Background and Strategy

The Disability Integration Act establishes a comprehensive civil right to ensuring the full integration of people with disabilities and disabled seniors in the community. Instead of focusing on changing Medicaid, the legislation strengthens the ADA’s integration mandate in order to accelerate Olmstead implementation. This approach was selected for a number of reasons:

- The infrastructure to address this issue exists in Medicaid. We still lack a fundamental – and enforceable – right to freedom and integration.
- The primary injustice ADAPT is concerned with is that people with disabilities are forced to give up their basic freedom to get the assistance they need to live. This approach aligns the language of the legislation with our intent and framing of the issue. Focusing the legislative language in this manner allows the Disability Community to more easily mobilize our community.
- Although Medicaid is currently the primary payer for LTSS, there are other funding streams and payers of LTSS – including managed care entities – which are not currently covered and should be subject to enforcement of an integration mandate.
- Linking the right to community living within the statutory language tied to any specific funding stream would potentially result in losing these protections if new funding models were established or implemented.
- Full community integration requires broader changes than can be accomplished if we only change Medicaid policy. For example, states need to address the availability of accessible, affordable, integrated housing that is independent of service delivery which is really outside the scope of changes to Medicaid.
- Because the new statutory language is not embedded in the Medicaid program, it can establish a more rigorous definition of “community” and establish a standard that states must meet without limiting the availability of Medicaid funding for settings that don’t qualify. This strengthens our civil right to community integration without undercutting state flexibility in developing their Medicaid programs, reducing opposition we should receive from providers that operate settings we wouldn’t consider truly “community”.
- The ADA Amendments Act addressed the needs of people with less significant disabilities who had been excluded from protection under the Act by court decisions. In a similar vein, although it does not amend the ADA, this bill addresses the needs of people who have their rights denied because society has deemed them “too disabled” to be integrated in society and they have not been able to secure their rights under the existing Act.

Section 1 – Short Title.

Self-explanatory.

Section 2 – Findings and Purpose.

The Findings and Purpose were based on the HELP Committee report (July 2013): “Separate and Unequal: States Fail to Fulfill the Community Living Promise of the Americans with Disabilities Act”. That report recommended that Congress 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. The report and this recommendation were well received by the Disability Community.

Section 3 – Definitions.

The Disability Integration Act specifically defines “Long Term Services and Supports” as the assistance provided to individuals with disabilities in accomplishing, acquiring the means or ability to accomplish, maintaining, or enhancing activities of daily living, instrumental activities of daily living, health-related tasks or other related functions, tasks or activities. The legislation then clarifies the ADA’s integration mandate as it applies to a public entity, defined in a manner consistent with Title II of the ADA, and expands the protections to any LTSS insurance provider, which includes any public or private entity that directly funds or pays for long term services and supports.

The legislation defines an “Individual with an LTSS disability” as an individual with a disability who requires assistance in accomplishing activities of daily living, instrumental activities of daily living, or health-related tasks in order to live in the community, who is currently in an institutional placement or is at risk of institutionalization if that person does not receive community based long term services and supports.

The legislation does NOT define “institution” because the names of institutions vary widely across the states, we did not want to limit the right to people in specific institutions, and we didn’t want to give the status quo the opportunity to rename the institutions as a way to maintaining them.

Instead, the legislation defines “community-based” as services and supports that enable the individuals with LTSS disabilities to live in the community and lead an independent life. It then describes the settings that are considered community-based which exclude segregated settings and group residences of more than four unrelated individuals with LTSS disabilities.

Although there is a commonly understood definition of Activities of Daily Living, states individually define “Health Related Tasks” and “Instrumental Activities of Daily Living” so the bill creates broad national definitions of these terms that are based on the needs of individuals with LTSS disabilities.

Section 4 – Discrimination.

The section of the Disability Integration Act that defines discrimination is modeled on the approach that was used in Title III of the ADA with a general rule and specific prohibitions. The general rule states, “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.”

The legislation then identifies specific prohibitions to address the various policies and mechanisms that have been used to limit access to home and community-based LTSS.
These are:

(1) Using eligibility criteria and other policies to prevent an individual with an LTSS disability from receiving community-based long term services and supports. This would address "gaps" in states that prevent people from qualifying for community-based LTSS because of the type of disability they have, their age, or the age they became disabled;

(2) Enforcing policies that limit the availability of community-based long term services and supports for individuals with LTSS disabilities such as service or cost caps which prevent people with the most significant disabilities from living in the community;

(3) Not providing a community-based long term services and supports that an individual with an LTSS disability needs to live an independent life in the community and fully participate in society, such as not allowing people to get assistance with health related tasks or safety monitoring;

(4) Having policies that interfere with the ability of an individual with an LTSS disability to fully and meaningfully participate in community life, including requirements that they receive services and supports, such as day or employment services, in a congregate or disability-specific setting;

(5) Having policies that delay or restrict access to services, like waiting lists;

(6) Failing to establish adequate rates to attract quality attendants;

(7) Failing to provide services and supports on an intermittent, short-term or emergent basis that are needed for community integration, like crisis support or respite services;

(8) Imposing policies, such as a requirement that individuals use informal supports, that limit the ability of individuals with LTSS disabilities to live independently in the community and fully participate in community life;

(9) Failing to provide individuals with LTSS disabilities community-based long term services and supports as an alternative to institutionalization;

(10) Failing to ensure that all institutionalized individuals are regularly notified of and, if they want, provided community-based long term services and supports; and

(11) Failing to make reasonable modifications when they are necessary to allow individual with LTSS disabilities to receive community-based long term services and supports.

