

**EXAMINING CLASS ACTION LAWSUITS AGAINST
INTERMEDIATE CARE FACILITIES FOR INDIVID-
UALS WITH INTELLECTUAL DISABILITIES
(ICF/IID)**

HEARING

BEFORE THE
SUBCOMMITTEE ON THE CONSTITUTION
AND CIVIL JUSTICE
OF THE
COMMITTEE ON THE JUDICIARY
HOUSE OF REPRESENTATIVES
ONE HUNDRED FIFTEENTH CONGRESS

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Letters Submitted by the Honorable Steve King, Iowa, Chairman, Subcommittee on the Constitution and Civil Justice. This material is available at the Committee and can be accessed on the committee repository at:

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AGAINST INTERMEDIATE CARE FACILITIES
FOR INDIVIDUALS WITH INTELLECTUAL
DISABILITIES (ICF/IID)**

TUESDAY, MARCH 6, 2018

HOUSE OF REPRESENTATIVES
SUBCOMMITTEE ON THE CONSTITUTION AND CIVIL JUSTICE
COMMITTEE ON THE JUDICIARY
Washington, DC.

The subcommittee met, pursuant to call, at 10:09 a.m., in Room 2141, Rayburn House Office Building, Hon. Steve King [chairman of the subcommittee] presiding.

Present: Representatives King, Goodlatte, DeSantis, Cohen, and Nadlar.

Staff Present: Jake Glancy, Clerk; John Coleman, Counsel; James Park, Minority Counsel; Danielle Brown, Minority Deputy Chief Counsel and Parliamentarian; David Greengrass, Minority Senior Counsel; and Veronica Eligan, Minority Professional Staff Member.

Mr. KING. The Subcommittee on The Constitution on Civil Justice will come to order. Without objection, the chair is authorized to declare a recess of the committee at any time. We welcome everyone to today's hearing on the examining class action lawsuits against intermediate care facilities for individuals with intellectual disabilities.

I now recognize myself for an opening statement. Today's hearing will examine class action lawsuits against intermediate care facilities for individuals with intellectual disabilities known as ICF/IIDs. Defined by Federal statute, an intermediate care facility or ICF is an institutional form of care that provides health or rehabilitative services to individuals with intellectual disabilities and is eligible for optional medical benefits it meets both statutory and regulatory requirements.

According to Centers for Medicare and Medicaid Services, CMS, quote, "This program serves over 100,000 individuals with intellectual disabilities and other related conditions. Most have other disabilities, as well as intellectual disabilities. Many of the individuals are non-ambulatory, have seizure disorders, behavior problems, mental illness, visual or hearing impairments, or a combination of

the above. All must qualify for Medicaid assistance financially.” closed quote.

While all 50 States have at least one ICF, there has been a major ideological shift in recent decades away from institutional care to community-based services. In 1999 for example, the Supreme Court held in *Olmstead v. L.C.* that individuals with intellectual disabilities have the right to live in the community rather than in institutions, if, quote, “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.” closed quote.

In recent years, actions by the Department of Justice, as well as class action lawsuits brought by government funded protection and advocacy attorneys have led to closures of many ICFs across the country. The original decision in *Olmstead v. L.C.* reads to me as use commonsense. I think we are going to examine some commonsense here today as we listen to the witnesses.

And according to testimony submitted for today’s hearing these closures have posed a significant risk for individuals with acute forms of disabilities who need special, around the clock care. Community-based services such as group homes, according to many parents, are insufficient to provide the amount of care their sons and daughters need and without the availability of effective forms of care like ICFs, these individuals are being denied the freedom to chose where they live and work and even with whom they associate.

I would like to thank our witnesses for being here today. I look forward to your testimony.

And I now recognize the ranking member of the full committee, Mr. Nadler, for his opening statement.

Mr. NADLER. Thank you, Mr. Chairman.

Mr. Chairman as we consider today’s narrow topic of class action lawsuits against Intermediate Care Facilities that care for individuals with intellectual disabilities, we must be sure that our focus is always on this key question, how can we ensure that people with mental disabilities receive the best care possible appropriate to their individual circumstances?

Since the 1960s aided by the advent of psychotropic drugs, there has been a national effort to move away from caring for people with mental disabilities in large institutions. Today there is a broad consensus that where possible people with intellectual disabilities should be integrated into their communities, in less restrictive settings. This has been aided by the Americans With Disabilities Act and the DOJ regulations implementing the ADA, which requires State and local governments to administer programs in the most integrated setting appropriate to the needs of individual.

In 1999 the Supreme Court made clear in *Olmstead v. L.C.* that with respect to persons with intellectual developmental disabilities who have been institutionalized in intermediate care facilities, unjustified institutionalization of such persons constitutes unlawful

segregation of persons with disabilities and therefore is a violation of the ADA.

The court clarified in *Olmstead*, however that the obligation of States to integrate institutionalized persons into community-based programs attached only where one, the State's medical professionals conclude that such placement is medically appropriate; two, the resident of the institution does not oppose placement in a community based program, and three, such placement can be reasonably accommodated in light of the State's resources and need of others who have mental disabilities.

The *Olmstead* court endeavored to promote the integration of persons with mental disabilities into the mainstream of American society, while being flexible enough to recognize that not all such persons are able to live in a community setting, that they may require a higher level of care than community programs may be able to provide.

Some families of persons with intellectual disabilities are concerned however that the carefully balanced approach set forth by the court has in practice become a biased toward community integration even when an individual would be best served by remaining in an institution. These family members believe that the institutionalization efforts have placed their love ones at unnecessary risk, by denying or eroding their ability to remain in an institutional setting which may be necessary for their care.

They are concerned that when States move individuals out of institutional settings and into community-based care, such placements have sometimes been used as an excuse for the State to save money and to reduce its commitment to care of individuals with disabilities with predictable and often tragic results.

