

Statement of Peter Kinzler

At the Hearing

**“Examining Class Actions Against
Intermediate Care Facilities for Individuals
with Intellectual Disabilities (ICFs/IID)”**

Before the

Constitution and Civil Justice Subcommittee

House Judiciary Committee

March 6, 2018

Summary of Peter Kinzler's Testimony

- I am the father of Jason, who is 42 years old chronologically but functions at the intellectual level of a 6-month old. Jason was forced to move from his Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) home of 37 years into a group home as a result of the settlement of a Department of Justice (DOJ) suit involving all the residents of Virginia's ICFs/IID. I am also a longtime officer of VOR, a national organization that advocates for choice and quality care in all settings for people with I/DD.
- Federal law and the Supreme Court's *Olmstead* decision support the right of individuals with intellectual disabilities (I/DD) to live in the "most integrated setting appropriate to the(ir) needs," while respecting their right to choose where they live.
- DOJ and the Protection and Advocacy Program of HHS (government-funded advocacy attorneys) use federal dollars to undermine the right to choose to remain in an ICF/IID (essentially the intensive care unit of the disability system) by bringing class actions that sweep all individuals with I/DD who reside in ICFs/IID into the suit.
- The case in Virginia, where Jason and I reside, illustrates how DOJ has undermined federal disability law and the human consequences of its actions:
 - Before filing a complaint, DOJ consulted with a wide range of officials and staff, but *not* with the families and guardians of the individuals with I/DD.
 - DOJ pursued its case despite the near unanimous opposition of the families.
 - DOJ opposed the families' motion to intervene, thereby forcing us to raise nearly \$125,000 to hire an attorney to make the court aware of our opposition.
 - Virginia, mistakenly believing that moving the residents into the community would save money, established an arbitrary closure schedule that forced families to choose between a different ICF/IID located 160 miles away and a group home closer by.
 - Virginia's closure timetable, supported by DOJ, was not tied to the creation of community resources sufficient to handle highly disabled individuals like Jason.
 - As a result, many individuals were placed in lower-cost areas much farther away from their families and their "support community" (other non-disabled people with whom they interacted regularly).
 - Because the community was not ready, people leaving the ICFs/IID have experienced a mortality rate 88 percent higher than the mortality rate in the ICFs.
- Virginia is not an isolated case nor is DOJ the only federal entity bringing these suits:
 - The government-funded attorneys of HHS have filed more than 40 class actions to close ICFs, despite Congressional directives that the law not be read as supporting the closure of institutions.
 - Separately, DOJ has brought more than 40 actions in recent years.
- Death and abuse
 - Since the early 1990s, academic studies and multiple investigative news reports have documented high rates of mortality and abuse for people forced to leave ICFs.
 - In January of 2018, HHS found that there are "systemic problems" that place the health and safety of residents of group homes "at risk of serious harm."
- Recommended reforms
 - Request DOJ to halt further actions until they have identified the causes of the deaths and abuse and remedied them.
 - Enact legislation that enables individuals with I/DD or their families/guardians to exercise their right to remain in an ICF/IID in DOJ and P&A class actions.

My name is Peter Kinzler. I appear today, first, as an advocate for my son Jason, a longtime resident of an Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) who now resides in a group home as a result of a Settlement Agreement between the Department of Justice and the Commonwealth of Virginia. I appear, second, as a 33 year member of VOR, a national organization that supports choice and quality care in all settings for people with intellectual and developmental disabilities (I/DD).

I have two requests: (1) that the Committee take all actions necessary to change the policies of past administrations to one that respects the federally-authorized care choices of families and guardians for their loved ones, as required by the Americans with Disabilities Act (ADA); and (2) that the Committee urge the administration to suspend further deinstitutionalization activities until the causes of widespread abuse and death in group homes are identified and remedied.

