



The Americans with Disabilities Act at 25

Cause for Celebration and Renewed Resolve

July 2015

NATIONAL
DISABILITY RIGHTS
NETWORK

Protection & Advocacy for Individuals with Disabilities



“At its heart, the [Americans with Disabilities Act] is simple.... This landmark law is about securing for people with disabilities the most fundamental of rights: ‘the right to live in the world.’ It ensures they can go places and do things that other Americans take for granted.”

- Senator Tom Harkin¹



A Letter from the Executive Director

The “right to live in the world” – this is the measure of progress NDRN explores in our Americans with Disabilities Act (ADA) 25th Anniversary report.² We celebrate that in the past 25 years there has been an increase in the number of people with disabilities participating in all aspects of community life, from home ownership and employment to sports and the arts.³ The first “post-ADA” generation is now joining the workforce and raising families. They have been nurtured in a world where people with disabilities stand proud and demand civil rights. This generation is more likely to expect inclusive programs, policies, and workplaces, and to view segregation as a discriminatory, failed practice of the past.

For twenty-five years, the Protection and Advocacy System agencies (P&As) have been the largest enforcer of the ADA.⁴ P&As have assisted thousands of people to access community based services and supports.⁵ Key to this work is to advocate on the systems level for a robust range of community-based services and supports so that options are available to meet all levels of need and facilitate individual choice and autonomy. Equally key is P&A monitoring of these settings and services to ensure they are safe and facilitate a life in the community like that which individuals without disabilities may take for granted.

Our nation has made substantial progress, but the right to community integration is fragile, and there are issues on the horizon that must be challenged or the ADA integration mandate, as we know it, will be gone. For example:

- Funds are shifting away from large facilities for individuals with disabilities and are being used to fund smaller, but equally isolating group residences.
- We are seeing a proliferation of segregated disability-only villages, built with the intentions to keep people safe and protected from the public, as did the disability-only institutions of the recent past that became sites of horrible abuse and neglect.

- While it is more common for students with disabilities to be appropriately supported in general education classrooms, it is still standard for educators to steer students with intellectual or behavioral disabilities to segregated settings.
- For individuals with a diagnosis of mental illness, continued stigma, and public misunderstanding of what mental health services are effective, have led more states to pass involuntary outpatient commitment laws rather than increase funding for effective community based mental health services.
- A small minority of family members and owners of institutions are gaining an outsized influence over Olmstead compliance actions.

The best antidote is not to go back to the failed policies of segregation, but to vigorously enforce community integration laws. As barriers are removed and more people with disabilities have the opportunity to join in community life, outmoded beliefs about the effectiveness of community services, and the abilities of people with disabilities, are challenged and shattered.

We urge the adoption of our recommendations for federal and state action to speed up access to community-based services and supports for Americans with disabilities.

Twenty-five years of the ADA has proven that America benefits when communities are accessible, and all its members have the supports they need to contribute to its success. NDRN and the P&A Systems will continue to speak out against policies that cause needless segregation of people with disabilities.

Sincerely,



Curtis L. Decker, J.D.

Executive Director

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I. Executive Summary

In this report, we review the progress our nation has made since the historic enactment of the Americans with Disabilities Act (ADA) in 1990. We highlight the critical role that P&As have in enforcing the ADA integration mandate, protecting and advocating for people with disabilities still trapped in institutions and ensuring those now living in their community of choice are able to access the supports and services they need to be successful.

Our report calls attention to disturbing national trends that threaten to distort and weaken the promise of full community integration. Among them:

- Moving from Large Facilities to Smaller but Equally Isolating Settings
- A Proliferation of Intentional “Disability-only” Settings.
- Outsized Influence of A Small Minority of Individuals Over Olmstead Enforcement Activities
- Public Demand for Increased Use of State Psychiatric Hospitals and Involuntary Outpatient Commitment.
- School System Reluctance to Move away from Segregated Classrooms.

Finally, the report provides recommendations for federal and state action to mitigate these threats and to vigorously promote community-based services and supports for Americans with disabilities.

The recommendations include (see page 33 for full list):

Congress:

Recommendations

- Support increased Medicaid funding for HCBS programs. These are cost-effective programs that help people with disabilities and seniors live in their communities. Cuts to Medicaid will: weaken implementation of the 2014 federal regulations raising standards for HCBS programs; negatively impact crucial programs; and potentially put states at risk for violating the ADA integration Mandate.
- Oppose changes to the 2014 HCBS rule that would hinder accomplishing the spirit and goal of the rule to offer supports that provide people with meaningful access to community life. The HCBS rule is the culmination of decades of

advancement and bipartisan solutions to provide people with disabilities and seniors access to the broader community.

- Support creation of a Protection and Advocacy Health Advocacy Program to protect the rights of Medicaid beneficiaries. This was the recommendation of the National Council on Disability (NCD), an independent federal agency charged with advising the President, Congress, and other federal agencies on disability policies.⁶ NCD called on Congress to fund a P&A health advocacy program after finding that protections are needed for beneficiaries with disabilities who experience due process violations from managed care utilization controls.⁷

Administration:

Recommendations

- The Office of Special Education Programs (OSEP) monitoring process must add a least restrictive environment component. This would mean that if OSEP identifies that a state is overly relying on segregated placements, it will be flagged as a concern for the agency to address.
- In all settlement agreements between the DOJ and States regarding community integration, include a provision that the State will fund the P&A in that State to monitor community settings where transitioning individuals live and provide advocacy to such individuals.
- The Center for Medicare and Medicaid Services (CMS) should view the P&A Network as part of their panoply of independent quality enforcement strategies and provide funding to allow the P&As to monitor disability service systems receiving Medicaid or Medicare funding.

States:

Recommendations

- States should take advantage of the opportunity presented by the 2014 CMS rules governing funding for HCBS settings to responsibly phase out segregated living and work environments and replace them with funding for integrated housing and supported competitive employment options.

II. Introduction

In the 25 years since the historic enactment of the Americans with Disabilities Act (ADA), there has been an increase in the number of people with disabilities participating in all aspects of community life, from home ownership and employment to sports and the arts.⁸ Part of the ADA's power is that it advances community integration from several fronts, bringing cohesiveness to the piecemeal structure of disability rights that has been building since the 1970's.⁹ The ADA is a universal ban of discrimination on the basis of disability in employment, transportation, telecommunications, public accommodation, and public services. This report celebrates the importance of the ADA's ban on discriminatory segregation and institutionalization of people with disabilities.¹⁰

In 1999, in the case of *Olmstead v. L.C and E.W.*,¹¹ the U.S. Supreme Court ruled that unnecessary segregation and institutionalization of people with disabilities constitutes discrimination under the ADA. The plaintiffs, Lois Curtis and Elaine Wilson, had spent the majority of their lives in state hospitals. For the last several of these years their treatment teams acknowledged that they no longer met the requirements for involuntary confinement, but the state refused to release them to a community-based program with appropriate services. With representation by attorneys from the Atlanta Legal Aid Society, Ms. Curtis and Ms. Wilson asserted their rights under the ADA all the way to the Supreme Court. The high court made it clear that public entities must provide services to qualified individuals with disabilities in the most integrated settings appropriate to their needs. This right is frequently referred to as the "ADA integration mandate" or simply "Olmstead."

