Testimony of Caroline A. Lahrmann

for the

Constitution and Civil Justice Subcommittee

Examining Class Action Lawsuits Against Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs)

March 6, 2018

Summary

- Caroline Lahrmann is a mother of twins with profound intellectual and developmental disabilities (I/DD). She has been at the forefront of efforts in Ohio to fight a Protection & Advocacy (P&A) class action that attacks ICF homes, a Congressionally authorized program under Medicaid.

- P&As are a program funded by HHS. Each state is required to have a P&A to protect and advocate the rights of individuals with developmental disabilities. P&As have become politicized and ideologically driven. Many only protect the interests of constituents capable of handling community settings, while they undermine the interests of constituents too disabled to live in the community who need and choose ICFs.

- Federal law and the U.S. Supreme Court *Olmstead* decision support the right of individuals to choose ICF care. Class actions against ICF homes defy the Americans with Disabilities Act (ADA) and *Olmstead* that honor the *individual* and make each person's unique needs and choices paramount in accessing accommodations for persons with disabilities.[1]

- Issues at stake in a class action against ICFs are of a very personal nature (health care, where and with whom to live). Resolving these questions on a class basis in federal court abridges the rights of class members whose interests are different from those of the named plaintiffs.

- For families of absent class members who wish to protect their loved ones' interests, the hurdles to intervene in a class action are very high. Obtaining legal counsel for such complicated, protracted litigation costs hundreds of thousands of dollars. Families in Ohio have had to raise $100,000 to date and counting.

- Legal ethics alone should cause class actions by P&As to be prohibited. These actions attack the interests of a P&A's own clients – those class members who want to remain in their ICF homes. No other attorney can act antagonistically toward their own client.

- Chief Judge Edmund Sargus made clear what was at stake for ICF residents when he granted their intervention in the Ohio suit, "Thus, the Court finds that the rights of those individuals who do not wish to move from their residence in an ICF are directly impacted in this suit. Those rights were not protected until the Guardians filed their Motion to Intervene." [2]

Actions the Committee Can Take to Protect Individuals With I/DD and Their Choices

1. Prohibit P&As from bringing class actions that attack the interests of their own constituents. P&As should seek relief for their constituents on an individual basis.

2. Initiate oversight of the P&A program to ensure that P&As properly carry out their duties under the law – to protect and advocate the rights of all individuals with developmental disabilities, not push an ideological or personal agenda.

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[1] "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle and benefit from community settings...nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it. *Olmstead* v. L.C. 527 U.S. 581, 601-602

[2] Chief Judge Edmund Sargus, Opinion and Order, Ball v. Kasich, 2:16-cv-282, July 25, 2017, pp. 16-17

Introduction

As a parent of 18-year-old twins, Henry and Elizabeth, with profound intellectual and developmental disabilities (I/DD), I have been at the forefront of efforts to fight the Ball v. Kasich class action (No. 2:16-cv-282) brought by Disability Rights Ohio (DRO) against the State that threatens the ICF homes of approximately 5,900 Ohioans. DRO alleges in its complaint that thousands of individuals with I/DD are "institutionalized" and "segregated" in ICF homes of 8 beds or more. Many of these individuals are Ohio's most disabled and medically fragile citizens with conditions such as severe and profound intellectual disabilities accompanied by multiple co-morbidities such as quadriplegia, epilepsy, and respiratory disorders. Many are tube-fed and/ or non-verbal. Others have serious behavioral concerns. DRO seeks an injunction from the Court ordering the state of Ohio to partially or wholly remove funding from its system of private and state run ICFs, a Congressionally authorized program under Medicaid.

DRO is Ohio's Protection & Advocacy (P&A) agency, a program under HHS. Each state is required to have a P&A, that were established by the Developmental Disabilities Assistance and Bill of Rights Act. P&A's are charged "to protect and advocate the rights of individuals with developmental disabilities." Too many P&As are ideologically driven and protect the rights of only those individuals who can handle and benefit from community settings, while undermining the rights of individuals too disabled to live in the community. P&As use class actions to reduce or eliminate ICF homes and the health care they provide. In doing so, they act antagonistically towards their own clients who need and choose ICFs.

