
- Post-Polio Health International
- Self Advocates Becoming Empowered (SABE)
- Service Employees International Union (SEIU)
- Solve ME/CFS Initiative
- TASH
- The ADA Legacy Project
- The Community Consortium
- The Congress of Disabled Persons Against Exploitation
- The Sunrise Group
- Transverse Myelitis Association
- United Spinal Association
CURRENT SYSTEM: SEPARATE AND UNEQUAL

- Senate HELP Committee Report (2013):
  - “States Fail to Fulfill the Community Living Promise of the Americans with Disabilities Act”

- Nearly 25 years after ADA

- 14 years after *Olmstead v. L.C.*
WHY DO WE NEED DIA?

- States are not focused on transitioning people in facilities back into the community.

- States continue to put people in institutional settings.

- When people are transitioned, it’s unclear if they’re transitioned into the community.

- States should be reallocating institutional dollars to support community settings.
WHY DO WE NEED DIA?

- Senate HELP Primary Recommendation:

  “Congress should amend the ADA to clarify and strengthen the law’s integration mandate in a manner that accelerates Olmstead implementation and clarifies that every individual who is eligible for LTSS under Medicaid has a federally protected right to a real choice in how they receive services and supports.”
**DOES DIA AMEND THE ADA?**

- New Law
- Civil Rights, not Medicaid Programs
  - Rights follow People, but programs can be evaded
  - Constitutional Right: accurate & persuasive frame
- Establishes Right to Choose Where to Receive Services
CONSTITUTIONAL RIGHT

- Declaration of Independence:
  “We hold these truths to be self-evident: that all men are created equal; that they are endowed by their Creator with certain inalienable rights; that among them are life, liberty, and the pursuit of happiness...”
CONSTITUTIONAL RIGHT

“...all men are created equal...”

All Men? All People? Equal in all Rights?

What about disabled people?
DISABILITY INTEGRATION ACT

- Right to Live in the Community is Right #0 for the exercise of liberty and the pursuit of happiness.
- So fundamental that nondisabled people don’t even think of it as a right.
THE RIGHT FOR ALL PEOPLE WITH DISABILITIES TO LIVE IN THE COMMUNITY

- If we don’t have the right to live in the community, we can’t exercise our rights under the ADA.

- Without adequate community-based services and supports, we can’t live in the community.

- DIA recognizes in statute the right to community living.
**How does it work?**

DIA prohibits Medicaid & other insurance providers from denying community based services to an individual who is eligible for institutional placement.

“No public entity or LTSS insurance provider shall deny an individual with an LTSS disability who is eligible for institutional placement, or otherwise discriminate against that individual in the provision of, *community-based long-term services and supports* that enable the individual to live in the community and lead an independent life.”
What is a Public Entity or LTSS Insurance Provider?

- **Public Entity**
  - Funds or provides ADLs, IADLs, or Health Related Tasks
  - Is a State or Local Government

- **LTSS Insurance Provider**
  - Provides or pays for ADLs, IADLs, or Health Related Tasks
  - Operates in Interstate Commerce
**WHO IS AN INDIVIDUAL WITH AN LTSS DISABILITY?**

- Person with a disability under ADA, who:
  - Requires assistance with ADLs, IADLs, or Health Related Tasks
  - Is in an institution or at risk of institutionalization
What is Community-Based?

- Dwelling owned by the person or their family
- Dwelling rented under same terms as ordinary lease
- Group setting < 4 people with disabilities who:
  - Control of access of the home
  - Can eat whenever they want
  - Can come and go whenever they want
  - Have the same terms as ordinary lease
  - Do not have their tenancy tied to services (landlord cannot also be a service provider)
- Other settings *in the community*
What are Long-Term Services and Supports?

- Assistance with ADLs
  - Activities that people tend to do daily without help.
    - Eating, bathing, dressing, toileting, transferring

- Assistance with IADLs
  - Activities that allow a person to live independently.
    - Housework, meal prep, money management, care of others.

- Health Related Tasks

- Other tasks related to the above
Broad General Prohibition

If Medicaid or another LTSS insurance provider would pay for a person to go to a nursing facility, then that insurance provider must also pay for that person to receive the same services and supports to live in the community!
CHOICE, not FORCE!

- DIA does not undercut the ability of the individual to choose institutional placement.
- DIA does not restrict funding to assisted living and group homes.
- DIA simply ensures people with disabilities have a real choice.
WHAT ABOUT SPECIFIC PROHIBITIONS?

There are eleven specific prohibitions

- **Insurance providers cannot:**
  1. Screen out people by eligibility
  2. Impose service and cost caps
  3. Fail to provide a specific service
  4. Screen out by regulations & requirements
Specific Prohibitions

Insurance providers cannot:

5. Impose waiting lists
6. Provide inadequate payment to support a workforce
7. Fail to provide intermittent supports and services
8. Require the use of informal supports
Specific Prohibitions

Insurance providers cannot:

9. Fail to offer community based services before institutionalization

10. Fail to notify people in institutions of their right to live in the community

11. Fail to make reasonable accommodations to allow a person to live in the community
Does DIA Support Informal Caregivers?

- Yes!

- DIA makes it illegal to require people with LTSS disabilities to utilize informal supports.

- DIA also requires insurance providers to support informal caregivers.
Any other important aspects?

Yes!

Public entities **must** ensure that there is sufficient **affordable, accessible, integrated housing**.
HOW WILL THIS ACTUALLY WORK?

- **Regulations** released within **24 months**.

- Self-Assessments must be completed within **30 months**.

- Transition must be complete within **12 years**

- Incentive: 5% Federal Enhanced FMAP
  - Certain costs identified in Transition Plan
How will this actually work?

- DIA specifies what to do, not *how* to do it.
- States decide how they will get there.
- Federal Government reviews & incentivizes State plan.
ENFORCEMENT

- U.S. Department of Justice can bring cases against States and insurance companies for discrimination.

- Individuals can bring cases.

- Courts can award punitive damages.
What Can I Do To Help?

- Call your Senator!

- Call your Congressional Representative!

- Capitol Switchboard:
  (202) 224-3121

- Find Yours Here:
  [www.whoismyrepresentative.com](http://www.whoismyrepresentative.com)
RESOURCES

 Disability Integration Act:
  • http://www.disabilityintegrationact.org/

 Read the Bill:
  • https://www.unitedspinal.org/pdf_advocacy/SupportCivilRightsPeopleDisabilities.pdf

 Contact Me!
  • swoodward@cdrnys.org
To ask us a question or make a comment, please type it in the “Questions” box.

QUESTIONS?

THANK YOU!
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