People Who Are Incapable of Making Residential and Other Life Choices: My Son Jason

My son Jason is not like other 42 year olds. He cannot speak, he cannot dress himself and he cannot use the toilet by himself. Despite his chronological age, he functions in most areas like a 6 month to one year old. That is because he has Angelman Syndrome, which typically is associated with profound intellectual disabilities (the most severe category of these disabilities), the eating of inedible objects and a high pain threshold. There are other people like Jason, many of whom also have severe behavioral or health problems, who need help in performing all the daily functions of living that you and I take for granted.

People like Jason are a fraction of the I/DD population, the vast majority of whom can, with some assistance, function fairly well living in individual or group homes, hold jobs and engage in social interactions. The problem for the Jasons of the world come when they are lumped in with the larger group of people with I/DD and asked to do what they are incapable of doing. "One size fits all" definitely does not apply to the diverse disability community. Their limitations are why we family members have to make many important decisions for them, including housing. The right to make these decisions is typically legally sanctioned by a court through the granting of guardianship.

Guardians make different choices, from individual homes to group homes to ICFs/IID. These categories are on a continuum of care options from the fewest to the most services. For 37 years, Jason's mother and I found that, with the higher levels of staff and medical care in an ICF/IID, Jason was able to maximize his community integration in an environment that protected his health and safety. The *Olmstead* decision recognized that some people with I/DD are so disabled that they need ICF/IID care and, for them, such care provides the most integrated setting:

We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings.

* * *

the ADA is not reasonably read to impel States to phase out institutions, placing patients in need of close care at risk . . . "Each disabled person is entitled to treatment in the most

integrated setting possible for that person — recognizing that, on a case-by-case basis, that setting may be an institution.”¹

State and Federal-State Funded “Institutional” Care

For most of the 20th century, residential care for people with I/DD was left to the states and private entities. Given the knowledge of the time and the limitation of state resources, many people with I/DD were inappropriately placed in large state-run institutions that far too often provided warehouse care under awful conditions. I could never have placed Jason in such a place.

Fortunately, in 1971, the Congress set out to remedy the bad conditions by authorizing Medicaid to share with the states the cost of care through the creation of the Intermediate Care Facilities for the Mentally Retarded program (now, ICFs/IID), which are provided at the option of states. With federal dollars came federal standards that greatly improved the quality of care. With time and changing attitudes, most higher functioning people have long since left the pejoratively labeled “institutions.” The population of ICFs/IID dropped from 146,134 in 1986 to 77,444 in 2015,² with the vast majority of remaining residents having severe to profound I/DD and have severe behavioral problems and/or are medically fragile. For them, an ICF/IID functions in a continuum of care for people with I/DD as the equivalent of an intensive care unit in a hospital system.

Key Federal Disability Law Regarding Community Integration and Choice: The Developmental Disabilities Assistance and Bill of Rights Act (DD Act), the Americans with Disabilities Act (ADA) and the *Olmstead* decision

The DD Act. The DD Act was adopted in 1975 and has been amended several times since then. It specifies that, “the treatment, services, and habitation for an individual with developmental disabilities should be designed to maximize the potential of the individual and should be provided in the setting that is least restrictive of the individual’s personal liberty.”³ The law created three programs to carry out its mission. Among those programs is Protection & Advocacy, the government-funded advocacy attorney program that has filed over 40 class action lawsuits with the purpose of closing ICFs/IID.

The ADA. The ADA, enacted in 1990, requires public entities to provide services “in the most integrated setting appropriate to the needs of qualified individuals with disabilities.”⁴ This mandate is balanced with preservation of individual choice, including the right to reject a placement: “Nothing in this part shall be construed to require an individual with a disability to accept an accommodation, aid,

¹ *Olmstead v. L.C.*, 527 U.S. 581, 601, 605 (1999).

² U.S. Department of Health and Human Services, *2016 CMS Statistics*, 37; University of Minnesota, *In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends 2015* (November 2017), 69.

³ 42 USC 15009(a)(2).