Olmstead is synonymous with freedom for thousands of Americans with disabilities who were forced to live in segregated institutional settings in order to receive necessary services and supports. It is a source of hope for thousands more Americans with disabilities who currently reside in the community with the supports they need, but live with the fear that the loss of these supports could force them into institutions.

For more than a century laws have been in place to segregate and isolate people with disabilities in large public hospitals away from society.¹² These laws enforced a "charity" model of disability services, removing individual rights and treating adults with disabilities like children to be protected by others.¹³ Twenty-five years since the enactment of the ADA these attitudes still persist and feed the notion that people with disabilities are somehow less worthy of the rights we demand for all other Americans.

With this societal attitude, it is no wonder that the institutions we created for people with disabilities were often underfunded and under resourced, making them harbors for victimization, abuse and neglect of people with disabilities. Historically, and still today, individuals with disabilities are oftentimes simply warehoused in these facilities and offered little, if any, treatment or education. Beginning in the 1970's, major media sources began to make the public aware of dangerous conditions in these institutions and horrendous abuse and neglect of children and adults living within these buildings. In response, Congress created the Protection and Advocacy System (P&As).

Consisting of 57 agencies, the P&A System is the largest provider of legal services to people with disabilities and P&As are the primary enforcer of the ADA and the Olmstead decision. P&As serve every state, the District of Columbia, U.S. territory, and the American Indian Consortium including the Hopi, Navaho and Paiute Nations in the Four Corners region. P&As are authorized under various federal statutes to provide legal representation and related advocacy services to protect the rights of individuals with disabilities and investigate incidents of abuse and neglect of individuals with disabilities in institutions and the community. The National Disability Rights Network (NDRN) is the nonprofit, voluntary membership association for the P&A Systems.

An important part of P&A work is ensuring individuals with disabilities have access to appropriate, safe community housing with the services they need to facilitate community integration, independence and autonomy. P&As have assisted thousands of individuals access home and community based services and supports (HCBS). As used in this report "HCBS" encompasses the full spectrum of services and supports to people with disabilities that enable the development of relationships and a life in the community, including safe, affordable accessible housing, transportation, recreation, employment, and education. Equally important to P&A work helping people access HCBS is monitoring these settings and the delivery of services to ensure that people are safe and free of abuse or neglect.

A recent report by the National Council on Disabilities (NCD) reinforces how important it is for our nation to continue to enforce Olmstead and build robust HCBS options. NCD reviewed the research on outcomes since the *Olmstead* decision, and found "The preponderance of research...supports the conclusion that smaller, more dispersed and individualized community settings further integration and positive outcomes for individuals with disabilities."¹⁴

As we celebrate the progress our nation has made developing HCBS over 25 years, our mood is tempered by the knowledge that this progress has been unnecessarily slow. Individuals often seek P&A assistance after waiting years to get out of segregated settings, even when their own doctors agree that life in the community is more appropriate for them.¹⁵

The ADA requires states to eliminate unnecessary segregation of persons with disabilities and to ensure that individuals with disabilities receive services in the most integrated setting appropriate to their needs. This right to community integration is fragile, and there are constant pressures on states to not to enforce it. We must be vigilant against rollback and stagnation. In the next section we highlight the work of the P&As to enforce the ADA integration mandate.

III. Highlights of P&A Community Integration Advocacy

“Everything from appropriate psychiatric discharge planning, to personal care, to supported employment, to community-based dentistry options: quality supports are the cornerstone of the Independent Living movement.”

- Mark Stroh, Executive Director, Disability Rights Washington

A. Promoting the Full Range of Community Based Community Supports Necessary for Community Integration

P&A community integration advocacy considers the full range of community supports and services necessary to ensure individuals are able to live in safe settings with supports to facilitate participation in all aspects of society. P&As work to increase access to quality personal assistance services; reliable, accessible transportation; inclusive education; competitive, integrated employment options; and accessible welcoming communities. Below are some examples of individual cases and class actions illustrating P&A advocacy to help individuals access a range of services to be successful in the community and to monitor these services to ensure they are appropriate, safe, and promote independence and autonomy

i. Affordable Housing:

The Georgia Advocacy Office (the Georgia P&A) represented WS, a trained interior designer. Several years ago, a serious automobile accident shattered his dreams of opening his own design business. Medical bills from required major surgeries to repair his spine and hip devoured his savings. Additionally, he experienced massive flare-ups with Crone’s disease. Differences in lifestyles had caused seemingly irreparable rifts in his family, and friends who had invited him to come to Atlanta to live, and they no longer welcomed him in their home. Alone at a metro hospital for weeks and facing homelessness on the streets of Atlanta, WS became suicidal. He was transferred to Georgia Regional Hospital in Atlanta, where the P&A met him. After spending 5 months in the state psychiatric institution, WS was approved for a housing voucher. With P&A advocacy, WS found his own apartment, negotiated bridge funding, was assigned to a case manager, and was connected with peer supports services and taking steps toward employment.

ii. Education Services and Supports

Disability Rights Hawaii (the Hawaii P&A) represented a 17-year-old boy living on the island of Maui with his parents until he was admitted to the Queen’s Hospital psychiatric residential program for adolescents. The admission resulted after officials at the individual’s high school determined that the he had made a credible threat to commit a dangerous act on campus grounds. The boy’s father contacted the Hawaii P&A seeking assistance in securing mental health services on Maui. The P&A arranged for a meeting with school personnel, parents and the Children’s Mental Health Division to develop a plan of action. The P&A advocate found that the teen had been removed from special education while in intermediate school and worked to have him reinstated on an expedited basis. Working with school officials, parents, and the Children’s Mental Health Division to develop an IEP and Coordinated Service Plan, the team developed a wraparound education and mental health service model in the child’s home. Private contract physicians and state agencies worked together and the teen was able to earn the credits needed to receive his high school diploma. He returned to the school campus to work with his computer teacher to develop programs, participated in all senior activities/graduation ceremony, secured part time employment, achieved a functional level of mental health stabilization and completed application to a local community college. The Children’s Mental Health Division provided services to ensure transition to the Adult Mental Health Division services.

iii. Medicaid Coverage of Community Based Services and Supports

Disability Law Colorado (the Colorado P&A) assisted Ms. G. to remain in the community, living independently in her own apartment. Ms. G. received Medicaid coverage for home based aide services help with household chores and to provide supervision when in the community. Ms. G. had been on the waitlist for a different Medicaid program that covered more of the health services she required. After several years, she finally got off the waiting list for the new Medicaid program. Unfortunately, once she was assessed for service needs under the new program, she was allocated much less home aide services. This meant Ms. G. would no longer have enough aide services to provide both household help and supervision while in the community. The P&A assisted Ms. G.’s parent/guardians to file an appeal to challenge the support level decision and advised Ms. G during the Medicaid hearing. The P&A further advocated to have the client’s support needs assessment redone, as it had been years since it was last completed and Ms. G’s circumstances had changed. The state agreed to redo the needs assessment and the revised score resulted in the award of increased aide home assessment hours. Ms. G. remains in her own apartment with enough aide assistance to be able to attend church and other community activities.

In 2012, the Kansas Governor privatized Medicaid with three for-profit, out of state businesses that were publically traded and featured in Fortune 500 magazine.¹⁶ This new program was called KanCare.



The “most integrated setting” means one that “enables individuals with disabilities to interact with nondisabled persons to the fullest extent possible....”

