

Communication with Rep Pallone and Energy and Commerce staff regarding DIA

Bruce Darling

Mon 7/1/2019 2:55 PM

To:ndla-steering-committee@googlegroups.com <ndla-steering-committee@googlegroups.com>;

On June 18th, representatives from ADAPT met with Jeffery Carroll and Tiffany Guarascio Energy and Commerce committee senior staff. The meeting did not go well, with Mr. Carroll indicating that DIA would not be moving forward without his approval, highlighting his statement that he "holds the keys" by shaking an imaginary set of keys with his hand in our faces. Ms. Guarascio repeatedly stated that the bill was "not ready for prime time" and both stated that there isn't consensus on the problem that the bill is trying to address (institutional bias/unwanted institutionalization) so that it is unclear if the bill would solve it. At this point DIA is locked down by Democratic House Leadership.

We will be discussing this on today's NDLA call. It is being shared for reference.

Bruce

FIRST EMAIL

On Jun 19, 2019, at 3:59 AM, Bruce Darling <bdarling@cdrnys.org> wrote:

We are emailing you as a follow up to our meeting this afternoon. As we said at the start of the meeting, ADAPT's representatives came with a willingness to find a common path forward. We specifically expressed a willingness to be flexible with our timeframes as long as we could develop a mutually-agreeable plan that would move the Disability Integration Act (H.R. 555) out of the Energy and Commerce Committee in a timeframe that would allow the bill to be moved to the House floor this fall.

From the outset, you seemed completely unwilling to identify any common path forward. Among the three of our ADAPT representatives, we have nearly a century of experience in this work and have been scolded countless times for our civil rights activism, but after we are at the table we have always been able to move the discussion forward to the substance of the issues. Today was different.

Even after an hour of meeting and repeated efforts to find a common path forward, you continued to scold us using an extremely condescending tone. While you were free to raise your voices at us, you repeatedly stated that if we expressed any anger whatsoever that you would consider it "unprofessional" and you would walk out of the meeting. We politely and repeatedly requested that you show us the same level of professional respect you expected and tried to focus the meeting on the issues, but you seemed intent on continuing to demean or provoke us.

Our representatives have experienced hateful behavior in many forms. A Black Lesbian, a white woman raised in the south, and a gay man – all disabled – have experienced ableism, racism, sexism, and homoantagonism. We tried to explain that your treatment of us was inappropriate. Anita Cameron even asked if you thought it would have been appropriate to treat civil rights activists in the 1960s in such a manner. You pushed back that you didn't want to "get into a black-white thing." She tried to get you to understand that we were talking about a struggle for civil rights, but you dismissed that argument entirely.

You made it clear that "the deal" you were offering the Disability Community is a "table-setting" hearing – one which would only talk broadly about the issues and would not allow DIA to move out of Committee. It would happen at some undefined time in the future. The Disability Community would have to agree that we would accept this up front and stop any and all protests against Democrats – including Representative Pallone. If we refused to abide by your terms, you would refuse to

allow Energy and Commerce staff to do any work on DIA and the bill would die.

To illustrate the power of your negotiating position, you told us that the Disability Community will not get the Disability Integration Act unless Jeff Carroll says we can have it.

To emphasize that further, you leaned toward us and said that you “hold the keys” moving your hand in the air as if you were shaking a set of keys in our face. ADAPT’s logo is an illustration of someone breaking the chains to illustrate how freedom has been denied Disabled Americans and we are breaking free of our bondage. It seems clear that you either do not understand the experience of Disabled Americans who have been literally locked away in institutions where other people “hold the keys” to our freedom or you were deliberately using this as a method of triggering, demeaning and provoking us. Regardless of your reason, the behavior was offensive. We deserve to be treated with respect and in a manner that acknowledges our unique experiences and the deep oppression people in our community face.

You illustrated your power in other ways. At one point during the meeting, you seemed to be threatening to take some action in the Energy and Commerce Committee to force the Judiciary Committee to hold their own hearing and markup. You said you would do this because it is your belief that Democrats on that committee don’t really support the bill and that they were “hiding behind Frank Pallone.” Our experience with these members suggests otherwise. We hardly think that Jerrold Nadler, Sheila Jackson Lee, Karen Bass, Hakeem Jeffries, or David Cicilline need to hide behind Representative Pallone. Your comments seem unnecessarily disrespectful.