Efforts by families to defend against Ball v. Kasich have been enormous and not without tremendous personal and financial costs. The worry and strain protracted class actions place on average Americans already facing great difficulties in life cannot be overstated. That these Americans never asked to be included in the litigation is even more frustrating for them. Efforts to fight the class action have involved notifying families, explaining potential ramifications, informing families of the actions they can take to protect their loved ones' rights, fundraising to hire legal counsel, and researching and seeking appropriate counsel. Notification efforts are difficult as families are dispersed throughout the state and are connected to hundreds of private and public facilities. Contact information is protected by privacy law. Suffice it to say that we have not come close to notifying all families affected.

In April 2017, failing to overcome the financial hurdle to hire counsel, I drafted a pro se Motion to Intervene joined by eight other pro se guardians representing a total of 10 individuals. Joinders to our motion were filed by 99 more pro se guardians. In July 2017, families rejoiced when Chief Judge Edmund Sargus granted our motions and recognized our loved ones' legally protectable right to an ICF.

As intervenors, we raised sufficient funds to hire counsel and filed a motion opposing class certification. We await the Court's ruling on certification. Families have painstakingly raised $100,000 to date and counting. Litigation costs place intense pressure on our ability to maintain our defense, especially considering that we are up against a federally funded entity in our P&A.

But what is most striking is the simple truth stated by Chief Judge Edmund Sargus when he granted our intervention: **"**Thus, the Court finds that the rights of those individuals who do not wish to move from

their residence in an ICF are directly impacted in this suit. *Those rights were not protected until the Guardians filed their Motion to Intervene."* [3]

The rights of individuals with I/DD should not be subject to such chance, especially when those rights involve such personal decisions as where, how and with whom to live and what form one's health care should take. Individual rights should never be relegated to subordinate status by forced participation in a class action that seeks an outcome counter to one's own interests. The fact that the class action is brought by an agency charged by law to protect the interests of *all* class members adds further insult to injury.

Distinguished members, I urge you to prohibit the use of class actions designed to remove ICF homes from the fragile individuals who depend upon them. This is no way to administer the Americans with Disabilities Act (ADA) which holds individual needs and choices in the highest regard.

Class Actions Attacking ICFs Are An Inappropriate Means to Seek Relief Under the ADA

If the ADA is about anything, it is about the *individual* and ensuring that each individual with disabilities can have access to all that we as Americans hold dear.

Thus, the U.S. Department of Justice's (DOJ) Final Rule on Nondiscrimination on the Basis of Disability in State and Local Government Services states that "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."[4] In making this statement, the DOJ recognized the importance of the individual as well as the diversity of the population of Americans with disabilities.

Class action lawsuits brought by P&As and DOJ against states ignore the unique facts of absent class members and make presumptions about their needs and desires. These actions sweep vulnerable persons into an appeal for small community settings regardless of the capacities and preferences of each unique and precious member of that class. To truly understand what is at stake, think about yourself. Think about the decision-making you make with respect to where to live, how to live, with whom to live, and what form your health care will take. Think about how personal these decisions are and imagine them being decided by a federal court and a P&A arguing for a "single stroke"[5] solution, as is being argued at this very moment in Ohio. My children and thousands like them who are similarly situated, are waiting to see how a class action is decided to find out how they will live the remainder of their lives. Their homes and their communities of care and friendship, and for many, their lives, are at stake.

Can you imagine any other American citizens who would put up with such personal life decisions being determined in this way? I cannot. If it is not OK for you or for me, why is it OK for persons with intellectual and developmental disabilities? Massive civil rights violations are taking place with these class actions, and we are all to blame if we sit silent and do nothing.

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[3] Chief Judge Edmund Sargus, Opinion and Order, Ball v. Kasich, July 25, 2017, pp. 16-17

[4] 28 C.F.R § 35.130

[5] Complaint, Ball v. Kasich, p. 26; and Plaintiffs' Reply and Supplemental Evidence in Support of Motion for Class Certification, Ball v. Kasich, p. 4.

