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. 2427
  - Sponsor: Schumer (NY)

- Currently working on House introduction
  - Have your Representative contact Tony Cárdenas’ office about initial cosponsorship!
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
  - Civil Rights: accurate & persuasive frame
- Establishes Right to Choose Where to Receive Services
CIVIL RIGHTS

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...”
Civil Rights

“...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 prohibitions?

Yes!

Specific prohibition for public entities:

Public entities cannot fail to ensure that there is sufficient affordable, accessible, integrated housing.
HOW WILL THIS ACTUALLY WORK?

- Regulations released within 18 months.

- Self-Assessments must be completed within 12 months.

- Transition must be complete within 10 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 Representative!
- Capitol Switchboard: (202) 224-3121
- Find Yours Here: www.whoismyrepresentative.com
EDUCATE YOUR LEGISLATORS

Tell them why Disability Integration Act is important!

- Attendants are being lured away to better paying jobs
- People are unwillingly trapped because of lack of housing
- Those who cannot “self-direct” their services are left in institutions
SHOW THEM, DON’T TELL THEM!

- Share stories/examples –
  - I’m only 30, I’m too pretty for a nursing home and I belong in the community.
  - I take a pill every 8 hours. I shouldn’t have to be in an institution because I need someone to give me a pill.
SHOW THEM, DON’T TELL THEM PT. 2

- I’m in a consumer directed program that requires me to hire/fire/schedule another person for services and I am unable to do it. This should not be a reason I am forced out of my home and into an institution.

- Show them you are passionate about keeping people in their own homes!
QUESTIONS?

- Disability Integration Act: http://www.disabilityintegrationact.org/
- ADAPT’s info on DIA: http://www.adapt.org/main.diamain
- Contact Us: DIA@cdrnys.org