Although we were not able to spend much time talking about the bill itself, we were able to identify a number of specific issues.

You feel that there is not consensus on the problem that DIA is trying to address which is why you are only offering a “table-setting” hearing.

Over the past 29 years, the Disability Community has put a great deal of work on this issue while establishing a record of the problem. Below are reports and Congressional hearings that are relevant to DIA. Most importantly, the Senate HELP Committee Report “Separate and Unequal: States Fail to Fulfill the Community Living Promise of the Americans with Disabilities Act” (July 2013) was used as the basis for the Disability Integration Act. The issues have already been clearly identified and legislation drafted to address them.

The National Council on Disability Report – “Olmstead: Reclaiming Institutionalized Lives” (August 2003):
<https://ncd.gov/publications/2003/Aug192003>

The April 2004 Senate Finance Committee Hearing:
<https://www.finance.senate.gov/hearings/strategies-to-improve-access-to-medicaid-home-and-community-based-services>

The January 2008 Energy and Commerce Health Subcommittee Hearing:
<http://dayinwashington.com/day-in-washington-podcast-18-medicaid-and-community-choice-act-hearing/>

The HELP Committee Report - “Separate and Unequal: States Fail to Fulfill the Community Living Promise of the Americans with Disabilities Act” (July 2013):
<https://www.help.senate.gov/imo/media/doc/Olmstead%20Report%20July%2020131.pdf>

You said that there are groups within the Disability Community who oppose DIA.

Although you said that there are groups within the Disability Community opposing DIA, you could not identify a single group. As we understand it, there is not a single organization on record opposing DIA, however, there are over 800 aging, disability, civil rights, social justice and faith based organizations supporting the bill. They are listed here:
<http://www.disabilityintegrationact.org/dia-supporter-list/>

First, any organization that isn’t willing to take a public position is not credible and should not be treated as such. Second, your unwillingness to identify the source of this pushback raises questions about whether such pushback even exists. Even if it does exist, refusing to identify the source prevents there from being any effort to resolve the issues, essentially giving a single organization veto power over an entire community’s fight for civil rights. This is an indefensible position.

You suggested that there “many unanswered questions” about DIA.

We received a list of four (4) questions and verified multiple times that these were the ONLY four questions being raised by Representative Pallone and the Energy and Commerce staff. We answered all four questions in detail. When we asked you what additional questions you had, you refused or were unable to identify any. Again, we are happy to work through specific issues with you, but in order to do that you need to tell us what they are. Raising vague concerns and not being able to identify specific issues with the bill lacks credibility. To make it easier to find the answers we provided, we have included them below.

You said the work the Disability Community has done to secure cosponsors is meaningless.

It was deeply disturbing for you to say that Members just “put their name on anything.” Our community has had very thoughtful conversations with our members of Congress as we sought their support for the Disability Integration Act. Although you dismissed the civil rights aspect of the bill, we have found that members have understood the intent of the bill and recognized the civil rights issues at stake. Dawn Russell tried to give you an example, citing how one of the members of the Colorado delegation sought information from HHS and, when he signed on, he clarified that he believed this was a civil right – not a Constitutional right. Although you dismissed him because he is a Republican, we felt that this was a good example of the work we have done.

You said you needed technical assistance from HHS and DOJ because you don’t know that it is possible to implement the bill.

We have indicated in several meetings with you and your team that Senator Schumer sought technical assistance from Health and Human Services and the Department of Justice. We do not know the format that is typically used to provide such feedback, but in 2015 we worked with Senator Schumer’s staff using a track-changes version of bill language to identify issues, offer feedback and edit the language with legislative counsel. It is our understanding that the bill language was provided to the agencies and they sent back the bill with notes in track changes. We then provided specific comments, either accepting suggestions or providing an explanation for the bill language as written. We have attached a PDF of the track changes versions to this email so that you can review them. Senator Schumer’s office may have additional materials that they did not share with us.

You said “the bill isn’t ready for prime time” multiple times.