I wonder if class actions against ICFs benefit *any* of the individuals with disabilities affected by them, even the named plaintiffs. Due to the protracted nature of these actions, the adjudication of plaintiffs' claims often takes longer than if plaintiffs were to seek relief as individuals. Instead of litigation, plaintiffs could ask the state for community placement. In Ohio, "exit waivers" are available to ICF residents who wish to move to a community setting. Requesting an exit waiver would have resolved plaintiffs' claims in Ohio without a lawsuit.

As the lead guardian intervenor in Ohio fighting the Ball v. Kasich class action, I hear from families often: "How can the P&A discriminate against my child like this," "Isn't our P&A supposed to protect my child's rights," and "Why are our tax dollars paying for this?"

The law clearly is on the side of individuals accessing Congressionally-authorized Medicaid certified ICF homes and on the side of family members and guardians serving as the primary decision-makers[6] in their disabled loved ones' lives. Responsibility is also on the side of families who carefully access the needs of their family member and thoughtfully determine the safest, most appropriate, and loving home for them. The foundational U.S. Supreme Court *Olmstead* decision is also on the side of individuals and their families. *Olmstead* emphasizes throughout its majority and concurring opinions that "nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle and benefit from community settings...nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it."[7]

In his concurring opinion in *Olmstead*, Justice Anthony Kennedy warned of the harmful effects of litigation,

> "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 ned of medical care and treatment out of appropriate care and into settings with too little assistance and supervision."[8]

Sadly for residents of ICFs, Justice Kennedy's warning has gone unheeded. Many have lost their lives.

Bottom line, families do not care about labels – ICF, HCBS, community-based, institutional. Families think of homes, caregivers, supervisors, friends, nursing, therapy, activities, community outings, and proximity to family – the things that matter in their loved ones' lives, keep them safe and healthy, and make them happy. Bringing federally funded class actions to deny thousands of private decisions lovingly made by families is not an appropriate use of the P&A program.

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[6] 42 U.S.C. 15001(c)(3)(2000)

[7] *Olmstead*, 601-602

[8] *Olmstead*, 610

Class Actions Against ICFs Have Caused Severe Hardship and Death

Class actions against ICF homes have led to abuse, neglect and death in small community settings devoid of the expert staffing and supports needed to handle the unique and overwhelming demands of care connected to individuals with complex needs. California[9], Georgia[10], and Illinois[11] are just three examples of states whose citizens with intellectual and developmental disabilities paid dearly, many with their lives, from deinstitutionalization activities prompted by class actions.

This is not to say that community-based settings are not appropriate for many individuals. It is simply to say that community settings are not appropriate for all individuals, as the U.S. Supreme Court found in *Olmstead*.[12] Just as conditions exist with the elderly, such as Alzheimer's, that require individuals to seek higher levels of care, the same can be said for individuals with I/DD. The difference is that for individuals with I/DD these conditions are typically manifest at birth.

Class Actions Defy *Olmstead's* Three-Pronged Test Which Protects Civil & Human Rights

To protect civil and human rights, the *Olmstead* Court established a three-pronged test for determination of community placement: 1) the State's treatment professionals determine that such placement is appropriate; 2) the affected persons do not oppose such treatment; and 3) taking into account the resources available to the State and the needs of others with mental disabilities.[13]

Class action lawsuits prevent this careful case-by-case analysis from taking place by sweeping all class members into a single appeal for community settings, regardless of each class member's capacities and preferences. Class actions also override the State's autonomy over its own funding system (the third prong) raising serious federalism concerns as noted by Justice Kennedy in his concurring opinion.[14]

What P&As Say

In its complaint against ICFs, DRO alleges that seeking relief through individual claims would not remedy what it terms "systematic" issues.[15] But, there is nothing in the statute that established the P&A

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[9] David Strauss & Robert Shavelle, *"Mortality in Persons with Developmental Disabilities After Transfer into Community Care,"* American Journal on Mental Retardation, 1998, Vol. 102, No. 6, 569-581, www.lifeexpectancy.com/articles/cm1.pdf

[10] Tom Corwin & Sandy Hodson, *"Girls Death Among 500 in One Year in Community Care,"* The Augusta Chronicle, March 29, 2015, http://chronicle.augusta.com/news-metro-health/2016-10-18/girls-death-among-500-one-year-community-care