⁴ 28 CFR 35.130(d).

service, opportunity, or benefit provided under the ADA or this part which such individual chooses not to accept.”⁵

The DD Act Amendments of 1993. After the ADA was adopted, Congress, in the DD Act Amendments of 1993, amended the DD Act to include the “primary decisionmaker” language which recognizes the key role family members play in making decisions for their loved ones with I/DD: “individuals with developmental disabilities and their families are the primary decisionmakers regarding the services and supports such individuals and their families receive, and play decisionmaking roles in policies and programs that affect the lives of such individuals and their families.”⁶

The Statement of Managers language was crystal clear: “the goals expressed in this Act to promote the greatest possible integration and independence for some individuals with developmental disabilities may not be read as a Federal policy supporting the closure of residential institutions.”⁷

The *Olmstead* decision. The only Supreme Court decision interpreting the ADA is the *Olmstead* decision, and it interpreted the ADA as a matter of legislative construction and not of Constitutional interpretation. Specifically, the Court established a 3-prong test for what constitutes “unjustified” institutionalization; i.e., when “discrimination may require placement of persons with mental disabilities in community settings rather than in institutions:⁸

when the State’s treatment professionals have determined that community placement is appropriate, **the transfer from institutional care to a less restrictive setting is not opposed by the affected individual**, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities.⁹

In addition to recognizing the right to choose to remain in an ICF/IID, the Supreme Court, as I mentioned previously, acknowledged that the I/DD population was not monolithic by stating that institutional care is appropriate for some individuals:

We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings. . . . Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it.¹⁰

The DD Act Amendments of 2000. After *Olmstead*, the Congress affirmed its expectations for the P&As by adding the language “including regarding choosing where the individuals live from available options”¹¹ to the primary decisionmaker language to make it absolutely clear that the DD

⁵ 28 CFR 35.130(e)(1).

⁶ Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1993 (Findings, Purposes and Policies), 42 USC 15001(c)(3)(1993).

⁷ H. Rept. 103-442 (March 21, 1994).

⁸ *Olmstead* (**emphasis added**), at 607.

⁹ *Id.*

¹⁰ *Olmstead*, at 601-602.

¹¹ DD Act, 42 USC 15001(c)(3)(2000).

Act programs were to respect family choice with regard to all decisions, including the place of residence.

Despite the clear language in all federal disability legislation and by the Supreme Court, DOJ and P&A continue to impose their ideological choices on individuals with I/DD – “community living for all” – overriding the explicit wishes of families. They have been able to do this, in part, because the Congress has not reauthorized the DD Act of 2000 since it expired in 2007.

DOJ and the P&A Advocacy Attorneys Are Misinterpreting Federal Disability Law Ignoring Family Wishes for Placement and Causing Grave Harm to People with I/DD

I have no quarrel with the ADA and *Olmstead*. I think they are good law. My quarrel is with how these government-supported entities enforce – or “mis-enforce” – the law and the often horrific impact of these policies on the people they are supposed to be helping.

DOJ has unilaterally replaced the first prong of *Olmstead* with its own community – biased test. The Supreme Court’s first prong is that “the State’s treatment professionals have determined that community placement is appropriate.” The Department of Justice, in its enforcement statement interpreting the ADA and in its court filings, cites the first prong as, “Such (community-based) services are appropriate,”¹² a very different test. DOJ’s rationalization is that States could force the professionals to support continuation of ICF care:

If courts do broadly defer to the state’s own professionals in *Olmstead* litigation – or worse, require a decision from a state’s treating professional before allowing an individual to obtain relief – then states have a ready means to circumvent the integration mandate. Professionals who work for the state can simply be directed or pressured to say that individuals cannot be properly served in community settings.¹³

To the contrary, most states have chosen to close ICFs when confronted with a class action suit, in part because of the expense of defending the action and in part because they have been told that community care will be less expensive. In Virginia, members of our family group were pressured by the treatment professionals time and again to move our loved ones *out of the ICF* into the community (A common staff comment to parents was, “You should move your child out before there are no good community placements left.”) The treatment professionals told us that the Commonwealth was pressuring them to push people out, not to keep them in.