- ADA 28 C.F.R. Pt. 35, App. B at 673.

The **Disability Rights Center of**

Kansas (the Kansas P&A) and numerous disability advocates noted problems with the program design that were causing significant life and health consequences for Kansans with disabilities. The P&A received a flood of calls from Kansans seeking help. The managed care entities were violating numerous federal Medicaid requirements and the P&A represented many people at hearings. In addition, the P&A published a White Paper detailing the problems people with disabilities were experiencing with KanCare and made common sense recommendations to comply with federal law and improve the system, without the need for legislation. The paper drew public attention and spurred the Governor to make several positive changes.

iv. Monitoring the Quality of Community Services and Supports

The **Native American Disability Law Center** (the Native American P&A) received a report from a mother who had concerns about the care her adult son, JR, was receiving at a supervised group home. The P&A visited JR and suspected that he was not receiving appropriate medication or care. The P&A held meetings with JR, his mother, group home staff, and the JR’s case manager; they identified and discussed several incidents; and changes were made to his services and the manner in which they were provided. The P&A also determined that some of JR’s concerns raised more systemic issues about policies and practices at the group home, such as medication lapses and lack of proper staff oversight. The P&A arranged for staff re-training and the institution of new policies. Meeting with JR after the changes had been implemented, he reported to the P&A that he was happy and had access to the services he wanted.

v. Ensuring most integrated setting appropriate

South Dakota Advocacy Services (the South Dakota P&A) was called by a guardian seeking a less restrictive placement for their ward, TP, who was a person with developmental disabilities and had been involuntarily committed to a state hospital. TP had experienced significant issues with overuse of alcohol after moving out of his parent’s home into his own apartment. He lost his job and after incidents where he was



found in public drunk, TP was committed to the hospital for alcohol counseling. When the alcohol treatment was completed he refused to agree to not drink again, so his commitment was extended for several months. Though the hospital determined that TP was sober and no longer a danger to others, it refused to lift the involuntary commitment. At this point TP's guardian contacted the P&A. The P&A held several conversations with the hospital staff to determine what their concerns were with the client's return to the community. In consultation with TP and his guardian, it was arranged that the involuntary commitment order would be lifted, and TP would stay in the hospital on a voluntary basis until a community placement could be located. Finding a suitable community placement and providers meeting TP's needs took several weeks. At one point a placement was identified, but TP halted the discharge until the group home found him a roommate that was not twice his age. TP also wanted to ensure his housemate had interests not related to alcohol or hanging out in bars. Several months after moving to the community, the P&A checked back with TP and he reported no concerns.

Disability Rights Iowa (the Iowa P&A) became aware of Jack while investigating a complaint of abuse at the skilled nursing facility where he lived. When P&A staff introduced themselves to Jack he was sitting in a wheelchair staring out the window of the day room. Upon learning that he was speaking to a P&A advocate, Jack immediately asked, "Can you help me leave this place?" After making inquiries, the P&A discovered that the social workers at the nursing home had no information about the Medicaid HCBS programs that would enable Jack – and others -- to receive community supports. The P&A arranged a training for the nursing facility staff and helped Jack complete applications for two waivers he was eligible for. As it turned out, an application had been submitted for Jack to participate in the states "Money Follows the Person" (MFP) Medicaid waiver several years prior, but, the program transition coordinator gave him only one choice of an apartment, which was far from his family. When Jack declined the apartment, he was dropped from the program. When completing the new applications, the P&A took some time to get to know Jack and to make his preferences clear on the applications. Some options were presented and Jack chose a community address in a neighborhood near his sister. The P&A then worked with nursing home staff and community providers to arrange community supports and assist Jack through the transition process. Jack is doing well and sees his sister often.

Since 2010, **University Legal Services** (the District of Columbia P&A) has advocated for DC to develop and implement a system of transition services for nursing facility residents seeking to live in the community, including assistance with applications to obtain identification documents, housing, and linkages to long-term care services. One part of this effort was to encourage the city to make use of its underutilized "Money

Follows the Person” Medicaid program, which gives the District additional federal monies to help residents in DC nursing facilities return to their communities with supports. The P&A eventually had to file a class action lawsuit on behalf of DC residents in nursing facilities who preferred to move back to the community.¹⁷

As this case progresses through the court, the P&A continues to advocate for clients like Mr. M., a gentleman in his 60’s who finally returned to the community after 2 years in a nursing facility. Mr. M received a slot in the MFP program, the P&A helped him apply for an accessible apartment, he was approved, and he signed his lease. This was the easy part, however, because over the next few months the P&A continued to represent Mr. M fix to fix many barriers. Among them, the District’s failure to help him transmit necessary paperwork from the nursing facility to each of the home health agencies that agreed to provide Mr. M services; then DC’s failure to timely pay for his furnishings with his MFP allotment, or to pay his rent timely pending his discharge, and finally, the city’s failure to properly notify the Social Security Administration to ensure that his benefits would be restored and sent to Mr. M’s new address.

B. Promoting Full Enforcement of New Standards For Medicaid Community Based Services and Supports

Nationwide, P&As are educating stakeholders about a new federal rule which sets standards for Medicaid funded home and community based services and supports.¹⁸ One of the goals of the rule is to ensure that individuals receiving services and supports through Medicaid’s HCBS programs have full access to the benefits of community living and are able to receive services in the most integrated setting.¹⁹ The standards help ensure that these settings do not isolate residents and that policies and services in these settings facilitate community integration. The regulatory changes also give individuals fundamental new rights to engage in the community, control their personal resources, and seek employment and work in competitive settings.

The rule gives states up to five years to bring their Medicaid HCBS into compliance. States are required to develop and implement an “HCBS transition plan” identifying how it will access its current HCBS services and settings, bringing existing HCBS up to compliance and develop new HCBS that will met the requirements of the rule. Transition plan development is required to be transparent and reflect stakeholder input.²⁰

P&As are working individually and in coalition to advise states on development of the transition plans and on the array of HCBS that must be developed. P&As are also sharing their knowledge of specific community settings and services to assist states and

disability advocates to identify settings which do not comply with the HCBS Rule. Some examples are:

Minnesota’s HCBS plan indicated the intent to reduce reliance on its multi-bed therapeutic foster care homes. While it sounds good, the **Minnesota Disability Law Center** (the Minnesota P&A) knew trouble was ahead, because the state was not considering what would replace these homes. Minnesota has two main sources of funding for HCBS, one specifically for congregate foster homes, the other for unrestricted housing assistance. The housing assistance program is used to fund individual supportive housing. Unfortunately, not many Medicaid beneficiaries can take advantage of this program because it provides only \$200 per month which, combined with SSI, is not enough to fund housing. Compounding the problem are state policies that make it easier for providers to be reimbursed under the congregate foster homes program than the housing assistance program. For both reasons, developers are less inclined to develop individual supportive housing. The Minnesota P&A notified the state, disability advocates, and Centers for Medicare and Medicaid Services (CMS) of their concerns and explained that the transition plan must also provide for the removal of barriers to individual supportive housing.

The **North Dakota Protection and Advocacy Project** (the North Dakota P&A), in coordination with several other disability advocates, strongly disagreed with the initial finding of CMS site



“Rather than utilizing the rule as an opportunity to develop true community settings, DHS is trying to squeeze its existing services into the definition of the rule.”