Furthermore, some have argued that when class action litigation is filed to enforce *Olmstead*, individuals with disabilities and families do not have an adequate ability to participate in the case or to opt out, even though the court's decision will inevitably impact the care available to the individual. For this reason back in the 111th and 112th Congresses, our former colleague, Representative Barney Frank, introduced legislation that would have effectively curtailed the use of class action to enforce *Olmstead* by quote, "Protection and advocacy" Agencies, which are Federally funded entities charged with enforcing the rights of persons with disabilities.

Among other things the bill would have imposed a presuit notification requirement and would have given residents at intermediate care facilities that are the target of a potential lawsuit or their legal representatives the right to opt out of a punitive class before a class action could be filed against their facility.

Opponents of this legislation argue that the bill would make it too difficult to pursue class relief on behalf of institutionalized persons with intellectual disabilities by making it too hard to form a class in the first place by giving potential defendants facilities the opportunity to intimidate residents into opting out of a potential class action.

Moreover, they noted the bill was unnecessary to the extent that it was intended to help class members who objected to a class action because rule 23 of the Federal Rules of Civil Procedure which governs class actions already includes a number of procedural pro-

tections for class members. These include the newest requirements for class certification and the ability of class members to challenge any proposed settlement agreement that might effect their interest. It is almost axiomatic that class actions are a key tool of civil rights enforcements, including the enforcement of rights to protect people with disabilities from unjustified segregation. Therefore, we must be wary of legislative efforts to curtail their use. As a society we have made much progress in breaking down physical and social barriers against persons with disabilities since the ADA's enactment.

Efforts to undermine enforcement through litigation could threaten to turn the clock back. At the same time, the U.S. recognizes some litigation may have unintended consequences. For too long many people with intellectual disabilities were shunted to the outskirts of society with fundamental dignity and value ignored. You must be mindful that in protecting the rights of individuals to be cared for in community based settings, we have an equal duty to protect the rights of those for whom an institutional facility is more appropriate. Ensuring that each person with mental disabilities receives the level of care best suited to their individual needs requires a careful balance.

I look forward to hearing from our witnesses today as to how we can best strike this balance. And I yield back the balance of my time.

Mr. KING. The chair thanks the gentleman from New York for his opening statement now. Recognizes the chairman of the full committee, Mr. Goodlatte for his opening statement.

Chairman GOODLATTE. Well thank you, Mr. Chairman. I appreciate you holding this very important hearing.

Today's hearing examines the devastating effects of class actions on the availability of Intermediate Care Facilities for individuals with intellectual and development disabilities across the country. Underlying these lawsuits is a pervasive belief that institutionalized care has little or no place in our society today. Martha Bryant, a constituent of mine, has come here to testify about the tragic circumstances of her son's death last year after the Central Virginia Training Center in Lynchburg, Virginia, closed its doors to her family.

While this scheduled closing, as well as the closings of three other institutional facilities in Virginia were ultimately the result of a settlement agreement negotiated by the Department of Justice under the Obama administration the policies underlying DOJ's claims are the same as those advanced by class actions.

In recent years, several cases brought by the civil rights division specifically the special litigation section have blatantly disregarded the choice requirement set forth in *Olmstead v. L.C.* In *Olmstead*, the Supreme Court ruled that unjustified institutionalization is discrimination under the Americans with Disabilities Act, which according to law encourages States to administer services in the most integrated setting appropriate to the needs of qualified individuals with disabilities. The court in *Olmstead* specifically affirmed the right of choice by holding that an individual has a right to reject placement. The court also recognized that the community is not the most appropriate place for some individuals.

It is stated and I quote, 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.

Nevertheless, we are seeing a national trend towards deinstitutionalization due in part to DOJ's efforts and through dozens of class actions that have been filed with the purpose of closing intermediate care facilities, as well as other Medicaid license facilities.

Like DOJ's enforcement actions, class actions often sweep up individuals who do not wish to participate because they are filed under rule 23(b)(2) of the Federal Rules of Civil Procedure. Under rule 23(b)(2), plaintiff's attorneys are not required to notify potential members of the class and inform them of the right to opt out if they so wish.

In 2012, I cosponsored a bill with former Representative Barney Frank to correct this issue and look forward to our witnesses' recommendations about whether this legislation should be introduced again.

I would like to especially welcome Ms. Bryant and also our other witnesses. I thank you for being here and sharing your stories with us.

Mr. Chairman, I yield back.

Mr. KING. I thank the chairman of the full committee. Without objection, other members' opening statements will be made part of the record.

And now I will introduce the witnesses. Our first witness is Martha Bryant of Amherst County, Virginia, who joins us to tell her story. Our second witness is Caroline Lahrmann, Ohio State coordinator for VOR. Our third witness is Alison Barkoff, the co-chair of the Consortium of Citizens With Disabilities. And our final witness is Pete Kinzler, an attorney and a long time officer of VOR.

The light switch will turn from green to yellow indicating that you have 1 minute to conclude your testimony. When the light turns red it indicates that it is time to wrap it up. Before I recognize the witnesses, it is the tradition to swear you in this morning so please stand to be sworn in, the witnesses.

Do you swear that the testimony you are about to give before this committee is the truth, the whole truth and nothing but the truth so help you God?

Thank you. You may be seated. And let the record reflect that all the witnesses responded in the affirmative. Now I recognize our first witness, Ms. Bryant, please turn on the microphone Ms. Bryant and we are glad to hear your testimony.

TESTIMONY OF MARTHA BRYANT, MOTHER AND RN, BSN, AMHERST COUNTY, VIRGINIA; CAROLINE LAHRMANN, MOTHER AND FORMER PRESIDENT OF VOR, COLUMBUS, OHIO; ALISON BARKOFF, SISTER AND CO-CHAIR, CONSORTIUM OF CITIZENS WITH DISABILITIES; AND PETER KINZLER, FATHER AND ATTORNEY, ALEXANDRIA, VIRGINIA

TESTIMONY OF MARTHA BRYANT

Ms. BRYANT. Mr. Chairman and members of the committee, I am the voice of twin sons, Taylor and Tyler Bryant. And unfortunately, I am the voice of a dead son. Tyler Bryant was forced out of Central Virginia Training Center on January 17, 2017. I also want to recognize my mother who is my rock here, Ms. Esther Stinnett from Amherst who does the road trips with me, and has been there in the hospital and the ICUs, and has certainly been my support ever since a triplet pregnancy and we happen to be country neighbors so she is close by.