Most importantly, regardless of its hypothetical musings on the subject, ***DOJ has no authority to change what the Supreme Court held.*** In doing so, they have radically altered the meaning of *Olmstead*. Instead of looking to the people with hands-on, day-to-day experience for their professional judgment, the government looks to its own experts (itself) to decide when people should

¹² Statement of the Department of Justice on Enforcement of the Integration Mandate of Title II of the Americans with Disabilities Act and *Olmstead*, 2.

¹³ Samuel Bagenstos, The Past and Future of Deinstitutionalization Litigation, 34 Cardozo L. Rev. 1, 36 (2012).

be moved into the community. And, of course, their answer is, always, “community for all.” The effect is to substitute DOJ’s preference for the actual first test of *Olmstead*.

DOJ and the P&A advocacy attorneys undermine the second prong of *Olmstead*, individual choice. DOJ and the P&A advocacy attorneys of HHS have also, in practice, ignored the specific right of individuals to reject the government’s choice by bringing these actions despite the opposition of the overwhelming number of parents and guardians in many cases.

Since 1996, Protection and Advocacy attorneys, under a program authorized by the DD Act, have filed 42 class action suits with the sole purpose of closing institutions. The conditions of care were not at issue in any of these cases. Similarly, DOJ has moved away from enforcing quality of care in ICFs, which it is specifically authorized to do under the Civil Rights for Institutionalized Persons Act, to seeking to close ICFs under its ADA enforcement powers. Between 2009 and 2014, DOJ brought ADA enforcement actions in more than 40 matters in more than 25 states.¹⁴

The Practical Problems Families Face in these Federal Actions: Barriers to Exercising Choice and the Limitations of Intervention

The nature of these actions makes it very difficult for families and guardians to exercise their right of choice. By definition, DOJ actions sweep all the residents into the suit and the only way to get out is to file a motion to intervene and oppose class certification.

Similarly, P&A class actions are filed under Rule 23(b)(2) of the Federal Rules of Civil Procedure, which applies to cases that seek injunctive relief. Unlike cases seeking monetary damages, where Rule 23(c)(2) requires notification to potentially affected individuals before the case is filed and affords them the right to opt out of the suit, Rule 23(b)(2) cases do not afford such protections. In these cases, where very vulnerable individuals’ lives can be radically affected, the individuals have no right to opt out and there isn’t even a requirement to give them notice of the suit until there is a proposed settlement agreement or court decision. By using this approach, DOJ and the P&A advocacy attorneys lock everyone into the case, thereby making an end-run around the *Olmstead* choice requirement.

Because of the lack of notice requirement, years ago, the families of individuals with I/DD were often not even aware of a class actions involving their son or daughter. As VOR, a family-led organization, began to monitor P&A class actions, it helped make families aware of the threat. Even with that information, because of the nature of the suit, families’ only recourse to vindicate their rights to choice is to join the suit. Because they are not entitled to do so as parties, the only way to join is to file a motion to intervene. It is a costly process, particularly because the P&As and DOJ always oppose family intervention, even though the intention and real world effect of their actions is to close the residents’ ICF/IID homes.

¹⁴ U.S. Department of Justice Civil Rights Division website, *Olmstead Community Integration for Everyone – Olmstead Enforcement*.

In **Virginia**, I experienced first-hand how the existing process is stacked against the families of ICF/IID residents. DOJ's findings letter cited with pride the wide range of people DOJ consulted during its investigation:

[W]e interviewed persons in statewide leadership positions in the Department of Behavioral Health and Developmental Services ('DBHDS'); CVTC (Central Virginia Training Center) administrators, professionals, staff and residents; community providers; Community Service Board directors; and individuals receiving services in more integrated settings in the community.¹⁵

The only group DOJ didn't interview was the parents and relatives of the residents of the ICFs/IID, the only people authorized by *Olmstead* to make these decisions.