– North Dakota P&A letter to CMS

reviewers that disability-only group housing, next to a large institution for people with intellectual and developmental disabilities, met the requirements for HCBS waiver funds. The P&A conducted its own site review using the same survey questions as the CMS reviewers, documenting numerous policies and practices that appeared to violate the new rule. This coalition of disability agencies sent CMS a letter with their concerns and as a result, the agency conducted a second survey and provided additional training for site reviewers.

C. Enforcing ADA The Integration Mandate In Segregated Non-Residential Settings

The ADA integration mandate also applies to segregated day programs and sheltered employment settings.²¹ Additionally, any work or day program that receives HCBS funding must meet the requirements of the new HCBS rule.²² A 2013 NDRN Report on sheltered workshops points out that such settings are not eligible for HCBS funding. The report compiled the results of P&A monitoring visits in sheltered workshops across the country and concluded that:

In the best of situations, sheltered environments, segregated work, and the sub-minimum wage does not truly provide a meaningful experience for workers with disabilities. Workshop tasks are often menial and repetitive, the environment can be isolating, and the pay is often well below the federal minimum wage. In the worst situations, the segregated and sheltered nature of the lives of workers with disabilities leaves them vulnerable to severe abuse and neglect.”

- *Segregated and Exploited: A Call to Action – NDRN report (2013)*²³

In contrast, the HCBS rule requires person-centered services and supports that facilitate access to community. An example of this is customized employment. This type of employment is person-centered and driven by the interests, strengths and conditions for success of each individual. It is real work for real pay in integrated settings. A customized job is a set of tasks that differ from the employer’s standard job descriptions but are based on actual tasks that are found in the workplace and meet the unmet needs of the employer. Practitioners and innovators in customized employment accomplish customized job descriptions through job carving, negotiated job descriptions, and job descriptions specifically created to meet the employer’s unmet needs.

In 2012, **Disability Rights Oregon** (the Oregon P&A) brought the first lawsuit seeking to enforce the Olmstead mandate in non-residential settings.²⁴ The class action represents people with intellectual or developmental disabilities who, with the support of the State, are employed in sheltered workshops. The lawsuit argues that Oregon is violating the ADA integration mandate by over-relying on sheltered workshops and failing to make integrated supported employment available to all persons with disabilities who want and can benefit from such services. The P&A collected evidence that:

1. 61% of people receiving employment services in Oregon are in sheltered workshops; and only 16% are in individually supported employment;

2. People with intellectual disabilities in Oregon remain in sheltered workshops an average of 11-12 years; and
3. The lack of supported employment options in Oregon creates a virtual pipeline from school to segregated employment.

The case is ongoing but has had some success, including the intervention of the U.S. DOJ in support of the P&As claim.²⁵ DOJ has been very clear that the ADA integration mandate applies in sheltered work and employment settings,²⁶ and has conducted investigations in other states and found them in violation of the ADA for over-relying on sheltered workshops at the expense of integrated employment options.²⁷

A state may be violating the ADA’s integration mandate if it relies on segregated sheltered workshops to provide employment services for people with intellectual or developmental disabilities who could participate in integrated alternatives, like integrated supported employment with reasonable modifications....”

- Americans with Disabilities Act Update: A Primer for State and Local Governments (U.S. Department of Justice, 2015)

D. Collaborating with DOJ to Leverage P&A and DOJ Resources

P&As often collaborate with the U.S. Department of Justice (DOJ) in support of Olmstead enforcement. Of the 51 Olmstead cases the DOJ identifies being involved in, 22 are cases brought by the P&A.²⁸



“P&As have played a central role in ensuring that the rights of individuals with disabilities are protected, including individuals’ rights under Title II’s integration mandate.”

- The U.S. Department of Justice *Technical Guidance on Olmstead June 2011 Q. #17.*

When the DOJ lends support to a P&A Olmstead lawsuit, it customarily carries weight with the judge and helps the P&A leverage its limited funding and resources. Another successful form of P&A/DOJ collaboration is for the P&A to use its federal authorities to monitor all locations in which services, supports, and other assistance are provided, and share its findings with DOJ, so that the DOJ can initiate its own investigation. When this occurs the P&A usually stays available to the DOJ to help gather information and inform disability advocates and stakeholders. Below are examples of these forms of collaboration.

Disability Rights New York (the New York P&A) litigated on behalf of over 4,000 individuals with mental illness living in “transitional adult care homes.”²⁹ The state considered these settings to be community-based even though they were at least 100 beds in size, with at least a quarter of its residents diagnosed with a mental illness. New York’s criteria for “community-based” was that individuals could come and go as they please. Beyond this however, the procedures followed in the setting were typical of those found in institutions. The owners of the home managed and controlled any money residents received and individuals were provided very little autonomy over their daily lives. The lawsuit charged that NY’s heavy reliance on these settings and failure to develop or offer more integrated housing options violated the ADA. The U.S. DOJ supported this position and intervened during the remedy phase of the suit, and participated in the appeal. The DOJ also filed its own complaint raising similar claims. In 2013, New York settled with the DOJ agreeing to develop new scattered site, individualized supportive housing for individuals with mental illness, and to provide residents the necessary social and health supports to live and participate in the community.³⁰

Disability Rights North Carolina (the North Carolina P&A) was closely watching the progress of the adult care home litigation in New York because it had been monitoring similar settings in North Carolina and was alarmed by similar failures to provide adequate services to residents. The P&A issued several reports to the state documenting preventable deaths and serious injuries of residents in these homes, accompanied by recommendations for improving conditions and assisting residents to move to individual supportive housing in the community. As a result of P&A documentation the DOJ opened an investigation in the state and identified numerous violations of the integration mandate and other civil rights. In 2013, North Carolina settled with the DOJ and agreed to provide community mental health services, housing and employment for thousands of its citizens with mental illness.³¹

IV. Emerging Threats to Community Integration

A. Policies that Move Individuals from Large Facilities to Smaller but Equally Isolating Settings

Many states have committed to shifting away from large intermediate care facilities (ICF's) for individuals with disabilities to community-based residences. Unfortunately, instead of independent homes, these settings are often shared group housing, and instead of a home atmosphere, the settings institute policies and practices often used in large institutions to promote structure and efficiency rather than autonomy and choice.

A letter from **Disability Rights Ohio** (the Ohio P&A) to Governor Kasich, on July 14, 2014, expresses this exact concern:

The State is constructing new ICF facilities to house individuals who leave state-operated developmental centers and other large ICFs. Moving from a large facility to a smaller facility will not mitigate the inherent segregation. Our investigation found that even smaller ICFs are highly segregated and do not provide or allow for the integration that the law requires. By committing to construct and maintain these new facilities, the State is subjecting yet another generation of Ohioans with developmental disabilities to a life of segregation.

The 2014 CMS rule setting standards that any Medicaid funded setting or service must meet in order to be labeled “community-based” will help ensure that individuals will be offered appropriate community-based settings that truly facilitate a life in the community like those without disabilities.³² If implemented as intended, Medicaid funded HCBS settings will allow residents to control their personal resources, and seek employment and work in competitive settings, as appropriate.