I certainly support the opt-out legislation. I tried every branch of government to stop the force—being forced out of Central Virginia Training Center. And I refused to sign a document from Virginia, Department of DBHDS that said that Hiram Davis was a training center.

So let's go back to what happened. My sons were—their reason for disability is prematurity, they were triplets, they were 29 weeks gestation. So they have had disability from the beginning and they have had profound intellectual disability around 9 to 15 months level. They are nonverbal, nonambulatory. They also have spastic quadriplegic cerebral palsy, epilepsy, asthma, reactive airways, they use wheelchairs, tube feedings, trachs, oxygen. So probably some of the most severely impacted by Central Virginia Training Center. And I was definitely surprised when I got the phone call at school in August of 2016 saying that they wanted to close their building by December, because the projected closure of Central Virginia Training Center was going to be 2020 and I thought that more people with better ability to go to community would go before my sons. But my sons' building was selected to be closed and so 42 people were caught up in this executive decision in Virginia.

So of the 42, 36 were changed the level of care to ICF, but six people were selected to be forced out and my sons were the first two to go without consent. So I did not consent. They were forced by a letter and an order by acting commissioner Jack Barber. And we left on a cold January morning, probably the worst time of the year to go out with fragile people. And they were transferred to Hiram Davis Medical Center, which is on the Central State campus in Petersburg, which is 139 miles away. And I have to say that Hiram Davis is not a training center, even though it serves people with intellectual disability.

I think the most profound shock is it has mentally ill, forensics and sex offenders. They today—Taylor is on the third floor of a nonADA building, under a current fire marshal citation. It is his sixth move in a year. And just a few weeks ago he was moved to the third floor from the second floor because of bed bugs.

So when we arrived, which takes hours to go from Amherst to Petersburg, we—if we arrive on a weekend or after 4 o'clock, we

are locked out. They have one operational psychiatric elevator. We have to be escorted to the floor. He is in a nonADA, ward-style room with no sink, four beds. Often we see people left in bed all day long with hospital gowns.

When I asked for Taylor and Tyler to get up on a Saturday, it was like changing the culture. They weren't used to people being up on weekends. And of course my sons were used to being up and dressed in street clothes and having a life on weekends.

But back to Tyler, what happened with Tyler. Tyler didn't tolerate the trip. He was the more—he weighed 2 pounds and 7 ounces when he was born. He was in the hospital for 2 months at UVA and Tyler has always had a rocky asthma life. So basically he was forced out, 49 days in the hospital, most of those ICU days, told he could not go back to Hiram Davis and dead less than 2 months after out of CVTC. And he died in a Richmond hospital when I couldn't be there. I got a phone call when I was in my kitchen that I had a dead son in Richmond.

So I fully support this and I have listed care concerns, many care concerns, many ongoing care concerns.

Mr. KING. Thank you, Ms. Bryant, appreciate your testimony.
Ms. Lahrman.

TESTIMONY OF CAROLINE LAHRMANN

Ms. LAHRMANN. Thank you, Chairman.

My name is Caroline Lahrman, I am the mother of twins, Henry and Elizabeth with profound intellectual and developmental disabilities. With all the challenges that our children face I could never have imagined that one day we would also need to fight to save their home, the loving home that we carefully chose for them. The home is a private charitable organization that we created 60 years ago when Otto and Mildred Heinzerling walked into their local bank, mortgaged their home, and started a care center for infants with profound needs. Who would have thought that this act of charity would be attacked one day by a public entity, and that the careful and responsible care decisions of families would be undermined?

At one time I too thought that decisions about healthcare and where and with whom one lives were private decisions. That could not be subject to litigation, certainly not in Federal court through a class action. But since 2016, Ohio families have been fighting a class action that threatens the healthcare and homes of 5,900 of Ohio's most disabled citizens, individuals who need intensive supports in ICFs not only do they need these facilities, these individuals have chosen these facilities.

The public entity I speak of is a protection and advocacy agency a P&A. Federal law stipulates that P&As protect and advocate the rights of individuals with development disabilities. But these agencies lack oversight. They have become politicized and ideologically driven. In many States P&As only protect the rights of individuals who can handle community settings, while they undermine rights of those individuals too disabled to live in the community. Individuals like Ms. Bryant's son.

Our P&A in Ohio, Disability Rights Ohio, also called DRO, filed a class action against the State that alleges that 5,900 ICF resi-

dents think as one, that they all have the same capacity and desires, regardless of their disabilities to leave their homes, their communities of friends and caregivers and their healthcare to live in small community settings.

DRO seeks what it terms a quote, single stroke solution to resolve class claims. Think about what that means. The lives of 5,900 citizens decided in a single stroke. Consider what is at stake, where to live, with whom to live, your healthcare. These are highly personal decisions. Can you imagine any other American who would put up with having these matters decided on a group basis in Federal court? I can't. If this treatment is not okay for you or for me, why is it okay for persons with intellectual and developmental disabilities? It is not okay and the DOJ tells us that.

In its final rule on nondiscrimination on the basis of disability, the DOJ wrote, public entities are required to ensure that their actions are based on facts applicable to individuals and not on presumptions as to what a class of individuals with disabilities can or cannot do.

Think about that, a class of individuals. But with class actions, P&As make presumptions about persons with disabilities and then sweep them all into a single class. In his concurring opinion in *Olmstead*, Justice Kennedy spoke of the harmful effects of litigation and we have seen those here today. It would be unreasonable—I am sorry, this is what Justice Kennedy said in *Olmstead* in his concurring opinion.

It would be unreasonable, it would be tragic, were the Americans With Disabilities Act 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. Justice Ginsburg in *Olmstead* said, the ADA is not reasonably read to compel States to phase out institutions, placing patients in need of close care at risk, but that is exactly what these class actions do. As such, and Chairman, I appreciate you referencing this in your statement, at such the *Olmstead* court set up a careful three-prong test for community placement that is to be applied on an individual basis, not a class basis.