Had DOJ bothered to ask the families, they would have found that almost all were opposed to having their loved ones move into the community. For example, in October 2012, a detailed written survey answered by about 40 percent of the authorized representatives at Northern Virginia Training Center (NVTC) found 97 percent would choose to have their residents stay at NVTC. Also, in two meetings with more than 175 authorized representatives at CVTC, in 2011 and 2012, not one hand went up when the families were asked if they wanted the residents to move.¹⁶

With DOJ having already filed a complaint and a proposed consent decree, the only option to participate was by filing a motion to intervene. Because DOJ and Virginia opposed our intervention, the families of the more than 1,000 ICF residents statewide had to spend hundreds of hours soliciting funds in order to raise the \$125,000 it took to hire a lawyer just to file and adjudicate a motion to intervene. The judge ruled in favor of intervention, recognizing the obvious impact the suit would have on residents:

The Petitioners are all Training Center [ICF/IID] residents who wish to continue receiving institutional care in their current settings. As such, their interests are certainly affected by a lawsuit alleging deficiencies in their care and a consent decree whose stated purpose is to prohibit the unnecessary institutionalization of Virginians with ID/DD. They are even members of the 'Target Population' identified in the Agreement. . . . In short, the Petitioners have a federally protected right, under *Olmstead* and the ADA, to receive the appropriate care of their choice. That care is the central focus of the Complaint, thus the Court must permit the Petitioners to intervene in this matter.¹⁷

Several hundred thousands of dollars later, it turned out that the rights of intervenors were far fewer than those of the parties. The intervenors were left out of many discussions with the court and the

¹⁵ U.S. Department of Justice, Civil Rights Division, Findings Letter to the Honorable Robert F. McDonnell, Office of the Governor, Re: Investigation of the Commonwealth of Virginia's Compliance with the Americans with Disabilities Act and of Central Virginia Training Center (February 3, 2012), 3.

¹⁶ The reaction of Virginia families is not unusual. For example, in *Coffelt v. Department of Developmental Services*, No. 91-6401 (CA. Super. Ct. Jan. 1994), the California P&A proceeded with a class action with 14 named plaintiffs on behalf of approximately 2,500 people, despite the fact that 98% of family/guardian respondents surveyed opposed P&A representation of their families.

¹⁷ *United States v. Virginia*, Civil Action No. 3: 12cv59-JAG, Memorandum Order (May 9, 2012), 4.

families' wishes were ignored in the final settlement agreement. Despite the opposition of nearly 100 percent of NVTC families, NVTC was closed in January of 2016.

In opposing family efforts to keep open a smaller, streamlined ICF/IID on NVTC grounds, Virginia and DOJ were both driven by a "one size fits all" ideology, that all people with I/DD are capable of living in the community. In addition, Virginia had to factor in the cost of litigation and was no doubt swayed by DOJ's cost argument. In its Findings Letter, DOJ argued that the average ICF per person cost was \$194,000 versus an average group waiver cost in the community of \$76,000, concluding that "Virginia can serve nearly three people in the community for each person in a training center."¹⁸ Given its long waiting list for services, Virginia saw closing ICFs as an opportunity to reduce the waiting list for community homes. Unfortunately, these numbers bore no relationship to reality and, since the Agreement was signed, the number of individuals with I/DD on Virginia's waiting list has increased from 6,074 on March 13, 2012 to 12,221 in October of 2017.¹⁹ As some of this increase was surely due to the gross underestimation of the cost of care for the former residents of NVTC, people on the waiting list who desired community homes were also victims of DOJ's overreach.