[11] Michael Berens & Patricia Callahan, *"Suffering in Secret,"* Chicago Tribune, November 21, 2016, http://www.chicagotribune.com/news/watchdog/grouphomes

[12] "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 in an institution." *Olmstead*, 605

[13] *Olmstead*, 607

[14] *Olmstead*, 610

[15] Complaint, Ball v. Kasich, p. 26

program[16] that stipulates a P&A is to seek systematic change of any kind, let alone the elimination of a Congressionally authorized program. The statute speaks of protecting and advocating the rights of *individuals* with developmental disabilities. And, the P&A statute refers to ICFs and home and community based services (HCBS) on equal terms, simply stating that the State shall provide the P&A with reports on both programs, to the extent such reporting is available. Oversight needs to be brought upon the P&A program to bring these agencies back in line with the statute so that individuals with disabilities are not harmed by an agency pushing an ideological agenda.

DRO argued in its Response In Opposition to ICF Guardians' Motion to Intervene that the purpose of their litigation is to make more community options available, not remove the ability of residents to remain in their ICF homes.[17] But, that assertion is disingenuous as it ignores two realities: 1) Unlike 35 years ago, the DD System of Ohio (and those of all states), is already overwhelmingly weighted toward community settings. The choice that is most lacking is the ICF choice, not the community choice. Most families are not even told that the ICF choice exists, or if they do find out about the ICF choice, they are coerced and shamed by State agents into not choosing it; 2) States face a finite amount of resources with a seemingly unending supply of priorities both within their State DD Systems and without. Therefore, a federal court ordering a state to make more resources available for community settings means taking resources away from a state's ICF program. In doing so, some or all ICF homes will inevitably close.

But, the closing of ICF homes is not a concern of disability advocates – it is their goal. Co-counsel on DRO's suit in Ohio, Sam Bagenstos, demonstrated a disregard for the rights of ICF residents when he wrote "one wonders why people with disabilities who want to and can live in the community should be forced to wait to ensure that other people with disabilities retain the option of living in an institution."[18] That a civil rights attorney holds this viewpoint is unfortunate, especially for ICF residents in Ohio – Mr. Bagenstos' latest target.

Equally concerning, P&As know that community settings are not appropriate or safe for all individuals, yet these agencies continue to file class actions to force individuals into them, regardless of need. Vicky Smith, Executive Director of Disability Rights North Carolina, made it known that P&As are aware of potential dangers in community settings when she stated, "So, let's just be clear that people with intellectual and developmental disabilities living in community are not safe. And, that's what we found with the project that Curt (Curt Decker, Executive Director, National Disability Rights Network) referenced earlier to go out and look at and use the same kind of monitoring strategies and techniques that we use out at our DD centers (i.e. ICFs), and we still have some in North Carolina."[19] P&As know what families know – ICF homes keep their residents safe.

On July 1, 2014, DRO sent a letter to Governor Kasich threatening litigation against Ohio's ICF program. DRO demanded that future admissions to ICFs occur only in "exigent circumstances (an

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[16] 42 USC 15043

[17] Plaintiffs' Response in Opposition to the Motion of Intervenor Plaintiffs, Ball v. Kasich, pp.1-2

[18] Samuel R. Bagenstos, The Past and Future of Deinstitutionalization Litigation, 34 Cardoza L. Rev. 1, 39 (2012)

[19] Panel Discussion, "The Disability Rights Movement: Immediate Challenges," August 4, 2015, 47:06 minute mark, https://www.youtube.com/watch?v=daGi_mstQy0

emergency or crisis, for example)," and that "admissions be short-term only, and that discharge planning occur immediately upon admission."[20]

In making these demands, DRO acknowledged that there are individuals with intellectual and developmental disabilities who cannot handle and benefit from community settings. However, in DRO's worldview, these individuals and their families are consigned to live in a constant state of emergency readiness – ICFs are to exist for "exigent" needs and discharge planning is to begin the moment life-sustaining care is received – "immediately upon admission".

This is not what the *Olmstead* Court intended, but through class actions, P&As seek to make it so.