DRO's lawsuit has inflicted great personal and financial costs on the families of Ohio. Families have had to raise \$100,000 and counting for legal defense against a Federally funded entity. But in fighting to protect our family member's rights, we do not deny the rights of the plaintiff to seek relief. We object to the class action nature of that relief and sweeping others into litigation counter to their own interests, counter to their own disabled children's interest. Plaintiffs should seek relief as individuals, as these are highly particularized claims.

This committee can correct the civil rights violations that are occurring with these class actions. I know that some have talked about an opt out, but I am sorry, I have seen what has happened in Ohio, and if these class actions move forward, no matter if some opt out, they are still going to be affected some day if their facility closes. And if they opt out, they may not be able to appear at the fairness hearing at the end of the settlement.

So I personally believe that these class actions should be prohibited. I believe that class actions by P&As that attack Medicaid accommodations that are needed and chosen by their own constituents should be prohibited. Think about what I just said. P&As bring class action against Medicaid accommodations that are needed and chosen by their own clients. What other attorney can act antagonistically toward their client? And that is one of the basic ethics of being an attorney.

Legal ethics alone should prohibit these class actions. Your assistance in this matter will restore rights to tens of thousands of citizens with disabilities throughout the country who live in fear of their protector and advocate in class actions. Thank you, sir.

Mr. KING. Thank you Ms. Lahrmann.

Now I recognize Ms. Barkoff for your testimony. Ms. Barkoff.

TESTIMONY OF ALISON BARKOFF

Ms. BARKOFF. Thank you for the opportunity to testify today. My name is Alison Barkoff and I am a disability lawyer and the sister of an adult with an intellectual disability. When my brother was born 40 years ago, our family was told the only place for him was an institution and was immediately offered a spot as is required by law. We weren't offered any services to keep Evan at home and spent the next 2 decades piecing together help from school, friends and our religious community. Finally, at age 23, Evan received community services allowing him to achieve things that he was told would be impossible.

I have also gotten to know people who transitioned to the community from the very institution where Evan could have been. An institution that closed not because of a class action lawsuit, but it closed because the dwindling number of people in the State's institutions and the huge demand for community services. And seeing some of those individuals with good services and support thrive and do well in the community has showed me what is possible. But not everybody has those opportunities. People like Brenda Boose, a single mother who is number 1,025 on a community wait list, with an estimated 8 year wait for health. She quit her job to take care of her son, sold her car and feared having to place him in an institution against her will.

A settlement agreement in Virginia that focuses on expanding community services has given them the services they need to stay together.

People like Earl H., a young man with significant medical needs, a tracheotomy, a g-tube, 24/7 care needs, who had to leave his family's home and enter an institution when he turned 21 and aged out of the children's system. Again because of a lawsuit in Illinois, he is able to live back at home.

People like Pam Wright who faced almost a decade of barriers trying to get her two children out of an ICF in Virginia. Again, because of the expansion of services, her sons are now living together with 24/7 medical support near their family.

These people's experiences are an important part of today's conversation too. These lawsuits are about helping them too. They are not about taking away an option for institutional care. Those deci-

sions can only be made by State legislatures as court, after court, after court has made clear.

While there are many differences in views across our community, including at this table, I think we have many shared concerns. People with IDD are at risk of abuse, neglect and exploitation in all types of settings. In institutions, in group homes and even in family homes. And there are tragic and absolutely unacceptable circumstances where people are hurt or even die because they do not get services that are adequate to meet their needs.

Public funds for services, particularly Medicaid, are stretched thin, exacerbating these problems. To keep our loved one safe and healthy, we need to make sure people are watching and that we have every tool at our disposal to hold systems accountable.

Ms. BARKOFF. I understand the committee is considering changing Federal rules governing class actions, rules that apply to every other person's access to the judicial system. Only in cases involving people with IDD in institutions. I urge you not to make those changes. They will not help address these real problems and could even make them worse. They are also unnecessary.

Existing rules are flexible and already provide opportunities for people to impact the goals, direction and remedies in class actions. For decades class actions have been a way to address harm to a group of people, a tool of last resort when other efforts do not work. The basic human and civil rights of people with IDD are too often and too easily violated. Limiting class actions would decrease oversight of services, increase risk of harms to people with IDD, putting at risk health and safety, access to needed medical services and protections from abuse, neglect and exploitation.

We would never eliminate access to court and protections for a group of people without disabilities. Why would we do that for one of the most vulnerable populations and limit a tool designed to protect safety, liberty and happiness? We want our family members safe, and healthy and to have a good life. And to make that happen, we need more reliable services, quality care providers and in the worst cases we need a justice system that will hold accountable those who have done wrong to our loved ones.

Please do not take away a tool that can help protect my brother and other people with IDD. Instead, make it possible to provide better and more reliable services so that there is less need for class actions and more opportunities for every person with IDD to live happy and healthy lives. Thank you.

Mr. KING. Thank you Ms. Barkoff. Now the chair recognizes Mr. Kinzler for your testimony. Mr. Kinzler.

TESTIMONY OF PETER KINZLER

Mr. KINZLER. Thank you very much, Chairman King and Chairman Goodlatte. I am the father of Jason Kinzler who is 42 years old chronologically, but functions at the intellectual level largely of a 6 month old. Where you would place Jason on an IQ scale he would register in the single digits. As a result, he needs help with everything from eating, to dressing, to toileting. He requires 24 hour, round-the-clock care for his very survival.

I am also a long time member and official officer of VOR, a national organization of families that advocate for choice and quality

care in all settings. For 37 years Jason received excellent care at an ICF in Northern Virginia. In a facility that essentially serves as the intensive care unit of the ID system. In 2016, Jason was forced to leave his home when the DOJ lawsuit led to a settlement that closed it. The suit was the result of an ideological policy that DOJ calls community integration for everyone, not for those who want it, for everyone.