Closure Outcomes: Higher Death and Abuse Rates for Former ICF Residents in the Community

Unfortunately, DOJ and P&A advocacy attorneys pay far more attention to closing ICFs than they do to assuring the quality of care the former residents receive in the community. Justice Anthony Kennedy was prescient in his concurring opinion in *Olmstead* in foreseeing tragedies for severely disabled people forced into the community:

It would be unreasonable, it would be a tragic event, then, were the Americans with Disabilities Act of 1990 (ADA) to be interpreted so that states had some incentive, for fear of litigation, to drive those in need of medical care and treatment out of appropriate care and into settings with too little assistance and supervision.²⁰

Sadly, that is exactly what has happened.

The challenges of preventing death and abuse in the community. Let me state clearly upfront that I am pleased with the care my son Jason is receiving in his new group home. However, I was not given the choice to have him stay at NVTC.

Life in the community is more challenging for Jason and others forced to leave NVTC. It is hard to find doctors who take Medicaid, particularly specialists, and getting essential new equipment can take

¹⁸ DOJ Findings Letter, p. 3.

¹⁹ Wait List, Department of Behavioral Health and Developmental Services, Commonwealth of Virginia, October 2017.

²⁰ *Olmstead*, at 610.

months or even years to procure. By contrast, NVTC had a doctor in residence at all times and access to specialists through a program funded by the families.²¹

In Virginia, the families argued to make sure the necessary services and supports and quality assurance systems were in place in the community before moving people out of the ICFs/IID. Instead, Virginia insisted on adhering to its arbitrary closure schedule, with minor modifications, despite the fact that the community was clearly not ready to provide the necessary care in appropriate settings. DOJ identified the key to successful transition to the community as adoption of a new Medicaid waiver²² for community funding that would cover more services and provide the higher reimbursement rates needed to care for a population that, as a group, was much lower functioning than the average individual with I/DD living in the community. Because the new waiver had not been adopted at the time we were looking for a group home for my son Jason, no local provider would accept Jason because they could not be sure the yet-to-be-adopted waiver would provide sufficient funds to care for him properly. As a result, we had to place Jason in a residence in a less expensive part of Virginia that is more than twice as far away from us as NVTC was. Ironically, it removes and isolates Jason from his long-time “support community” (his family, volunteers at NVTC, and the people he knew from his community outings). That is just the opposite of what DOJ specifically wanted to retain.

That Virginia and other states have had trouble assuring quality care in the community for people leaving ICFs/IID is not surprising, given these systemic concerns in most states:

- (1) **Arbitrary ICF/IID closure schedules.** Such schedules do not reflect the challenges of moving very vulnerable people and rarely coincide with the development of the community structure needed to meet their needs.
- (2) **Pressure on states to skimp on needed services for the most disabled.** Almost all states are facing the challenge of trying to meet the growing demand for services for people with I/DD, as reflected in long wait lists for services. This puts pressure on them to reduce services for those with the most extraordinary needs, who are the costliest to care for. Limiting services for this population would put them at great risk.
- (3) **Access to medical specialists in the community is limited.** In contrast to the assured availability of all necessary specialists in ICFs/IID, it can be hard to find doctors in the community who will accept Medicaid.
- (4) **States’ conflicts of interest in doing their own assessments of outcomes.** There is an inherent conflict of interest in having a regulator assess the outcomes of its policies. The incentive is for them to overlook deficiencies that would reflect badly on them. To avoid this problem, most states do not track, analyze or publish mortality data. This leaves them blind

²¹ The Regional Community Support Center also offered services to people who couldn’t get them in community. The Center closed when NVTC did, depriving people in the community as well as those who lived at NVTC of these vital services.

²² The “waiver” is the term used for a federal-state program to fund services for individuals with intellectual and developmental disabilities in the community. It is called a waiver because the individual waives his or her right to care in an ICF/IID.

as to systemic problems. This problem could be addressed by having an independent entity make the assessments.