The **Disability Law Center** (the Massachusetts P&A) is one of dozens of P&As that submitted comments to CMS with recommendations for settings that must be addressed as part of the state’s plan for complying with the HCBS rule. The P&A writes:

DLC strongly opposes moving former ICF residents into planned “cottages” or apartments “literally across the street to an adjacent parcel of land does nothing to promote community integration, particularly in a

remote rural location with very limited access to transportation or vocational, social, recreational or educational opportunities. We do not believe that a residential placement so connected to the past attributes and stigma of institutionalization and so removed from community integration can pass the [requirements of the HCBS regulation].

Ultimately, the cottages were developed. The P&A is remaining in contact with CMS to ensure that HCBS funds are not spent for services in these settings.

B. The Proliferation of Segregated Disability-only Communities

Our nation is seeing increased development of disability farm communities and gated/secured disability-only communities.³³ Disability-specific farm communities are often in rural areas on large parcels of land, with little ability to access the broader community outside the farm. People who live at the farm typically interact primarily with other people with disabilities and the staff, live in homes only with other people with disabilities and staff, and generally do not leave the farm to participate in recreational and day programs, shopping and church services.”³⁴

Likewise, a gated/secured community for people with disabilities typically consist primarily of people with disabilities and the staff that work with them. Often, these locations provide residential, behavioral health, day services, social and recreational activities all within the gated community.”³⁵

Individuals who support these segregated settings often have the same good intentions as those behind traditional state hospitals and intermediate care facilities of the past, to create a special protected environment for their family member.³⁶ History tells us, however, that protectionist models of disability-only institutions can become sites that conceal horrible abuse and neglect.³⁷ Another concern is that limited state and federal Medicaid dollars will flow to these segregated settings thereby limiting a state’s ability to support a sufficient array of community based services and supports to comply with the ADA integration mandate.

The 2014 federal regulations setting standards for HCBS settings and services, discussed above, will make it difficult for farmsteads and disability-only villages to qualify for Medicaid HCBS funding. In fact, CMS issued guidance on “settings that isolate” under the rules. Farmsteads and disability-only villages were mentioned as an example of a setting that is likely to isolate.”³⁸

C. School System Reluctance to Move Away from Segregated Classrooms.

While it is more common for students with physical and intellectual disabilities to be appropriately supported in general education classrooms, educators still steer many students to segregated classrooms.³⁹ Studies have shown that inclusion in general education classrooms has positive effects on student learning.⁴⁰ It is also possible that students with disabilities, who experience only segregated classrooms, may be more likely to assume that after graduation, a segregated, protected employment and living environment is also most appropriate.

On May 15, 2015, the Obama Administration released a draft policy statement calling for greater inclusion of preschoolers receiving special education services.⁴¹ Disability advocates are working to ensure this call is realized, not only for preschoolers, but for all students for whom an inclusive classroom is the most integrated setting appropriate. For example:

In 2014, *SS. V. Springfield City and Public School District*,⁴² became the first ADA integration mandate case filed in Federal District Court on behalf of students with disabilities in segregated schools. Plaintiffs, including parents of children with mental and emotional disabilities, argue that the Springfield, Massachusetts school district is failing to provide reasonable accommodations for students with mental health needs and is unnecessarily placing these students in a segregated, inferior public day school. This separate school is comprised of physically segregated buildings where children with mental health disabilities are denied access to nearly all after-school sports, clubs and extracurricular activities that would be available to them if they attended their neighborhood schools.

Traditionally, students and parents have used the Individuals with Disabilities Education Act (IDEA) to argue for the services and supports they need to receive a free appropriate education in the least restrictive environment. Having an ADA Title II claim, in addition to an IDEA claim, is important because the ADA's non-discrimination mandates require school districts to provide different and additional measures to avoid discrimination against children with disabilities than they are required to under the IDEA. No decision has been reached yet, but the DOJ has filed a brief in support of plaintiffs' ADA integration mandate claim.⁴³

D. Misplaced Support for Involuntary Outpatient Commitment

For individuals with a diagnosis of mental illness, continued stigma and public misunderstanding of what mental health services are effective have led many states to pass involuntary outpatient mental health treatment laws (IOC).⁴⁴ These laws (also called “assisted outpatient treatment” (AOT)) are “court-ordered, community-based treatment for people with untreated severe mental illness.”⁴⁵ The orders come with legal criteria, however, a 2004 study, by the Judge David L. Bazelon Center for Mental Health Law, found that “a person with a mental illness can be committed in most of the 37 states that have IOC laws without any finding of imminent dangerousness to self or others. Even without any dangerousness requirement, a number of states explicitly allow police forcibly to pick up and detain people for mental evaluations if they have failed to comply with any provision in an IOC order.”⁴⁶ IOC is a serious infringement on an individual’s rights, and can deter individuals from seeking mental health services and supports.

P&As in several states have worked with physicians and policy makers to explain the importance of funding non-coercive treatments that better protect individual rights and are less of a deterrent to seeking mental health services and supports.

Disability Rights Ohio (the Ohio P&A) worked individually and in coalition to inform the public and state officials of concerns with the state’s plan to expand its involuntary outpatient treatment program. The program allows probate courts to order involuntary treatment of individuals that pose a risk of harm to themselves or others. The P&A explained that Ohio’s mental health system is already stretched by limited resources and expansion of the program will only divert more resources away from community-based services that can help to prevent individuals with mental illness from entering the criminal justice system.

The **Nevada Disability and Advocacy Law Center** (the Nevada P&A) became concerned when an AOT law was passed which failed to provide adequate due process for the individuals ordered for such treatment. The P&A raised these concerns with the public defender’s office which resulted in a series of meetings with the public defenders, disability groups, and other stakeholders. Ultimately, the parties agreed to comply with a set of stringent due process standards, and a process and to ensure individuals under outpatient commitment would receive the appropriate community services and supports.

One way to more effectively support individuals with mental illness is to enforce Mental Health Parity laws. **Disability Rights Washington** (the Washington P&A) sued Regence Blueshield⁴⁷ for violating the mental health parity law by imposing exclusions

and visit limits on coverage of neurodevelopmental therapies (such as speech, occupational and physical therapies) for individuals over 7 years of age with autism, developmental, or intellectual disabilities. The Court preliminarily ruled for plaintiffs and ordered Washington Regence plans purchased by private employers to remove these limits, after which the parties settled.

The **Disability Rights Washington** also supported access to appropriate mental health services by filing an amicus brief in the state Supreme Court seeking to end the state’s illegal warehousing of individuals with mental illness in community hospital emergency rooms without necessary mental health treatment.⁴⁸ State and Pierce County officials argued that this practice was occurring because of a lack of available certified psychiatric treatment beds. While the P&A did not dispute the lack of beds, it explained that, when the state detains an individual for the purpose of delivering treatment, state law requires such treatment to be delivered; the failure to adequately fund the treatment is not an excuse to violate state law. The Court agreed, holding that the government’s authority to use civil commitment for mental health treatment carries with it the obligation to meet patients’ constitutional rights to receive individualized treatment. As a result of the decision, Pierce County created additional psychiatric treatment beds, and developed a plan to fill in gaps in its mental health system so that people in a mental health crisis have better choices than hospital emergency rooms.

E. Campaign to Convince Policy Makers that Olmstead Requires States to Keep Facilities Open

A small number of individuals (among them owners of facilities, family members of facility residents, and unions representing facility staff) have sought, through policy and litigation, to stop states from downsizing or closing particular institutions.⁴⁹ The influence of these appeals are often enhanced by a lack of understanding of the community services now available, or perhaps, less consciously, by our nation’s long history of providing charity, not rights, to people with disabilities.