As has been already discussed, the rationale for bringing these cases, including the one in Virginia, lies in the ADA. The case in Virginia involved all 1,000 residents, more than 1,000 residents of all five ICFs. And while indeed the ADA does require care in most integrated setting appropriate to the individual's needs, at the same time the Supreme Court pointed out that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to benefit—to handle or benefit from community settings. That is the piece of the ADA and home-stead that we feel is not appropriately recognized, the right of choice, individual choice.

As Caroline made clear in her testimony, DOJ is not the only Federal entity that files class actions involving the residents of ICFs. Protection advocacy, attorneys, government funded by the HHS in the first instance also use Federal dollars to file class actions having filed more than 30 over the past 25, 30 years. They bring these cases under rule 23 (b)(2) of the Federal rules, which sweeps all individuals who reside in ICFs into the suit, with neither advanced notice nor the right to out. The effect is to vitiate the family's right to choice.

Let me talk a little bit about Virginia because its experience is apropos to that and the other States as well. Before filing the case, DOJ issued a report in which they indicated they consulted with a whole laundry list of people in the system. The only people not mentioned in that list and not consulted were the family members of the residents of the ICF. DOJ then pursued its case on behalf of everyone despite the survey showing that a mere unanimous opposition to the family to moving from their care.

DOJ then opposed our so-called right to intervene by posing this motion to intervene, forcing families to raise \$125,000 just to hire an attorney. While we won the intervention motion, the judge ignored our opposition and agreed to settlement negotiated between DOJ and Virginia. The agreement for those who wish to remain in ICFs forces us to choose in Northern Virginia between a local community placement, or an institution, or a facility that is 160 miles away, simply not reachable.

The agreement itself called for the development of a closure timetable not tied to the creation of sufficient community resources to handle the individuals. As a result, people were placed in lower cost areas much farther away from families and with less oversight. Because the community was not ready, studies have shown that people leaving facilities have experienced a mortality rate that is 88 percent higher than those who remained in the facilities.

Well, let's look at other outcome in a sense. If you look at since 1990—the early 1990s, VOR and others have cited academic studies in multiple investigative reports appearing in newspapers from the San Francisco chronicles, to the Georgia papers, to the New

York City Times documenting higher rates of mortality and abuse of people forced to leave facilities.

DOJ and the P&A attorneys ignored these reports. Now just 2 months ago, HHS issued a report that found that there are quote, “systemic problems” end of quote, that place the health and safety of residents group homes at risk of serious harm.

So Chairman Goodlatte asked earlier what we would recommend to the committee. Let me just recommend two things in closing. One, Chairman Goodlatte sent a letter to DOJ essentially asking them to hold further actions until they identify the causes of deaths and abuse and remedy them. And we fully support that and urge the committee to follow up with the Department of Justice.

As far as legislation goes, the Goodlatte-Frank bill does not address Federal Rules of Civil Procedure. They would require notice and opt out before filing a class action. And I might point out in closing that there are in fact other situations where the Federal Government creating a right to bring class action limited the rights in that.

So in both the Fair Labor Standards Act, the age discrimination and employment act, permit class actions only for those who opt in, and the Magnuson Moss act of the Federal Trade Commission requires a minimum of 100 plaintiffs. Thank you very much.

Mr. KING. Thank you, Mr. Kinzler, for your testimony as well. And the chair will now recognize himself for his 5 minutes of questioning. I turn directly to you to, Mr. Kinzler, and ask you, do you have any data on the numbers of institutions that have been closed as a result of class action lawsuits across this country?

Mr. KINZLER. Well, I don't have—I have data on the number of actions brought by P&A and the Department of Justice, but I don't have the actual numbers closed. There have been since 2009 DOJ has filed more than 40 actions. They are not all class actions, they participate in other actions as well. For seeking—essentially seeking the closure of facilities.

P&As have brought in excess of 32, 33 or more class actions again seeking—effectively seeking the closure. When one talks about, as we have heard earlier, the notion of class actions remedying abuse in facilities, since 1996 not one protection advocacy case has contained a claim alleging patterns of abuse. They have all been designed to close the facilities.

Mr. KING. Could you give us a picture of—you are familiar with, Virginia region, could you give us a picture of what it looks like in the State of Virginia as a result of all these class action lawsuits?

Mr. KINZLER. Well, this DOJ action called for—let me just cite what they said in their investigation so you will understand what exactly it is for, they said that the reliance on unnecessary and expensive institutional care both violates the civil rights of people with disabilities and incurs unnecessary expenses.

So the settlement agreement called for—required the State to come up with a plan to close four of five facilities. DOJ later pointed out said well, the plan doesn't have to be implemented, just have to come up with a plan within 1 year. Well, that plan was supposed to be done in consultation with the finance—the chairs of the finance—the Senate Finance Committee and the House Appropriations Committee.

That plan was submitted either the same day or the day after the settlement agreement was agreed to between DOJ and—so what they proceeded with now is to close facilities. And as I said you now have Northern Virginia and the south side that are already closed, one is going to remain open. But our choice if we wanted institutional care was to go to the facility where Martha's sons originally were, which is approximately 160 miles away it is just not feasible to get to.

Mr. KING. Were there any precedents established or any indication in any of these class action lawsuits that you are aware of that actually turned this thing in other direction that maybe fell down in favor of the institutionalized?

Mr. KINZLER. Yes. There are a couple of interesting cases, there was a recent district court case in Florida which held that the Department of Justice under Title II of the ADA has no jurisdiction even to bring the cases and dismissed the case. That is the only court that has done that, but it does it using considering the language where one section of the Title II says—identifies the Department of Justice, the second one doesn't. But there are cases where there have been no certification, the judge has—after hearing from families has—refused to certify them, certify a case.

And there have been cases, there was a case in Florida—another—case in Arkansas which was dismissed because the judge found the case was being brought on behalf of a group of people who didn't want the case to be brought.

Mr. KING. Thank you, Mr. Kinzler. I appreciate it.

I would now like to turn to Ms. Lahrman, you made the case that these are highly particularized claims, that these are individuals. And I want to know if you would like an opportunity to respond, unless there is a bit of a disagreement between you and Ms. Barkoff on this, do you care to respond to her testimony or anything you would like to add with regard to the individual situation?

