

Master Disability Issue Document

Links to all disability-related documents collected by Michael Forbes Wilcox as of June 25, 2014 9:00 AM

Our Perkins flyer:

Can be [viewed here](#).

Don's Connections:

<http://www.adapt.org/>

General Background:

According to [the US Census Bureau](#), nearly 1 in 5 (18.7%) of Americans self-identify as disabled. This means the actual number is probably higher, because some people prefer not to disclose, and others may not be aware (in the case of some developmental disabilities, for example). For those 65 and older, the rate is close to 50%.

Also, nearly a third (~30%) of households contain at least one disabled person.

Unemployment is rampant within the disability community. Estimates vary widely, but a true unemployment rate of 65% to 85% is quite believable. Reported rates may be much lower because many (if not most) disabled people have given up looking for work.

Poverty is also a chronic condition of many disabled people. Charlie Carr (Commissioner of Mass Rehab) has called the disability community the "largest minority in the world, and also the poorest and the one with the least political power."

Olmstead and the [Massachusetts Community First Initiatives](#)

Community First Vision Statement: *Empower and support people with disabilities and elders to live with dignity and independence in the community by expanding, strengthening, and integrating systems of community-based long-term supports that are person-centered, high in quality and provide optimal choice.*

- Community First Olmstead Plan
- Long-Term Care Financing Advisory Committee
- Community First Systems Transformation Grant 2005-2010
- Personal and Home Care Aide State Training (PHCAST) Grant Program

A ~46-page [background report](#) from February 2010 on how the Community First project was launched, with community involvement. Co-authored by Chris

Palames.

Recent developments include [the publication of federal regulations](#) re Olmstead. This commentary came from ADDP:

On 6/20/2014 2:45 PM, Tara Zeltner, ADDP Director of Government Affairs & Attorney wrote:

Feds Focus on Tying Federal Money to ADA

Since the passage of the Americans with Disabilities Act in 1991, and the U.S. Supreme Court Court [Olmstead](#) decision in 1999, ([Olmstead v. L.C., 527 U.S. 581 \(1999\)](#)) the federal government has been working to align its funding policies with a strong effort focused on persuading states to move aggressively away from congregate living and unnecessary segregation of people with disabilities in both residential and now increasingly in employment settings as well.

This effort has been most prominent in the effort to close state institutions serving people with developmental disabilities.



After an internal review and hearing process over the last five years, the **Center for Medicaid and Medicare Services (CMS)** has published the [HCBS Final Rule](#), advising states of its intention to support further efforts towards community integration, however CMS has

declined to offer specific implementation instructions to states.

On May 20, the National Association of Medicaid Directors (NAMD), the National Association of State Directors of Developmental Disabilities Services (NASDDDS), and the National Association of States United for Aging and Disabilities (NASUAD) sent a letter to CMS concerning implementation of the new regulation. While acknowledging CMS' extensive effort to promote integrated living in the community, the letter raises several concerns regarding CMS' expectations for state implementation plans and ongoing compliance activities. The letter recommends two overarching steps that could facilitate a more efficient transition process for states, and ultimately to ensure Medicaid clients will be able to fully integrate into their communities. These steps are:

- Consistent coordination with several entities within the Department of Health and Human Services (HHS); and
- Ongoing collaboration with state agencies responsible for overseeing and administering home and community-based systems.

The letter goes on to offer more detailed explanations and recommendations in the following four areas:

- Develop a systemic approach to implementation;
- Convene with states to enhance the understanding of the settings requirement;
- Ensure consistent messaging from all HHS entities; and
- Educate audit and program integrity entities.

The HCBS rule went into effect on March 17, 2014, and states are currently at various stage in implementation and transitioning to the requirements of the rule. Massachusetts DDS Commissioner Elin Howe is expected to appoint a stakeholder panel to study the impact of the final rule.

Assisted Suicide:

<http://www.notdeadyet.org/>

Anti-bullying:

I'm not sure how much detail we need to get into here, but Don should be aware that this is a huge issue in the disability community. Perhaps he could just make a statement in support of strictly enforcing existing laws and looking into making them even stronger and more inclusive.

Housing:

Increase the income cut-off so as to include more people

- [H3364](#) "An Act to promote housing creation for persons with disabilities

By Mr. Lewis of Winchester, a petition (accompanied by bill, House, No. 3364) of Jason M. Lewis and others for legislation to provide tax incentives to promote housing creation for persons with disabilities."