Deinstitutionalization Litigation Does Not Make Community Services More Available

As noted above, P&As wrongly believe that deinstitutionalization will make more community services available. They forget that persons leaving institutions still need a home and that significant resources are spent moving individuals from ICF homes to community homes. As such, the needs of individuals on HCBS waiting lists go unanswered.

Another oft-told misconception of disability advocates is that the cost of care is greater in institutional settings. This misconception ignores the fact that ICF residents typically have more severe disabilities making their cost of care higher, regardless of setting. It also ignores the proven concept of economies of scale that are created through shared resources when more people live together. Economies of scale are especially powerful when caring for individuals with complex needs given the specialized staffing and equipment required.

Failing to take into account the costs of all benefits received by individuals living in the community also perpetuates the misconception of higher cost for institutional care. An apples to apples comparison of ICF and waiver home costs is difficult to achieve as their funding models are entirely different. See Exhibit A. ICFs operate under an all-inclusive funding model that includes room & board, nursing, therapy, active treatment (day habilitation), case management, among other supports. The waiver is based on a separately contracted services model. In addition, many waiver recipients access supports outside of the waiver program such as Social Security Disability Income, Food Stamps, HUD benefits, case management, and Medicaid card nursing, therapy, and other services. The additional benefits waiver recipients access should be included in any study analyzing the costs of various Long-term Services & Supports, but they never are.

Exhibit A shows an apples to apples cost comparison between Ohio ICFs and Ohio's Individual Options (IO) waiver. The average cost of the IO waiver is higher than that of an ICF when ICF average cost is reduced by services not covered under the IO waiver. ($71,057 for IO waivers vs. $68,127 for ICFs in 2011)

This analysis is further supported by average program costs submitted by the State of Ohio in its Brief In Opposition to Plaintiffs' Motion for Class Certification in Ball v. Kasich. The Brief's Exhibit 4 indicates

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[20] Disability Rights Ohio letter to Governor Kasich, et. al., July 1, 2014, p. 6, https://www.disabilityrightsohio.org/assets/documents/dro_to_governor_kasich_et_al_re_icfs-iid.pdf?pdf=DRO_Letter_to_Kasich

that the average annualized cost for an Ohioan leaving a non-state operated ICF and moving to a waiver is $95,858 (as of July 10, 2017) in waiver costs. This figure does not include Medicaid state plan services, room and board, or case management costs. The average annualized cost for someone living in an ICF is $103,412 (FY 2016) which includes room and board and case management.

Going back to Mr. Bagenstos statement quoted above, getting rid of institutional care will not make it easier for individuals waiting for community care to obtain services. It will make it harder as individuals leaving institutions are, on average, as costly or more costly to serve in the community. HCBS wait lists will inevitably grow, as they already have. See Exhibit B. Waiting lists have nearly doubled in size nationwide since 2005 as ICF homes have closed due to deinstitutionalization caused by litigation and threats of litigation. The closing of institutional care has not been the great panacea promised by deinstitutionalization advocates, but nothing that curtails civil rights ever is.

Experience In Ohio and Other States

Ohio families' lead counsel, William Choslovsky, likens the P&A class action in Ohio to "the proverbial 'solution in search of a problem.'" Mr. Choslovsky has great experience with these suits. He is the brother and guardian of his sister who benefits from world class care at an ICF home in Chicago. Working pro bono, Mr. Choslovsky successfully protected families in Illinois against the Ligas v. Illinois class action.

DRO alleges in Ball v. Kasich that the State is segregating thousands of individuals with I/DD in ICF homes. Ohio families have shown otherwise. Through options counseling offered by the State and through grassroots advocacy, ICF residents and their families have shown that they overwhelmingly prefer and choose ICF homes over community settings. DRO was well aware of the preferences of ICF families before it filed Ball v. Kasich. Just six months prior, families had successfully advocated against state legislative policies backed by DRO that would have led to ICF closings, filing over 21,000 petition signatures with the state legislature. Furthermore, ICF residents in Ohio wishing to obtain a community placement can immediately receive an exit waiver or receive priority treatment on the waiting list. Likewise, individuals requesting placement in an ICF are offered diversion waivers to divert them from ICF homes. The State has made over 1,000 exit and diversion waivers available in Ohio, but these waivers are *undersubscribed*. If there was widespread segregation occurring in Ohio, these waivers should have been taken within weeks or at least months of their offering.