Ms. LAHRMANN. Yes. Ranking Member Nadler spoke about the balance here. And really the balance is by bringing these claims as individuals. You know, you cannot bring a lawsuit and then draw—I mean you can obviously, because they are doing it, but when you are drawing in people who have completely different needs. You know, Ms. Barkhof I saw her speak at a disability seminar in Washington last year. Her brother is extremely high functioning compared to my children.

My children are profoundly quadriplegic, they operate at the level of an infant, they have seizures. At any moment I might have to rush them to the emergency room at times. I mean, I'm afraid sometimes to take them certain places because of that. So I can't say that my children can live in a community to the degree that her brother can. That is why I think these type of cases should be brought on on an individual basis. I mean it wouldn't be right for me to bring a class action saying that everyone should live in an immediate care facility if someone is very high functioning, I don't think that is right. So I just think there needs to be some give and take here and it needs to be done individually.

Mr. KING. Thank you, Ms. Lahrman, I have run out of time. And the chair would now recognize the ranking member of this subcommittee, Mr. Cohen.

Mr. COHEN. Thank you, Mr. Chairman. I apologize for my tardiness. Firstly I would like to introduce my statement, I would have read it at the proper time but just introduce it for the record. This is a very difficult subject.

Mr. KING. Without objection so ordered.

Statement Submitted by Mr. Cohen of Tennessee. This material is available at the Committee and can be accessed on the committee repository at: <https://docs.house.gov/meetings/JU/JU10/20180306/106917/HHRG-115-JU10-20180306-SD005.pdf>

Mr. COHEN. In that statement I do address the difficulty, it is not a clear-cut issue on what to do. We want to deal properly with people with disabilities. We want to hold our courts open to different actions.

My father was a psychiatrist and the superintendent of a hospital many years ago and had an action filed against him by some civil rights attorneys under the idea that people in the institution should be dismissed. And taking psychotropics, et cetera. That was kind of en vogue in the 70s. The idea was that they would be cared for in the community, but the community didn't care for them and the money didn't flow with them. It didn't work. They couldn't get their monies, they didn't get medical attention and they become on the streets, homeless and wounded. There was a story I know my father liked and told me about called People Dying With Their Rights on. So tough situation.

The opening statement also questions why this is a very important issue why when we just recently learned 13 Russians were indicted for interfering with our elections. And it is clear and all of our security people know and have said that that is what the Russians want to do is disrupt democracy and our government. Why this committee has not held hearings on preserving our electoral system and making it safe from attack from the Russians, I would just raise that here and I see the chair my friend the chair is here of the committee, no more serious attack has been made than Pearl Harbor, the serious, no question every—but attacking our electoral system and trying to destroy democracy and no response from this committee at all. It is shocking.

Ms. Barkoff, let me ask you this, Mr. Kinzler asserted that the Department of Justice and the P&A system have undermined the second prong of Olmstead about filing lawsuits that deny individual choice as to whether an ICF resident should be placed in the community based program. Do you have a response to that?

Ms. BARKOFF. Yes, I do. Thank you.

First of all, in each of the lawsuits, and I would really encourage you to look at the settlement agreements and the decisions in this case, people's right to choose an ICF is not taken away. The point that you just raised, Congressman Cohen, about why these lawsuits are important. We can't—we need to address the lack of community services. And so when we were talking about early lawsuits under the constitution, what it didn't do was give a tool to expand communities. These lawsuits, I would encourage you to look at Virginia where there are 40 pages of detailed provisions about expanding community services in there. The provisions that relate to people inside of institutional settings, inside of ICFs is all about a process for individual choice. Again, I completely agree with Ms.

Lahrman that we need to look at people's different needs and people have different needs and choices. There is an individualized process where people are given information about what the options are, the ability to meet with other family members, both who are inside institutions and who have made the choice to move to the community, address what that process is like, what those kinds of concerns are like for people with disabilities themselves who are interested in speaking with other people with disabilities, there are those peer-to-peer and family-to-family supports. Opportunities to actually go and visit and look at a placement. So very much the individual choices is an essential and critical piece.

There is not required closures in any agreement that I am aware of and that is absolutely the case in Virginia. Far predating the Department of Justice getting involved, the legislature had developed a plan, they had rebuilt the Southeastern Virginia Training Center. The institutions had been built for 6,000 people, five institutions built for 6,000 people, and in 2012 there were 1,000 people left.

States across the country have been consolidating those services, not based on class action lawsuits, but based on the fact that the census has been dwindling there as there are more opportunities for people with the most complex needs, people with an ICF level of care, people who have 24/7 needs to live in the community. That is what has been driving closures and the over 200,000 people who are sitting on wait lists. Every person who has a right to be in an ICF immediately who meets that ICF level of care and States are figuring out how do we best use our resources to meet those needs.

Mr. COHEN. Thank you. Let me ask you this. Are you familiar with the protections that are in place to ensure that a resolution of a class actions suit is implemented?

Ms. BARKHOFF. Yes, I am. And there are opportunities both informally in advance of any kind of lawsuit being filed, as well as formal protections in the Federal rules. There are opportunities to participate before any kind of settlement agreement can be reached. A court has to hold a hearing to give all kinds of stakeholders opportunities to give input.

In Virginia there were several thousand people who showed up, thousands of letters and that impacted the agreement. There is opportunity for intervention and a judge must make findings in writing about the fairness of the agreement of different people's interests and how those are being balanced.

And for the Department of Justice there are already statutory requirements to have letter of findings publicly issued to engage the stakeholders and by statute they are required before filing any litigation to attempt to resolve those, and again then hold a public hearing. Intervention is common and it already exists in the rules if someone's rights are not already being represented by the existing parties.

Mr. COHEN. Thank you very much.

Ms. BARKHOFF. Thank you.

Mr. KING. Thank you. The chair will now recognize the Chairman of the Committee, Mr. Goodlatte, of Virginia.

Chairman GOODLATTE. Thank you, Mr. Chairman.

Ms. Bryant, I can remember when I learned that Tyler had died and was so moved by everything that had gone before that to try to create a situation where that circumstance didn't arise.