Honestly, given the lack of any specific concerns, it seemed that you were just saying this to provoke us. Although you insisted on being professional, we found your attitude toward a bill that was thoughtfully crafted with the Senate Minority Leader and thoroughly-vetted with multiple parties to be disrespectful. The Disability Community greatly appreciates the work of Senator Schumer and considers him to be a champion for our community by his work on this bill. We hope that moving forward we can have conversations about specific concerns and issues rather than simply throwing shade at the Senate Minority Leader, his staff and our collective work.

There are two other issues that seem important to document.

First, you chided us for protesting Democrats in the 116th Congress but doing nothing during the 115th Congress against Republicans.

As we politely pointed out the Disability Community – led by ADAPT – saved the Affordable Care Act and Medicaid from the Republican attacks during the 115th Congress. The protests we organized during the #SummerOfADAPT were historic in geographic scope and length of time. The three people you met with – and countless others – were arrested multiple times and physically assaulted or injured during these protests. This is relevant because the Disability Community – in doing this – has earned the right to be respected by Democrats and to expect the party to support our rights.

And finally, in blocking the bill Representative Pallone is "ready to take it on the chin".

Although you were deeply offended by our activism in securing DIA cosponsors a couple of weeks ago, we utilized a strategy that avoided immediately vilifying the Congressman, giving him the opportunity to fulfill a campaign promise to his constituents by cosponsoring the Disability Integration Act and to be a hero in our community. He told us that staff had failed to inform him that DIA was in the Energy and Commerce committee, so he is in an awkward position of having agreed to cosponsor the legislation but saying he cannot do so because he is chair of the committee. However at today’s meeting, you indicated that Representative Pallone is ACTIVELY BLOCKING the Disability Integration Act, understands that he is blocking a civil rights bill for Disabled Americans and is “ready to take it on the chin.” We appreciate you clarifying Representative Pallone’s position. We were concerned that staff may have failed to communicate vital information to him (as had happened previously), but we now understand that this is not the case and will proceed accordingly.

We have repeatedly asked to sit down and develop a plan to advance the bill. Instead, we have had a series of go-nowhere meetings where we are told conflicting information that appears to be "moving the goalposts." Even so, we remain willing to work with you, the Congressman and the committee to advance the Disability Integration Act if you can come to the table in a sincere effort to move forward.

FREE OUR PEOPLE!

On behalf of the ADAPT Community
Anita Cameron, Dawn Russell, and Bruce Darling

From: Bruce Darling
Sent: Thursday, June 6, 2019 2:03 PM
To: Stephanie Woodward; Dawn Russell; Kelly Buckland; Dara Baldwin; Gregg Beratan; Kathryn Carroll; Lindsay Baran
Subject: Responses to Energy and Commerce concerns/Please review and edit.

Below, please find the answers to the concerns about the Disability Integration Act that have been raised by Representative Pallone and leadership in the Energy and Commerce Committee.

1. There is a concern that it is inappropriate for the federal government to mandate states to do something without providing the funds to do it.

First, it is entirely appropriate for the federal government to ensure that states do not infringe on the constitutional rights of their citizens. Generally speaking, it would be considered unacceptable for a state to incarcerate an entire class of its citizens based on who they are as individuals because the rights guaranteed under the Constitution apply to all Americans. Even so, Disabled Americans are routinely forced into nursing facilities and other institutions where they are stripped of their personal liberties and denied the possibility of pursuing education, economic opportunity, career and family. Although some might argue that these disabled individuals can simply refuse unwanted institutionalization, when you require Long Term Services and Supports because you need assistance with the most basic functions needed to live (breathing, eating, bathing, toileting etc.) and you cannot receive that support in the community, you fundamentally have no choice. Your alternatives are to be locked away or die. You are essentially denied the due process protections that you would be afforded under the fourteenth amendment if you had been accused of committing a crime. Consequently, when states deny access to community-based services which results in unwanted institutionalization, they are denying their Disabled citizens their Constitutional rights. The Disability Integration Act which ensures that states – or LTSS insurance providers – are no longer allowed to infringe on the Constitutional rights of their Disabled citizens is an appropriate use of Congressional authority.