Mr. Choslovsky and Illinois families also demonstrated that widespread segregation in ICF homes does not exist when they fought Ligas v. Illinois. Families of ICF residents flooded the Court for the fairness hearing to object to settlement. The Court also received thousands of affidavits from families that spoke to the benefits of ICFs. In response, Chief Judge Holderman rejected the proposed settlement, *de-certified the class,* and ordered the intervention of the objectors after years of litigation.

In Pennsylvania, families fought to intervene in the Benjamin v. Department of Public Welfare of Pennsylvania (No. 1:09-cv-1182) and were finally granted intervention after the Courts discovered the interests of ICF residents were not represented by the class that had been certified.

Court Orders from these cases demonstrate that class actions against ICFs abridge the rights of those who want to remain in their ICF home,

> "Thus, the Court finds that the rights of those individuals who do not wish to move from their residence in an ICF, or those who are at serious risk of institutionalization who wish to obtain residence in an ICF, are directly impacted in this lawsuit. **Those rights were not protected until the Guardians filed their Motion to Intervene.**"[21] (Emphasis added.)

> "Accordingly, the Court finds that the Proposed Intervenors have a right under *Olmstead* to have their needs considered...**The interest the Proposed Intervenors have in this litigation is 'direct, significant, and legally protectable.**'"[22] (Emphasis added.)

Ohio families are grateful our intervention was granted, but the hurdles to entry were extremely high, subjecting the rights of our loved ones to much chance. Fundraising to pay legal fees puts intense pressure on families, many of whom are financially strapped or who are trying to save money in trust for their disabled child. Families in Ohio have had to raise $100,000 to date and counting in defense costs. That this fundraising is necessary to protect against a class action in which individuals have been swept against their interests is exceedingly frustrating. Equally frustrating is the fact that we are fundraising to protect our family members from an entity that was put in place to protect them. Let's be perfectly clear – P&As bring class actions against the interests of their own clients, namely those individuals who want to remain in their ICF home. What other attorney can act antagonistically against their own client? Legal ethics alone should prohibit P&A class actions that put their clients' interests at risk.

Let's Talk About Community

Ostensibly, class actions attacking ICF homes are being done in the name of community integration. I want to assure esteemed members of the Constitution and Civil Justice Subcommittee that the quality of life of our loved ones is a primary concern when families make placement decisions. My husband and I chose Henry and Elizabeth's ICF home because of the opportunities that are available to them there, opportunities that could not be provided to them in a small community setting. My children are the most integrated people I know. On a daily basis, they are among many loving caregivers, fellow residents, and volunteers. They are engaged in activities at home and on community outings. My children attend school on a daily basis and when they age out of school, they will attend a day habilitation program. My husband and I and our elder son visit them regularly, accompany them on community outings, volunteer at their school, participate with them in activities at their ICF, and bring them home to visit regularly. My children are exceedingly happy. The gleam in their eyes, their giggles, their smiles are testament to that.

For our children, a small community setting would be confining, limiting, and offer less opportunities for community integration. Community homes are staffed by just 1 or 2 people. Individuals like my children require 1:1 assistance in the community and need 2:1 assistance to lift them out of their wheelchairs to perform personal care. So, in reality, my children need two staff with them in the

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[21] Chief Judge Edmund Sargus, Opinion and Order, Ball v. Kasich, July 25, 2017

[22] Chief Judge Holderman, Opinion and Order, Ligas v. Illinois, No. 05-4331, April 7, 2010

community. Small community homes often have four residents. One or two staff cannot push four individuals in wheelchairs in the community, not to mention the specialized vehicles that are necessary for their transportation. ICFs are appropriately staffed to handle community integration for this level of need and provide the necessary transportation.

The long, wide hallways and doorways of my children's home allow my children to use adaptive therapy equipment such as tricycles and gait trainers. While it is difficult for my children to maneuver the bumpy pavement and ups and downs of outdoor terrain, they can ride their adaptive tricycle in the hallways of their ICF home. My son Henry also likes to wheel his wheelchair. He can independently explore the long hallways and common areas of his home and visit residents and staff along the way. He cannot go on a walk independently in the community as he is unaware of the dangers around him. These opportunities would not be available to my children in a small community setting where they would be bumping into walls and furniture. Additionally, the ICF allows my children to experience independence that would not be possible in the community.