Their legal challenges assert that state decisions to close institutions and move individuals into more appropriate community based settings constitutes discrimination against individuals with developmental disabilities who choose to remain in institutional settings, and violates the ADA.⁵⁰ This claim rests upon “part 2” of a three part test the U.S. Supreme Court included in the Olmstead decision for determining when community integration is appropriate -- whether “(1) the state's treatment professionals have determined that community placement is appropriate; (2) the transfer from institutional care to a less restrictive setting is not opposed by the affected individual; and (3) the

placement can be reasonably accommodated considering the available state resources and the needs of other people with disabilities.”⁵¹ Most courts have rejected this claim but challenges continue.⁵²

Attempts have also been made to halt a handful of Olmstead class actions by arguing that the legal requirements for a court to certify a class are not met. These arguments are counter to a robust line of court decisions that have certified Olmstead class action litigation.⁵³ Most Courts have dismissed these challenges to class certification, finding, for example, as the United States Court of Appeals for the Seventh Circuit. In *Ligas v. Maram*,⁵⁴ parents of residents who wanted to remain in the institution that was the subject of the class action argued that the class would not represent their interests, because the class sought to require the state “promptly to provide eligible Plaintiffs and class members with appropriate services sufficient to allow them to live in the most integrated setting appropriate to their needs.”⁵⁵ They argued that this relief “would leave them no ability to choose to remain in institutional care if they were eligible for community-based care.”⁵⁶ The Seventh Circuit disagreed ruling that, “If the plaintiffs succeed in class certification and win on the merits, the relief that they seek would only require that Illinois provide that which (they allege) it does not currently provide: the existence of appropriate services tailored to the needs of the individual.”⁵⁷

These suits can sometimes gain the support of owners of institutions. This was the case in an **Equip for Equality** (Illinois P&A) class action seeking services in the most integrated setting for residents of large institutions for individuals with mental illness.⁵⁸ Ultimately, the P&A and the State of Illinois agreed to a settlement that would ensure residents would receive community supportive housing and an array of crisis, peer-based, and rehabilitative services. Before the Court approved the settlement, however, the owners of these privately owned institutions, who had a financial stake in the growth and success of the facilities, spread misleading information about the proposed settlement, designed to scare residents from seeking to transfer to a community setting. This caused great confusion and residents and their families sent a flood of letters to the judge opposing the settlement. The P&A was forced to obtain a



“...to read that sentence in Olmstead as creating a right to institutionalization would turn the ADA and its integration mandate on its head and impermissibly create a new right under the ADA that was never intended by Congress.”

- U.S. Department of Justice Statement of Interest in *Illinois League of Advocates for the Developmentally Disabled v. Illinois Department of Human Services*

court order stopping the owners from sending inappropriate communication to residents and their families.⁵⁹

These challenges are a real threat to Olmstead enforcement. They sometimes result in fewer people with disabilities able to benefit from the remedy the litigation brings, they slow Olmstead enforcement, and make it more expensive to represent individuals who want to move from institutions back to their communities.

Conclusion

The best antidote is not to go back to failed policies of segregation, but to vigorously enforce community integration laws. As barriers are removed and more people with disabilities have the opportunity to join in community life, these outmoded beliefs about the effectiveness of community services, and the abilities of people with disabilities are challenged and shattered. NDRN and the P&A System will continue to speak out against policies that cause needless segregation of people with disabilities.

V. Recommendations for Federal and State Action

NDRN urges the adoption of the following recommendations for federal and state action to address threats to the ADA integration mandate, and speed up access to community-based services and supports for Americans with disabilities.

Congress:

Recommendation

Support increased Medicaid funding for HCBS programs. These are cost-effective programs that help people with disabilities and seniors live in their communities. Cuts to Medicaid will: weaken implementation of the 2014 federal regulations raising standards for HCBS programs; negatively impact crucial programs; and potentially put states at risk for violating the ADA integration Mandate.

Recommendation

Support the requested additional \$2.8 million in funding by CMS for FY 2016 to provide states with much needed technical assistance and guidance from the agency regarding implementation of the 2014 rule governing standards for HCBS services and supports. States depend on this assistance so that they can successfully transition their programs using sustainable and best practices.

Recommendation

Oppose changes to the 2014 HCBS rule that would hinder accomplishing the spirit and goal of the rule to offer supports that provide people with meaningful access to community life. The HCBS rule is the culmination of decades of advancement and bipartisan solutions to provide people with disabilities and seniors access to the broader community.

Recommendation

Support creation of a Protection and Advocacy Health Advocacy Program to protect the rights of Medicaid beneficiaries. This was the recommendation of the National Council on Disability (NCD), an independent federal agency charged with advising the President, Congress, and other federal agencies on disability policies.⁶⁰ NCD called on Congress to fund a P&A health advocacy program after

finding that protections are needed for beneficiaries with disabilities who experience due process violations from managed care utilization controls.⁶¹

Recommendation

Support adequate funding for the DOJ Civil Rights Division as it has been directed to ensuring and supporting state enforcement of the Olmstead mandate.

Recommendation

Increase the funding of P&As under the Protection and Advocacy for Individuals with Developmental Disabilities (PADD) and Protection and Advocacy for Individuals with Mental Illness Act (PAIMI) programs so that they have the resources to monitor community settings and provide advocacy to the individuals in such settings.

Administration:

Recommendation

Continue Department of Education (ED) technical assistance to states to ensure compliance with the ED guidance stating that the least restrictive environment (LRE) requirements apply to transition services, including job preparation, and that job coaches and other services meet the definition of supplementary aids and services to enable a person to participate in an integrated setting; and the draft guidance stating that LRE obligations applies to preschool settings.

Recommendation

The Office of Special Education Programs (OSEP) monitoring process must add a least restrictive environment component. This would mean that if OSEP identifies that a state is overly relying on segregated placements, it will be flagged as a concern for the agency to address.

Recommendation

In all settlement agreements between the DOJ and States regarding community integration, include a provision that the State will fund the P&A in that State to monitor community settings where transitioning individuals live and provide advocacy to such individuals.

Recommendation

The Centers for Medicare and Medicaid Services (CMS) should view the P&A Network as part of their panoply of independent quality enforcement strategies and provide funding to allow the P&As to monitor disability service systems receiving Medicaid or Medicare funding.

Recommendation

The Substance Abuse and Mental Health Services Administration should issue regulations to clarify that P&As have authority to monitor for abuse and neglect in all types of community settings (residential, non-residential, public and private) under the 2000 Amendments to the PAIMI Act.

Recommendation

CMS and HUD should ensure that the programs they oversee and the regulations they issue support the principle that all individuals with disabilities can live in their own home with supports and be employed in integrated settings. To this end, individuals with disabilities should have access to housing other than group homes, and other congregate arrangements that are primarily for people with disabilities.

Recommendation

CMS should ensure that P&As have immediate access to all surveys and reports, along with supporting information, prepared by CMS, its regional offices, and state Medicaid agencies regarding deficiencies identified in home and community based waiver settings.

States:

Recommendation

States should take advantage of the opportunity presented by the 2014 CMS rules governing funding for HCBS settings to responsibly phase out segregated living and work environments and replace them with funding for integrated housing and supported competitive employment options.