- (5) **States do not use ICFs/IID as a basis of comparison.** Maintaining ICFs for people who need them and whose guardians want them would enable states to improve care for people in the community by giving them a basis to compare outcomes. States could then adopt the practices from the different residential models that work best.
- (6) **The challenge of inspecting more residences for safety.** It is far harder and more costly to monitor the much greater number of group homes when an ICF/IID closes (for example, closure of a 160 bed ICF/IID would require a state to monitor 40 group homes instead, if everyone moved into a home with four people, the most common number). Moreover, there are far fewer people – families, staff and volunteers – going in and out of group homes to identify abuse.
- (7) **Economies of scale.** Because federal regulations are pushing people into smaller and smaller group homes and limiting the clustering of them, service providers cannot take advantage of economies of scale to reduce costs and increase safety and health.
- (8) **Community-only ideology.** Today’s ideology that every person with I/DD is best off in the community instead of an ICF/IID setting has blinded advocates to the high service needs that must be provided to this population in the community to protect them from abuse and death.

Samuel Bagenstos, Principal Deputy Assistant Attorney General, Civil Rights Division, in the Obama administration and a devout believer that all people can and should be served in the community, wrote a law review article in 2012. After pointing with pride to the dramatic reduction in the number of large ICFs, in a gross understatement, he wrote that the advocates of deinstitutionalization have been less successful in developing quality community services:

It should not be surprising that the coalition of deinstitutionalization advocates and fiscal conservatives largely achieved their goals of closing and downsizing institutions and that deinstitutionalization advocates were less successful in achieving their goal of developing community services.²³

This reality has become apparent in Virginia. As part of the Settlement Agreement between DOJ and Virginia, an Independent Reviewer is charged by the court with making regular reports on Virginia’s progress in meeting the terms of the Agreement. In December, he issued a report that concluded, six years after the Agreement was signed, that Virginia was still years away from having a quality assurance system in place that met the terms of the Agreement:

Its (Virginia’s) licensing regulations continue, however, to restrict the Commonwealth from requiring submission or attendance at trainings related to developing the required quality and risk management processes.

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²³ Bagenstos, *supra* n.13, 21.

[W]ithout revisions to its Licensing Rules and Regulations, the Commonwealth will continue to be unable to make substantial progress toward implementing the required risk and risk management system.²⁴

The tragic results of adhering to a “one size fits all” ideology without assuring that adequate quality assurance systems are in place are sadly and outrageously predictable.

Higher death and abuse rates in the community. Since the 1990s, VOR had been pointing to peer-reviewed studies and investigative journalism articles that identified higher mortality and abuse rates for people leaving the ICFs as a result of DOJ and P&A class actions. In California, for example, between 1996 and 2005, a series of three peer-reviewed studies found that the people who left an ICF experienced far greater mortality rates than those with similar disabilities who stayed behind, ranging from 44% to 88% higher.²⁵ A series of 56 investigative reports by the *San Francisco Chronicle* between 1997 and 1998 detailed the abuse, neglect and death that plagued California’s system of community-based care following the deinstitutionalization.²⁶

In **Virginia**, Dr. Robert Anthony, who has identified the failure of Virginia to put in place the necessary quality assurance systems to protect individuals with I/DD, has documented **an 88 percent higher mortality** rate for individuals moved from ICFs/IID to the community, relative to those who remained in the ICFs, after the Settlement Agreement.

In sum, common sense suggests that states would have to be extra vigilant and spend more money on quality assurance to protect the extremely disabled former residents of ICFs from harm when moved into community group homes. The kneejerk refusal of DOJ and P&A to consider abuse and death concerns because of their view that everyone should live in the community, despite VOR’s multiple warnings over decades about the dangers, has caused serious harm to many of our most vulnerable citizens who have been forcibly removed from their ICF homes.