Second, it is entirely appropriate for the federal government to ensure that states do not infringe on the civil rights of their citizens. The holdings of the Supreme Court in *Olmstead v. L.C.*, 527 U.S. 581 (1999), and companion cases, have clearly articulated that individuals with disabilities have a civil right to participate in society as equal citizens. However, many States still do not provide sufficient community-based long-term services and supports to individuals with disabilities to end segregation in institutions. While Congress expected that the integration mandate in the Americans with Disabilities Act would be interpreted in a manner that ensures that individuals eligible for institutional placement are able to exercise a right to community-based long-term services and supports, that expectation has not been fulfilled. States, with a few exceptions, continue to approach decisions regarding long term services and supports from social welfare and budgetary perspectives, but for the promise of the ADA to be fully realized, States must approach these decisions from a civil rights perspective. (This is taken from the findings of HR.555/S.117.) Under existing law, states can select specific populations of people who are eligible for home and community-based services while denying those services to others. They may limit the availability through eligibility criteria that excludes people with a specific type of disability or diagnosis, authorization limitations that exclude people who have more significant disabilities, or service restrictions that have the functional result of excluding people with certain needs based on their disability. The Disability Integration Act is civil rights legislation that ensures states are not allowed to discriminate on the basis of disability.

For those who understand disability within the framework of a social welfare or medical model or who view this issue strictly from the framework of a healthcare service issue, it will be difficult to easily understand these arguments, or to understand disability in the context of oppression and civil rights. However, the Independent Living Community has extensive materials on understanding this paradigm. For further information, go to: <https://www.youtube.com/watch?v=48-8m8i-38U>

Third, states already pay for this (and are already required to under federal law). Federal law literally requires state Medicaid programs to pay for Long Term Services and Supports for people in nursing facilities and – even in the absence of a federal mandate – states fund multiple forms of institutional placement. This legislation simply ensures that states do not perpetuate policies that force their Disabled citizens into unwanted institutional placement.

Fourth, community-based services are more cost-effective, so providing them helps states contain their costs. It is also commonly understood that community-based services are generally more cost-effective than institutional placement, and transitioning to home and community-based services saves money. This is supported by academic research. A published academic analysis of state spending data from 1995 to 2005 demonstrated that for two distinct population groups receiving long-term care services, spending growth was greater for states offering limited non-institutional services than for states with large, well-established non-institutional alternatives. That report said that the expansion of home and community-based services appeared to entail a short-term increase in spending, followed by a reduction in institutional spending and long-term cost savings.

<http://www.wvdhhr.org/oig/pdf/olmstead/do%20noninstitutional%20services%20reduce%20medicaid%20spending.pdf>

Although there are people for whom the cost of community-based services and supports is higher in the community on an individual basis, this is a very small number of people. Overall, the savings associated with providing services and supports in the community balances out the additional cost associated with this small number of higher-cost individuals.

Fourth, nothing in this bill would undercut a state's ability to manage their own Medicaid program. Other approaches to cost-control remain available to states. They simply would not be allowed to limit funding for services in such a way that an individual with an LTSS disability is forced into unwanted institutionalization. For example, states could change the Level of Care for institutional services as long as the effect doesn't undercut an individual's ability to live in the community such as applying a higher level of care to community based services while "grandfathering in" those who are in the institution at the original level of care. One way to address this would be to apply the more restrictive level of care to all people entering the system so the approach is even-handed with regard to setting.

2. There is a concern that DIA would have unintended negative impact on Olmstead litigation and settlement agreements.

The concern that the Disability Integration Act could undercut the ADA and Olmstead litigation and advocacy is entirely unfounded. The bill was written to avoid that.

The findings in the bill state that "While Congress expected that the ADA's integration mandate would be interpreted in a manner that ensures that individuals who are eligible for institutional placement are able to exercise a right to community-based long-term services and supports, that expectation has not been fulfilled." Additionally, the findings note that "The holdings of the Supreme Court in *Olmstead v. L.C.*, 527 U.S. 581 (1999), and companion cases, have clearly articulated that individuals with disabilities have a civil right under the ADA to participate in society as equal citizens. However, many States still do not provide sufficient community-based long-term services and supports to individuals with disabilities to end segregation in institutions."