Recommendation

States should fully comply with Department of Education guidance stating that the LRE requirements apply to transition services, including job preparation, and that job coaches and other services meet the definition of supplementary aids and services to enable a person to participate in an integrated setting, as well as fully comply with draft guidance stating that least restrictive environment obligations applies to preschool settings.

Recommendation

States should increase funding for accessible transportation means so that people with disabilities will truly have access to the community for recreation, employment, and other activities.

Recommendation

Increase state funding to facilitate supported employment, customized employment, and self-employment for people with disabilities so that they can work in integrated settings at a competitive wage.

Recommendation

Increase state funding for integrated housing for people with disabilities to allow individuals to fully live in the community.

VI. Endnotes

¹ Senator Tom Harkin, “Americans with Disabilities Act at 20: A Nation Transformed” (May 25, 2011) available at <http://www.huffingtonpost.com/sen-tom-harkin/ada-at-20-a-nation-transf b 659001.html>.

² Americans with Disabilities Act, § 42 U.S.C. § 12101 (July 26, 1990).

³ See e.g., National Council on Disability, The Impact of the Americans with Disabilities Act: Assessing the Progress Toward Achieving the Goals of the Americans with Disabilities Act, 105-106 (2007) at <file:///C:/Users/elizabeth.priaulx/Downloads/Assessing%20the%20Progress%20Toward%20Achieving%20the%20Goals%20of%20the%20ADA.pdf>.

⁴ This report uses the term “Protection and Advocacy (P&A)” because that is the name used in the federal authorizing statutes. The P&As themselves go by a variety of names, the most common form of which is “Disability Rights” followed by the name of the state. For the name of the P&A in your state go to www.ndrn.org/en/ndrn-member-agencies.html.

⁵ See e.g., Elizabeth Priaulx, National Disability Rights Network, Docket of Cases Related to Enforcement of The ADA Integration Mandate (July 2015) at http://www.ndrn.org/images/Documents/Issues/Community_integration/Updated_Docket_of_Instead_Cases_July_13_2015.pdf (identifying over a dozen class action lawsuits with P&A involvement, that together will assist thousands of individuals with disabilities to access community based services).

⁶ National Council on Disability, Part 1 Summary: NCD Medicaid Managed Care Forums (rec.2) (October 14, 2014) at <http://www.ncd.gov/publications/2014/11042014>.

⁷ *Id.*

⁸ *Supra* at 3.

⁹ See e.g., Arlene Mayerson, Disability Rights Education and Defense Fund, The History of the Americans with Disabilities Act: A Movement Perspective (1992) at <http://dredf.org/news/publications/the-history-of-the-ada/> (discussing how disability civil rights have evolved gradually over decades).

¹⁰ 28 C.F.R. § 35.130(d) (“[a] public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.”).

¹¹ 527 U.S. 581 (1999).

¹² See e.g. Minnesota Governor’s Council on Developmental Disabilities, Parallels in Time: A History of Developmental Disabilities (Chs. 3, 4) at <http://mn.gov/mnddc/parallels/index.html>

¹³ *Id.* (Ch. 5).

¹⁴ National Council on Disability, Home and Community-Based Services: Creating Systems for Success at Home, at Work and in the Community, (pgs.7, 8) (Feb. 24, 2015) at <http://www.ncd.gov/publications/2015/02242015/>.

¹⁵ See, Priaulx, *supra*, at 5 (identifying 59 ADA Integration Mandate cases on behalf of individuals in institutions and seeking community services).

¹⁶ See, <http://fortune.com/fortune500/> (Listing Centene, United Health Group, and WellCare, three managed care groups used in KanCare).

¹⁷ University Legal Services, Press Release *Day v. D.C. Lawsuit Moves Forward* (Feb. 15, 2012) at <http://uls-dc.org/Day%20v.%20DC%20moves%20forward%20flier%202.15.12.pdf> (identifying the low use of the MFP as one of several reasons for the lawsuit).

¹⁸ Centers for Medicare and Medicaid Services, Final Rule - CMS 2249-F – 1915(i), State Plan Home and Community-Based Services, 5-Year Period for Waivers, Provider Payment Reassignment,

Setting Requirements for Community First Choice, and CMS 2296-F 1915(c), Home and Community-Based Services Waivers (Jan. 16, 2014) at <https://www.federalregister.gov/articles/2014/01/16/2014-00487/medicaid-program-state-plan-home-and-community-based-services-5-year-period-for-waivers-provider#t-3>.

¹⁹ See, Centers for Medicare and Medicaid Services, CMS Fact Sheet: Home and Community Based Services (Jan. 10, 2014) at <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Downloads/final-rule-fact-sheet.pdf>.

²⁰ See, Centers for Medicare and Medicaid Services, Centers for Medicaid and Chip Services, CMCS Informational Bulletin: Final Rule - CMS 2249-F – 1915(i), State Plan Home and Community-Based Services, 5-Year Period for Waivers, Provider Payment Reassignment, Setting Requirements for Community First Choice, and CMS 2296-F 1915(c) Home and Community-Based Services Waivers (pg. 2) (Jan. 10, 2014) at <http://www.medicaid.gov/Federal-Policy-Guidance/downloads/CIB-01-10-14.pdf>.

²¹ U.S. Department of Justice, Civil Rights Division, Statement of the Department of Justice on Enforcement of the Integration Mandate of Title II of the Americans with Disabilities Act and *Olmstead v. L.C. (Ques. 12) (June 22, 2013)* at http://www.ada.gov/olmstead/q&a_olmstead.htm.

²² See, Centers for Medicare and Medicaid Services, HCBS Settings Toolkit Exploratory Questions to Assist States in Assessment of *Non-Residential* Home and Community-Based Service (HCBS) Settings (2014) at <http://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/home-and-community-based-services/downloads/exploratory-questions-non-residential.pdf>.

²³ At: [http://www.ndrn.org/images/Documents/Resources/Publications/Reports/Beyond Segregated and Exploited.pdf](http://www.ndrn.org/images/Documents/Resources/Publications/Reports/Beyond_Segregated_and_Exploited.pdf)

²⁴ *Lane v. Kitzhaber*, 283 FRD 587, 602 (D. Or 2012).

²⁵ *Lane v. Kitzhaber*, 12-CV-00138 (D. Or. May 22, 2013) (granting U.S. Motion to intervene).

²⁶ *Lane*, *supra* at 28.

²⁷ See, *U.S. v. Rhode Island*, 1:14-cv-00175 (D.R.I. 2014); and *U.S. v. Rhode Island and City of Providence*, 1:13-cv-00442 (D.R.I. 2013).

²⁸ See, http://www.ada.gov/olmstead/olmstead_cases_list2.htm (listing Olmstead cases with DOJ involvement).

²⁹ *DAI v. Patterson*, 653 F. Supp. 2d 184, 187–88 (E.D.N.Y. 2009) (The P&A was a named Plaintiff and co-counseled this case with the Judge David L. Bazelon Center for Mental Health Law).

³⁰ *United States v. New York*, 13-cv-4165 (E.D.N.Y. 2013).

³¹ *U.S. v. North Carolina*, No. 5:12-cv-557 (E.D.N.C. 2012).

³² See *supra* at 22.

³³ An NDRN website search conducted in October 2014, identified at least 30 farmsteads or planned disability-specific villages currently running or in the fundraising stage for development.