Couple of things. First, there have been other patients in this short period of time since these move have begun who have also I would say not survived the moves. Is that true?

Ms. BRYANT. Yes, sir. We had a 93-year old woman who lived next door to Taylor and Tyler at the training center and she was also forced to move at age 93 and she died within weeks. I think Tyler was the tenth death of training center out when they were trying to close that building.

Chairman GOODLATTE. Just from the Lynchburg training center.

Ms. BRYANT. Yes, from the Lynchburg training center. Tyler was the tenth death.

Chairman GOODLATTE. And how many were in the building before they closed?

Ms. BRYANT. Forty-two, when we got the letters.

Chairman GOODLATTE. Ten out of forty—two?

Ms. BRYANT. I am not sure if they were all central, but we have to think that Hiram Davis received people from south side as well and possibly from northern.

Chairman GOODLATTE. Can you explain the difference in the care between the two facilities where your son resided?

Ms. BRYANT. Oh, it is night and day difference. Central Virginia Training Center it was a skilled nursing facility, it was ADA compliant, it had been renovated in 2011, they lived in a first floor fire egress, 5-star facility with only one deficiency in 2016, beautiful rooms, bathroom, physical therapy, beautiful paint, open windows, light.

Chairman GOODLATTE. Did you consider that you and your sons were part of a community there?

Ms. BRYANT. Oh, definitely. In fact, he was 20 minutes away from me at work, 35 minutes away from us at home. We visited regularly. My mother visited often. My grandchildren went to see the boys there. I mean, it is like being on a college campus. You are not locked down, it is very different.

Chairman GOODLATTE. And the change was very sudden, it came far sooner than you had originally had been advised?

Ms. BRYANT. Yes. I rode in the ambulance with Taylor. The physician rode in the ambulance with Tyler. They were so worried about Tyler dying en route that I was asked to rent a helicopter for \$10,000 so Tyler could fly to Hiram Davis because they were concerned about Tyler dying just to go down the road.

Chairman GOODLATTE. Thank you.

Ms. Lahrman, why do P&As push for the elimination of ICFs if it is known that some individuals with profound intellectual and developmental disability needs institutional care to live?

Ms. LAHRMANN. I have received that question so much by families that I am trying to make aware of their rights. I am just a volunteer parent here and I am serving as somebody who's going around and explaining to them what is happening with these P&As. I don't know. I think it is ideological. I think that there are people that truly believe that everybody can live in the community regardless of their needs. I have heard those type of statements.

I would like to say that P&As do force closings by these actions, even before the actions are brought. States are so afraid they don't want to get bogged down in this litigation. In Ohio two centers closed before the litigation was even brought to try to keep this litigation from happening and DRO still went ahead and brought the lawsuit.

DRO was the P&A of the individuals whose centers closed, but DRO did not reach out to the people who were coming to the State legislature and saying, we don't want our center to close. They do not represent those individuals to retain their Medicaid accommodations. So no, DRO was more than happy to have those centers close. And you know, in this case what they are looking for is a single stroke solution to move people out.

Chairman GOODLATTE. So why are motions to intervene an important tool for families facing a class action lawsuit that they don't want to participate in?

Ms. LAHRMANN. If you—in my testimony in my larger testimony, the judge in our case, Judge Edmund Sargus ruled that without our intervention, our rights would not have been protected in this lawsuit. And in the Ligas case in Illinois, the judge basically said the same thing, without the intervention of their families, their rights would have been overlooked entirely.

Chairman GOODLATTE. Mr. Kinzler, per your statement, the Department of Justice offered a cost argument in the settlement negotiations with the State of Virginia, did they not? Claiming that the State could serve nearly 3 people in the community from each person in a training center?

Mr. KINZLER. Right, that as an argument—

Chairman GOODLATTE. Let me ask my question. Do statements like this essentially ignore the extensive care and services that persons with substantial disability like your son need.

Mr. KINZLER. Yeah. They tend to be apples to oranges comparison as assumed in your question. First of all, if you look at the community, people with this level of disability are 5 percent or less of the disability community. In the facilities, they are—I will give you an example of the demographics at Northern Virginia Training Center when it existed, 87 percent of the people had a diagnosis of severe profound intellectual disability.

In addition to that, 155 had two or more conditions, ranging from epilepsy, cerebral palsy, behavior disorders. One hundred thirty-nine couldn't dress themselves, 139 couldn't feed themselves or go to the toilet by themselves. So you're dealing one with a different population but also with a different constellation of services.

Chairman GOODLATTE. Thank you.

Mr. Chairman, my time has expired. I wonder if I might ask a question or two of Ms. Barkoff?

Mr. KING. The chairman is recognized for so much time as he may consume.

Mr. COHEN. I second that.

Chairman GOODLATTE. Thank you Mr. Chairman. The gentleman I hope will also be given that accommodation if he so desires.

Ms. Barkoff, in your written testimony you state, that "we have seen abuse and neglect in both institutions and community settings." Are you aware of any P&As bringing class actions to halt

these systemic problems at group homes or other community based settings?

Ms. BARKHOFF. So I am aware of a lot of advocacy that happens, you know. P&As spends maybe about 5 percent of their resources and time doing class actions. Now most of their—

Chairman GOODLATTE. But any with regard to—

Ms. BARKHOFF [continuing]. To abuse in group homes? I don't know of any class actions. I know of a lot of advocacy that happens there, in terms of what tools we have to bring litigation that the ADA certainly is not something that we could use to address that, the constitution that we have used in challenging State confinement. So again, as I described in my testimony, those don't apply in group homes. People with disabilities and the P&As would welcome the opportunity to have legal tools.

Chairman GOODLATTE. Class action lawsuits can be brought against public or private institutions, can they not?

Ms. BARKHOFF. Class action lawsuits can be brought public entities for funding, so when—

Chairman GOODLATTE. You are not answering my questions.

Ms. BARKOFF. I am sorry.

Chairman GOODLATTE. I want you to answer the question about whether or not private facilities can have class actions brought against them by an P&A?