The stated purpose of the bill is "to clarify and strengthen the ADA's integration mandate in a manner that accelerates State compliance." The legislation would do that by establishing a clear and enforceable statutory right to freedom. It is not uncommon to pass legislation that strengthens and clarifies existing law. Frankly, protections in Title II of the ADA duplicate provisions in Section 504 of the Rehabilitation Act. The Disability Community still moved forward to strengthen and clarify Section 504 by creating the ADA. Today, litigants use both laws in the same case. Provisions were also added to the version of the bill introduced in the 115th Congress specifically to ensure that the Disability

Integration Act would in no way interfere with Olmstead litigation.

Finally, ADA attorney Steve Gold authored a letter (<http://cdrnys.org/dia-attorney-letter/>) stating that the Disability Integration Act “not only enshrines in Federal statute the right to live in the community which Olmstead recognized, it takes what disability advocates have learned over the past eighteen years and creates another more powerful tool to effect the integration of people with disabilities.” The letter was cosigned by the following distinguished Disability Rights Attorneys:

- Samuel Bagenstos, J.D., Frank G. Millard Professor of Law at the University of Michigan (Previously Principal Deputy Assistant Attorney General for Civil Rights at the U.S. Department of Justice)
- Alison Barkoff, J.D., Director of Advocacy, Center for Public Representation (previously Special Counsel for Olmstead Enforcement at the U.S. Department of Justice’s Civil Rights Division),
- Curtis L. Decker, J.D., Executive Director of the National Disability Rights Network, Vanita Gupta, J.D. – CEO, Leadership Conference on Civil and Human Rights (previously Principal Deputy Assistant Attorney General and head of the U.S. Department of Justice’s Civil Rights Division)
- Jennifer Mathis, J.D., Deputy Legal Director and Director of Policy and Legal Advocacy of the Judge David L. Bazelon Center for Mental Health Law
- Silvia Yee, Esq., Senior Staff Attorney, Disability Rights Education and Defense Fund
- James Weisman, Esq., President & CEO United Spinal Association.

It may be helpful to explain how DIA clarifies and strengthens the Olmstead integration mandate. The bill makes some significant changes from existing Olmstead case law. These changes include:

- Creating a direct and clear statutory requirement for the community integration of Americans with Disabilities in regard to the provision of LTSS;
- Adding managed care organizations as directly covered entities;
- Establishing a new, stronger definition of “community-based”;
- Reducing the threshold of protection from “at serious risk of institutionalization” to “at risk of institutionalization”;
- Eliminating the treating professional role in determining whether community integration is appropriate for the individual with an LTSS disability;
- Establishing specific prohibitions addressing systemic discrimination which is not only permissible under current law, but rampant across the country (waiting lists, restrictive eligibility criteria, service gaps, cost caps, and inadequate rates);
- Requiring public entities to address the need for affordable, accessible, integrated housing that is independent of service delivery;
- Eliminating the fundamental alteration defense so that public entities will be required to modify their programs to assure that people with disabilities can receive LTSS in the community and can lead an independent life;
- Requiring public entities and MCOs to engage in a self-evaluation that has substantial public participation;
- Requiring public entities to develop and implement a transition plan with milestones or benchmarks;
- Establishing a process to assess compliance with the milestones and reward states that meet their deadlines; and
- Establishing the ability to be awarded punitive damages.

3. There is a concern that the bill allows people with disabilities to receive punitive damages.

Punitive damages were included in the enforcement section of the bill for several reasons.

First, there is nothing more sacred to Americans than our freedom, and individuals who have been unjustly incarcerated and denied the opportunity to live their life have a reasonable expectation of those that stole their freedom and years of their life be punished. Additionally, institutionalization does not just steal the freedom of Disabled Americans and their opportunity to live their lives, it actually shortens their lives. Studies have demonstrated that individuals in institutional settings regardless of age will have significantly shorter life expectancies than their independently living contemporaries. Because of the extreme impact of this discrimination, we included punitive damages.

Second, and more practically, punitive damages will ensure that Disabled Americans in institutions will be able to secure legal representation needed to fight for their freedom. Institutionalized persons will typically not have access to the financial resources needed to pay for legal representation. Additionally, there are very limited legal resources available to institutionalized individuals – particularly those who do not fall within specific funding streams for the Protection and Advocacy network. Consequently, in twenty years since the Supreme Court’s Olmstead decision, there has not been a single lawsuit of national significance addressing the institutionalization of physically disabled and elderly residents in nursing facilities. Securing statute without an appropriate enforcement mechanism renders the statute meaningless. Rather than have the federal government fund legal services to do this work by taxing Americans, we have chosen to require those that have perpetrated the discrimination to pay.