³⁴ See, Center for Medicare and Medicaid Services, Guidance on Settings that Have the Effect of Isolating Individuals Receiving HCBS From the Broader Community (2014) at: <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Downloads/Settings-that-isolate.pdf> (defining “disability specific farm community”).

³⁵ *Id.* (defining a “gated/secured community” for people with disabilities).

³⁶ See *e.g.*, Mission Statement of the Golden Heart Ranch® at http://www.goldenheartranch.org/j/index.php?option=com_content&view=article&id=48&Itemid=61 (stating the Golden Heart Ranch is “Dedicated to providing young adults with special needs the

opportunity to reach their fullest potential and enjoy a dignified quality of life, by creating and building a “life-center” residential community where they can live, learn, work and create solid friendships in a harmonious and caring environment that is emotionally and physically safe.”).

³⁷ See e.g. Rivera, Geraldo (1972), *Willowbrook: The Last Great Disgrace*, WABC-TV.

³⁸ See, *supra* at 38.

³⁹ See, Department of Education and Health and Human Services, Draft Policy Statement on Inclusion and Children with Disabilities, Executive Summary (pg. 1) (May 15, 2015) at <http://www2.ed.gov/policy/speced/guid/idea/memosdcltrs/inclusion-policy-executive-summary-draft-5-15-2015.pdf> (stating: “Children with disabilities and their families continue to face significant barriers to accessing inclusive high-quality early childhood programs and too many preschool children with disabilities continue to receive special education services in separate settings”).

⁴⁰ See e.g., Baker, et al., The Effects of Inclusion on Learning, *Educational Leadership* (1994) (“Considerable evidence from the last 15 years suggests that segregation of special students in separate classrooms is actually deleterious to their academic performance and social adjustment, and that special students generally perform better on average in regular classrooms.”); Cosier, et al., Does Access Matter? Time in General Education and Achievement for Students with Disabilities, *Remedial and Special Education* (2013) (“Our hypotheses that a significant relationship exists between time spent in general education contexts and achievement in reading and mathematics was confirmed by the findings.”); and Rea et al., Outcomes for Students with Learning Disabilities in Inclusive and Pullout Programs, *Exceptional Children* (2002) (Students served in Inclusive classrooms earned higher grades, achieved higher or comparable scores on standardized tests, committed no more behavioral infractions, and attended more days of school).

⁴¹ *Supra* at 43.

⁴² D. Mass., 3:14-cv-30116 (2014). Plaintiffs are represented by the Center for Public Representation, the Judge David L. Bazelon Center for Mental Health Law, and Bingham McCutchen.

⁴³ See, U.S. Department of Justice, Statement of Interest of United States of America, *S.S. v Springfield, Massachusetts*, No.3:14-cv-30116-MGM (2014) at http://www.ada.gov/briefs/springfield_ma_soi.pdf.

⁴⁴ See e.g., Csere, Updated Report: Involuntary Outpatient Mental Health Treatment Laws, Connecticut General Assembly, Office of Legislative Research (Jan. 2013) at <http://www.cga.ct.gov/2013/rpt/2013-R-0105.htm> (Citing the Treatment Advocacy Center for the finding that 44 states and D.C. have involuntary outpatient mental health treatment laws).

⁴⁵ *Id.* at 1.

⁴⁶ *Id.*

⁴⁷ *K.M., et al. v. Regence Blue Shield, et al.*, No. C13-1214-RAJ (W.D. Wash. Feb. 27, 2014), (unreported)

⁴⁸ *In Re Detention of D.C.*, 332 P.3d 423 (Wash. 2014)(banc) (The P&A amicus brief was supported by the National Alliance on Mental Illness Washington (NAMI) and the ACLU of Washington).

⁴⁹ See e.g., *AFSCME v. Ryan*, 773 NE2d 739 (Ill.App. 2002); Voice of the Retarded, VOR Policy and Position Statements (May 2013) at <http://vor.net/about-vor> (supporting a bill that would eliminate federal funding for any activity that “result(s) in forcing residents of federally-licensed ICF/IDD from their homes) and *Sciarrillo ex rel. St. Amand v. Christie*, 2:13-cv-03478-SRC-CLW (D.N.J. 2013), slip op., 2013 WL 6586569, *appeal pending*, (3d. Cir. Jan. 15, 2015) (Seeking to stop a Gubernatorial decision to close two New Jersey developmental disability centers, and move those who desire community placements to the community, and those who do not, to alternate New Jersey developmental disability centers.)

⁵⁰ See e.g., *Sciarrillo ex rel., id.*, (Seeking to stop a Gubernatorial decision to close two New Jersey developmental disability centers, and move those who desire community placements to the community, and those who do not, to alternate New Jersey developmental disability centers.)

⁵¹ *Olmstead*, 527 U.S. at 587.

⁵² E.g. *Illinois League of Parents of Individuals with Developmental Disabilities*, 60 F. Supp. 3d 856 (2014) (Federal District Court denied parents claim of ADA discrimination finding that state “officials were not motivated by discriminatory intent in closing the facility, but rather decision reflected national trend away from institutionalization of disabled populations, and there was no indication that residents were being treated differently than other developmentally disabled adults who were not subject to re-evaluation because they did not reside in institutional settings”); *Sciarrillo ex rel., supra* at 54 (“[t]here is no ADA provision that providing community placement is a discrimination. It may be a bad medical decision, or poor policy, but it is not discrimination based on disability.”)

⁵³ See, e.g., *Kenneth R. v. Hassan*, 293 F.R.D. 254, 271–72 (D.N.H.2013) (certifying class of adults with serious mental illness seeking expanded and enhanced community-based services); *Lane, supra*, at 28 (certifying class under Rule 23(b)(2) of “all individuals in Oregon with intellectual or developmental disabilities who are in, or who have been referred to, sheltered workshops” and “who are qualified for supported employment services”); *Oster v. Lightbourne*, (N.D.Cal. March 2, 2012) (certifying class of persons whose state in-home support services would be “limited, cut, or terminated” by 20% under a new law).

⁵⁴ *Ligas v. Maram*, 478 F. 3d 771 (7th Cir. 2007)

⁵⁵ *Id.* at 774.

⁵⁶ *Id.*

⁵⁷ *Id.*

⁵⁸ [Williams v. Quinn, 748 F.Supp.2d 892 \(N.D.Ill.2010\)](#).

⁵⁹ *Williams v Quinn*, No. 05 C 4673 (N.D. Ill. July 27, 2010) (unreported).

⁶⁰ National Council on Disability, *supra* at 18.

⁶¹ *Id.*

VII. Acknowledgment

This report was researched and written by Elizabeth Priaulx, Senior Disability Legal Specialist at the National Disability Rights Network. Curtis Decker, Executive Director, Janice Johnson Hunter, Deputy Executive Director for Legal Services, and Eric Buehlmann, Deputy Executive Director for Public Policy, edited the report.

Production was coordinated by David Card, NDRN Publications and Communication Specialist.

NDRN would like to give special thanks to Ron Hager, Senior Staff Attorney at NDRN, and Alison Barkoff, Director of Public Policy, Judge David L. Bazelon Center for Mental Health Law for their advice and support.

Thank you to the individuals with disabilities who have fought for their rights under the ADA and to the P&As, and other advocates, that work day in and day out to protect these rights.

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