Finally, not providing sufficient affordable, accessible and integrated housing to allow individual with LTSS disabilities to choose to live in non-congregate, independent housing in the community is also defined as a form of discrimination because you can't live in the community if you don't have a place to live.

It's important to note that we need affordable, accessible, and integrated housing, but this legislation clarifies that people should have the opportunity to live in housing that is independent of service provision because service providers - who also are the landlord - can use their authority as the landlord to undercut the autonomy of the people with disabilities they are intended to be serving. The bill does not eliminate such settings but defines it as discrimination if a person is not able to choose an independent alternative.
Section 5 – Administration

This section clarifies the responsibilities of the Department of Justice and the Department of Health and Human Services as it relates to this bill.

Section 6 - Regulations

Because public entities have failed to address these issues, more than 25 years after enactment of the ADA, this section of the Disability Integration Act establishes a robust framework for regulations which is most comparable to the transportation provisions in Title II of the ADA. This framework is an extension of the well-established self-evaluation and transition plan processes that already exist. The legislation requires that:

- Within two years of enactment of the legislation, the Attorney General and the Secretary of Health and Human Services shall issue regulations.
- Within six months after the regulations are released all public entities and LTSS insurance providers must complete a self evaluation. Public entities and LTSS Insurance Providers are required to carry out an extensive public participation process.
- Within one year of completing the self evaluation, public entities must submit a transition plan for addressing the issues identified in the self-evaluation and achieving the purpose of this legislation.
- The plan must address these issues as soon as practicable, but public entities have up to 10 years to complete the plan. The Secretary, through the Administration on Community Living, is charged with reviewing and approving state transition plans.

To support states in implementing these changes and ensure progress, the legislation authorizes an increase in the federal Medicaid match (FMAP) of five percentage points for community-based services when states meet the annual benchmarks in their transition plan.

Section 7 – Exemptions for Religious Organizations.

Self-explanatory.

Section 8 – Enforcement.

Under the Disability Integration Act, the Attorney General has the authority to enforce this law in a manner that is consistent with other titles of the ADA. Civil action may also be initiated by individuals. A person who believes they have been discriminated against in violation of this law may bring a civil action for preventive relief and the Attorney General may intervene if he certifies that the case is of general public importance. The enforcement section of the legislation includes provisions for actual and punitive damages and reasonable attorney fees. This was included because no other right is more fundamental than not being locked away without due process. It also addresses the underlying issue that people with LTSS disabilities would need legal representation to secure their freedom which has been very limited.

Section 9 – Construction.

Self-explanatory.
Support for this Legislation

The Disability Integration Act is supported by over 180 national organizations and over 800 state and local organizations across the country. These include:

- ADAPT
- American Association of People with Disabilities (AAPD)
- American Civil Liberties Union
- Amnesty International USA
- Association of Programs for Rural Independent Living (APRIL)
- Association of University Centers on Disabilities (AUCD)
- Autistic Self Advocacy Network (ASAN)
- Democratic National Committee
- Disability Rights Education & Defense Funds (DREDF)
- Families USA
- Human Rights Campaign
- Indivisible
- Justice in Aging
- Leadership Conference on Civil and Human Rights
- Little Lobbyists
- Little People of America
- Medicare Rights Center (MRC)
- MoveOn.org
- National Academy of Elder Law Attorneys (NAELA)
- National Association for the Advancement of Colored People (NAACP)
- National Association of Councils on Developmental Disabilities
- National Coalition for Mental Health Recovery
- National Council of Churches
- National Council of Jewish Women
- National Council on Aging (NCOA)
- National Council on Independent Living (NCIL)
- National Disability Leadership Alliance (NDLA)
- National Organization of Nurses with Disabilities (NOND)
- National Disability Rights Network
- National Down Syndrome Congress
- National Fair Housing Alliance
- National LGBTQ Task Force Action Fund
- Not Dead Yet (NDY)
- Paralyzed Veterans of America (PVA)
- Paraprofessional Healthcare Institute (PHI)
- Parent to Parent USA
- Service Employees International Union (SEIU)
- TASH
- The ADA Legacy Project
- The Leadership Conference on Civil and Human Rights
- United Spinal Association
- Women's March
- World Institute on Disability