4. The bill allows individuals to sue prior to the individual being forced into a facility.

Energy and Commerce staff have expressed a concern that the enforcement section in DIA, Section 8 of the bill, allows an individual to take legal action prior to the individual being forced into an institution. Specifically, the bill states, “The remedies and procedures set forth in this section are the remedies and procedures this Act provides to any individual who is being subjected to a violation of this Act, *or who has reasonable grounds for believing that such individual is about to be subjected to such a violation.*”

This language is based on the enforcement section in Title III of the Americans with Disabilities Act (ADA) which reads: “(a) In general (1) Availability of remedies and procedures The remedies and procedures set forth in section 2000a–3(a) of this title are the remedies and procedures this subchapter provides to any person who is being subjected to discrimination on the basis of disability in violation of this subchapter *or who has reasonable grounds for believing that such person is about to be subjected to discrimination in violation of section 12183 of this title.*”

This language was used in DIA to ensure that people with disabilities can avoid unwanted institutionalization. As an example, an individual with a disability may be notified that their services are going to be reduced by the state’s Medicaid program or managed care organization, putting them at risk of institutionalization. This bill language would give them the opportunity to take legal action to prevent that reduction in services so they can maintain their life in the community rather than have their services cut, be forced into unwanted institutionalization requiring them to fight the legal case from inside an institution, and then upon successful resolution need to rebuild their life in the community. In some cases, the consequences of service reductions could be even more dire, with individuals being forced to go without needed services in order to remain in the community. Our community has witnessed Managed Care companies significantly cutting services for people who need life sustaining assistance. In one case, a woman who had received round the clock assistance in New York for more than a decade from Medicaid because she needed suctioning to breathe had her assistance cut to only 78 hours a week. This meant that she would not have access to suctioning 90 hours a week, potentially putting her at risk of significant illness and death. This may seem like an extreme example, but not having even limited assistance with transferring can result in pressure sores which can become infected and result in death. Advocates all over the country have examples of people with Long Term Service and Support disabilities who have died because they did not have access to needed services.

<DIA DOJ Comments with AP responses 20151027.pdf>

<11232015_HHS TA_Update to CDR - BD edits.pdf>

SECOND EMAIL

On Jun 19, 2019, at 8:36 AM, Bruce Darling <bdarling@cdrnys.org> wrote:

NCIL has a national call this afternoon to update our community on priorities which obviously includes the Disability Integration Act - HR555. (NCIL was part of the team that crafted the bill.)

We understand that you met with the Congressman last night. As President of NCIL, I will use this email as the basis for my understanding of the current situation.

We remain willing to work with Congressman Pallone to develop a mutually agreeable plan to move our legislation forward. If that is possible early in the day, we can avoid unnecessary kerfuffle and celebrate the Congressman on today's call.

We do, however, understand that he is willing to "take it on the chin".

Bruce

Sent from my iPhone

THIRD EMAIL

From: Bruce Darling

Sent: Wednesday, June 19, 2019 2:21 PM

To: VanBuren, Rick; Jeffrey.Carroll@mail.house.gov; Fitzsimmons, Liam; Roberto.Sada@mail.house.gov; Tiffany.Guarascio@mail.house.gov

Cc: Dawn Russell; Anita Cameron; Stephanie Woodward; Dara Baldwin; Kelly Buckland; Lindsay Baran; sheryl@ncil.org; Sarah Launderville; aimparato@AUCD.ORG; tony@onewharf.com; jenniferm@bazelon.org; Marilee Adamski-Smith; Colleen Flanagan; Gregg Beratan; Carole Tonks; Luke Koppisch; Norman Smith; Laura Halvorson; Maggie Leppert; Mike Oxford; Ami Hyten; Jennifer McPhail; gupta@civilrights.org

Subject: Non-response IS a response!

It's a long email, but there has been plenty of time to respond.

For those from the Disability and civil rights communities who hoped there were back-channel conversations between Rep Pallone's staff and ADAPT, that is NOT happening.

Bruce

Sent from my iPhone