Ms. BARKHOFF. Yes. For example—

Chairman GOODLATTE. I have a follow-up question.

Ms. BARKHOFF. For example the group homes in New York State that's an example of thousands of people with psychiatric disabilities who are in large private group homes called adult care homes where people's right were being violated, people are unnecessarily there.

Chairman GOODLATTE. Any in Virginia that you are aware of.

Ms. BARKHOFF. I am not aware in Virginia. I know in private nursing homes where people with intellectual disabilities are not getting active treatment so my organization is involved in a lawsuit in Texas where thousands of people with intellectual disabilities and development disabilities are inappropriately placed in nursing homes. The care they are getting in nursing homes are inadequate.

Chairman GOODLATTE. Okay. Let me just—but not the small group homes or the community-based programs. So here is my question: Doesn't the lack of such cases, despite numerous reports of such abuse, some of which you have just cited, throughout the years, including a recent HHS report issued earlier this year, suggests that the P&As have an anti-institution agenda rather than an agenda to protect all people with IDD from abuse and to promote choice?

Ms. BARKOFF. No, I don't think that is the case. Again, the P&As have been working very hard around ensuring protections in the community. This report came out, and already, the P&As and other advocates around community services have approached the Centers for Medicare and Medicaid Services and the Administration For Community Living and absolutely asked to work with them on additional regulations for the communities.

Chairman GOODLATTE. Should families like Ms. Lahrman and Ms. Bryant and Mr. Kinzler have the opportunity to have advance notice of a class action lawsuit?

Ms. BARKOFF. I think that there are already opportunities for notice. I know that Congress has included in appropriations opportunities for notice, and I do think that—

Chairman GOODLATTE. You don't object to that?

Ms. BARKOFF. I don't know exactly what the proposal would be, but I do think engaging stakeholders and making that public is important.

Chairman GOODLATTE. And what about the right of families to opt out and deal separately, individually with the State, in the courts or through private negotiations? Should they have that right?

Ms. BARKOFF. The reason that Rule 23(b)(2) classes don't allow opt out is because it create changes across the board in policies that defendants put in place. It is—

Chairman GOODLATTE. But—

Ms. BARKOFF [continuing]. Unworkable to create an opt-out. And in addition, many cases now, as courts look at how to define cohesive classes, don't include people who oppose moving to the community. And the case that Ms. Lahrman referred to, the class definition does not include people who would oppose.

So already, the existing class action rules create opportunities to narrow classes to people who are cohesive when people are not included as part of the class, they—

Chairman GOODLATTE. So you don't object—

Ms. BARKOFF [continuing]. Have the opportunities—

Chairman GOODLATTE. You don't object to—

Ms. BARKOFF. I think the existing rules already.

Chairman GOODLATTE. They are just perfect.

Ms. BARKOFF. And the rules that apply to class actions across-the-board provides the type of protections that have been interpreted by the courts to make sure people have—

Chairman GOODLATTE. Mr. Kinzler, do you want to respond to that?

Mr. KINZLER. Yeah. There is no requirement for advance notice, so advance notice is not afforded.

As I mentioned, the DOJ situation, they list people they talk to in the administration, in the community, staffs, administrators. Everybody, except parents. So DOJ and P&A typically do not provide any notice. And both the special litigation section and P&As have issued things that all read like this community for everyone, for everything.

Chairman GOODLATTE. Ms. Lahrman, are you satisfied with the rules regarding the ability to opt out?

Ms. LAHRMANN. No, I am not. I mean, I have had to raise \$100,000 to try to get into this lawsuit with other families. I mean, that has been an incredibly stressful situation for me for the past two years.

I will tell you, that the lawsuit—I mean, the judge said our rights were not protected until we intervened. The class definition that Ms. Barkoff—and actually her organization is suing the State, along with Disability Rights Ohio—it does say the class does not

include people who don't oppose it. But how are you going to know if they oppose the community or not if you don't ask them? And none of these families even know that the class action is taking place. I mean, these are 6,000 people all over the State of Ohio.

When DRO announced their lawsuit, they actually did it in a private press event. I found out about it, and I went to the event. And the executive director said, You know, Ms. Lahrmann, this is really supposed to be a private press event, but I will let you stay. I mean, my children are affected by this class action.

Chairman GOODLATTE. Ms. Barkoff, I am very glad that your brother is no longer in an institution where I think, based on what you have told me, was very inappropriate for him to be there. And I think there are a lot of other people who are in those circumstances as well. But I also believe that the process by which this has been undertaken is very inflexible, doesn't recognize the fact that there are many people, probably a minority of all the people who are in facilities like this, but many, many people represented by the three people with you today, that it is inflexible.

It does not recognize their extraordinary circumstances and the needs of their children. And I think that we have to work together to find more flexibility for them so they are not swept up and treated the same way as other people who may well deserve to be in a class action.

I support legislation separate and apart from this issue that says that people in a class action have to have similar harm, similar circumstances to be included in a class, otherwise, they should be treated separately, individually, as most of us would want to be if we were sued by somebody.

So thank you. Thank you, Mr. Chairman.

Mr. KING. Thank you, Mr. Chairman. The chair will now recognize the ranking member, Mr. Cohen, for unanimous consent requests.

Mr. COHEN. Thank you. I have a series of statements from different groups of concern, including the American Association of People with Disabilities and Autism Society, et cetera, Epilepsy Foundation, I would like to enter into the record.

Mr. KING. Without objection, all of these documents will be included into the record. And this—

Mr. COHEN. Thank you.

Letters Submitted by Mr. Cohen of Tennessee. This material is available at the Committee and can be accessed on the committee repository at: <https://docs.house.gov/meetings/JU/JU10/20180306/106917/HHRG-115-JU10-20180306-SD005.pdf>

Mr. KING. Thank you, Mr. Cohen.

And this concludes today's hearing. And thank you to all of our witnesses for your testimony and your responses to our questions.

Without objection, all members will have 5 legislative days to submit additional written questions for the witnesses or additional materials for the record.

This concludes today's hearing. Adjourned.

[Whereupon, at 11:17 a.m., the subcommittee was adjourned.]