HHS Report finds widespread abuse of individuals with ID in group homes. Now, after all these lawsuits, and the threat of lawsuits, have closed most state-operated ICFs/IID, the federal agency most responsible for closing them has finally done an assessment of the results and it confirms what VOR has been saying for years. A January 2018 report by the U. S. Department of Health and Human Services found that “**Group Home Beneficiaries Are at Risk of Serious Harm**” and made the following holdings:

health and safety policies and procedures were not being followed. Failure to comply with these policies and procedures left group home beneficiaries at risk of serious harm.

²⁴ Report of the Independent Reviewer on Compliance with the Settlement Agreement, *United States v. Commonwealth of Virginia*, United States District Court for Eastern District of Virginia, Civil Action No. 3:12CV 059, October 1, 2016 – September 30, 2017 (December 13, 2017), 3.

²⁵ David Strauss, Theodore A. Kastner, and Robert Shavelle, *Mortality of Adults with Developmental Disabilities Living in California Institutions and Community Care, 1985 - 1994*, *Mental Retardation*, Vol.6 No. 5, 360-371 (October, 1998).

²⁶ To cite just a few other examples, Georgia reported **an extraordinary death rate of nearly 16%** (*Augusta Chronicle*, January 27, 2016); 1,200 “unnatural and unknown” deaths in group homes in New York (*New York Times*, 2011-2012); and hundreds of deaths in the District of Columbia (*Washington Post* reports since 1999).

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These are not isolated incidents but **a systemic problem** – 49 States had media reports of health and safety problems in group homes.²⁷

This is a national scandal, a triumph of ideology over reality.

The answer to improving care in the whole system does not lie in closing group homes, as some of the same people who advocated for them in the first place now suggest. It also does not lie in continuing to allow the government to, in essence, sue itself. By that, I mean that government entities – DOJ and the P&A advocacy attorneys created by federal law – are suing to close Intermediate Care Facilities for Individuals with Intellectual Disabilities, which are also authorized by federal law. They are filing suits despite the fact that the ICFs are in compliance with federal regulations. The answer lies in making group homes safer and respecting the residential choices of the families and guardians of individuals with I/DD, even when that choice is to reside in an ICF/IID.

Actions the Committee Can Take to Protect Choice and Improve Quality of Care

This Committee can make a major contribution to solving these problems by doing two things:

1. Per the December 6, 2017 letter from Chairman Goodlatte to Attorney General Sessions, require DOJ to “initiate a comprehensive investigation into the causes of the unspeakable number of deaths occurring across the country and suspend activities aimed at displacing fragile Americans from licensed ICFs/IID in good standing;” and
2. Require DOJ, under its authority, and P&A advocacy attorneys, in Rule 23(b)(2) class actions, to respect the right of choice under *Olmstead* by surveying the wishes of the families of ICF residents *before* deciding whether to bring a class action and, if they do bring a case, respect the wishes of the families as to whether they want their loved ones to be part of the action.

One model for protecting the rights and lives of individuals with I/DD is H.R. 2032, a bill “To protect the interests of each resident of intermediate care facilities for the mentally retarded in class action lawsuits by federally-funded entities involving such residents and in Department of Justice actions that could result in an agreement to move such a resident from that resident's facility.” H.R. 2032 was a bipartisan bill introduced by Chairman Goodlatte and Rep. Barney Frank in the 112th Congress, with 80 cosponsors.

Thank you for listening to our concerns. I hope I have made it clear that ICFs/IID play a vital role in meeting the needs of society's most disabled individuals and that it is time for the Congress to act to vindicate the choices of the families and guardians of individuals with I/DD in class action suits, as

²⁷ U.S. Department of Health and Human Services, Office of Inspector General, Administration for Community Living, and Office for Civil Rights, *Joint Report, Ensuring Beneficiary Health and Safety in Group Homes Through Implementation of Comprehensive Compliance Oversight (emphasis added)*, 3.

clearly required by the ADA and *Olmstead*, and encourage the administration to work with the states to put an end to the systemic problems in group homes that threaten serious harm.