Architectural Access:

- Improve existing codes to require new construction to take into account access and accommodations needed by disabled people (door widths in residences, low lighting options in workplaces, etc.).
- Increase training and awareness in local inspectors as to what ADA compliance means
- Bring day care centers into compliance for accessibility, for children with disabilities and for parents with disabilities

The Model Employer Initiative and H136 (Employment Issues):

- The working-age (16-64) non-institutionalized population in Massachusetts of people with a disability is [nearly 400,000 people, or about 9%](#) of all such people in the state. Nationally, 34.7% of people aged 16 to 64 years with a disability were employed in 2009. For people without a disability, the employment-to-population ratio was 71.9% in 2009, or about twice as high.
- The Patrick Administration established the Model Employer initiative, headed by [Ron Marlow](#), to try to make State Government a model employer when it comes to hiring and retaining disabled employees. Quite frankly, that has been an abject failure. The goal of the Model Employer program, as I understand it, was to have 12% of state employees self-identify. The actual number is less than 3%, which is essentially unchanged from 8 years ago. This is something that Don could pledge to fix.

- A related concept is the possible adoption of a policy similar to [Federal Schedule A](#). This program allows agencies to hire disabled applicants who are qualified for a job without having to go through a competitive process. I am told that the unions are not favorably disposed to this form of affirmative action, so Don might have to be careful about being too specific. He's already viewed as "anti-union" by some because of his opposition to casinos.
- The MRC has recently expanded its support of [LifeMAP](#), a coaching program of the Asperger's Association of New England (AANE). This is a good example of a successful public/private partnership that provides relatively low-cost support for people to achieve independence. It is a self-directed program, so it is not just about employment, but can also be about education or other life skills.
- [H136](#) "An Act to increase the Commonwealth's compliance with federal law meeting requirements of the Americans with Disabilities Act

By Mr. O'Day of West Boylston, a petition (accompanied by bill, House, No. 136) of James J. O'Day and others relative to job opportunities for people with disabilities. Children, Families and Persons with Disabilities"

- According to Joe Ballil of Easter Seals, "Over 81% of people with disabilities are not working according to the U.S. Bureau of Labor Statistics" and "The bill (H136) will require companies contracting with the Executive Offices of the Commonwealth to commit to hiring people with disabilities and training all employees involved in hiring decisions on the requirements of the ADA."
- Bill H136 **supporters** include: Easter Seals Massachusetts, Boston Center for Independent Living, The Arc of Massachusetts, AdLib Inc., Center for Living and Working, Cross-Disability Advocacy Coalition, Employment Advocacy Group, Disability Policy Consortium, Independence Associates, Inc., Independent Living Center of the North Shore and Cape Ann Inc., Massachusetts Advocates for Children, Massachusetts Developmental Disabilities Council, MetroWest Center for Independent Living, Northeast Independent Living Program, REDD Group, Rehabilitation, Inc., Southeast Center for Independent Living, Stavros, Triangle, Inc. and Work, Inc.
- For future consideration: About 30 states now have some form of [Employment First](#) policy. The document linked to here is about the California initiative, where legislation was passed late last year. This deserves further study as an area where Massachusetts could increase support for young people and adults with intellectual and developmental disabilities.

Miscellaneous:

Education (access to Community Colleges) and Public Transportation (or the lack thereof) come to mind. Also, the striking similarity of the needs of our community with those of the immigrant population. Inclusion. #ALLMeansALL

Medicare For All (not mentioned in our flyer):

One interesting side-note: Jason Lewis, who has been helpful in advocating for housing for disabled people, is also the lead sponsor of H1035, Medicare for All. I think Don should emphasize that this would be hugely beneficial to the disability community (and we should come up with some reasons why) and that he is the only candidate who has a plan for funding the programs we discuss here; the savings from implementing single-payer could be used for, among other things, fully funding existing programs and to create and expand services.

<https://malegislature.gov/Bills/188/House/H1035>

Restraint and Seclusion:

- [Federal legislation](#) has been pending for quite some time -- perhaps we need to take action in Massachusetts while waiting for that
- Close down the [Judge Rotenberg Center](#) (JRC)

Tax-advantaged Disability Savings Accounts:

The Arc of Massachusetts has [several legislative priorities](#) that include the Autism Omnibus Bill (H4047), which includes a provision for these accounts. This will probably pass this year, but would need to be implemented in the new Administration. The Arc also support H136.

Transform poverty programs to remove penalties for success for people with disabilities:

I think that Don should also show an awareness that many of the programs that provide assistance for disabled people are really poverty programs, not disability programs. As such, people are penalized for being successful. This should be changed so that there are not hard-and-fast cut-off points, but a scheduled reduction in benefits as income rises. For federal programs, this may require the state to provide additional funding to achieve this goal.

Removing penalties is my idea. Most people just complain about it. Such as Section 8 housing vouchers. And there are others. People who earn more than a certain amount can lose their benefits. Rather than have a hard-and-fast cutoff, I think benefits should be scaled back as income rises. As it stands, the system promotes paying people less than they are worth or prevents them from reaching their true earnings potential. This is a complex area since many of the programs are federal, and it's not clear how this would be implemented. But I'd like to see the conversation started.

Policy Suggestions and Examples:

Suggested [start for a policy statement](#) for the Berwick campaign, by Chris Palames.

[Remarks on disability rights](#) by Maura Healy on March 9, 2014

[Kate Donaghue's post on BMG](#) re Maura Healy's efforts to assure accessibility