So, when you hear disability advocates talk about community integration, please remember that community is in the eye of the beholder. Just like you and me, individuals with intellectual and developmental disabilities find community in different ways depending on their unique needs and wants. The *Olmstead* Court recognized this fact, "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."[23]

That community integration is not based on setting size and labels (ICFs vs. HCBS) is evident from the following two cases:

- Minnesota's P&A filed a class action alleging the State segregates people in small HCBS waiver settings of up to five beds.[24]
- Families in Indiana filed suit alleging their new waiver assignment reduced the number of hours their family members could access community activities. The Seventh Circuit Judge found,

> "Isolation in a home can just as 'severely diminish the everyday life activities' of people with disabilities. *Olmstead*, 527 U.S. at 601. In fact, although family relations might be enhanced at home if people are around, isolation in a home may often be worse than confinement to an institution on every other measure of 'life activities' that *Olmstead* recognized."[25]

These cases, combined with those discussed earlier, show that community is a highly personal concept that is not satisfied by simply placing individuals in small HCBS settings. Driving states to close ICFs does not mean "community integration for everyone" as DOJ proclaims on its *Olmstead* website.[26] The best means to assure the maximum integration for the diverse population of persons with disabilities is

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[23] *Olmstead*, 605.

[24] Murphy v. Minnesota Department of Human Services, No. 0:16-cv-02623

[25] Steimel v. Wernert, No. 15-2377, Beckem v. Indiana Family and Social Services Administration, No. 15-2389, p. 12

[26] U.S. Department of Justice Civil Rights Division Website, https://www.ada.gov/olmstead/

to provide a full continuum of care – HCBS and ICF – and let individuals and their families choose the most appropriate setting based on individual need. These decisions should not be made a class basis in a class action.

Needed Reforms

The Committee can improve the lives of Americans with intellectual and developmental disabilities and protect their rights by spearheading the following reforms:

1. Prohibit P&As from bringing class actions that attack the interests of their own constituents. P&As should seek relief for their constituents on an individual basis.

2. Initiate oversight of the P&A program to ensure that they properly carry out their duties under the law – to protect and advocate the rights of all individuals with developmental disabilities, not push an ideological or personal agenda.

Thank you for your service and your consideration of my concerns.

Caroline A. Lahrmann
March 6, 2018

Exhibit A

ICF/IID Homes Provide Safe, Compassionate, Cost-Effective Care

Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID) are a safe, compassionate, and cost-effective way to care for individuals with severe and profound intellectual and developmental disabilities (I/DD). When individuals with complex needs choose to live under one roof in larger numbers, efficiencies are gained which enable more people to receive the care they need for less cost.

Skilled nursing, personal care services, physical and occupational therapists, behavioral support staff, transportation, and room & board can be shared by the residents in one location. Continuity of care is maintained and safety enhanced.

Likewise, the extensive amounts of specialized equipment – medical, personal care, and therapy equipment – can often be shared by residents and can be obtained at lower costs. If ICF residents with complex needs were transferred to waiver settings, the cost to the taxpayer would be much greater as demonstrated in the Exhibit.

Exhibit: Cost of Care - Ohio ICFs and Ohio Individual Option (IO) Waivers

The charts depict an "apples to apples" cost comparison between ICF Homes and IO Waivers by subtracting from the ICF total average cost the cost of services not covered by the IO Waiver such as skilled nursing and room and board. The charts demonstrate that services under the ICF Home model are provided at a average lower cost than the similar set of services under an IO Waiver.

ICF Home Average Cost Per Year Per Individual **All Inclusive Model**	
ICF avg total cost	**$106,005**
Less room & board	($18,733)
Less skilled nursing	($10,021)
Less bed tax & other non-covered waiver services	($9,124)
ICF total avg cost *excluding non-covered waiver services*	**$68,127**

IO Waiver Average Cost Per Year Per Individual **Separately Contracted Services**	
Personal care	$47,748
Community transportation	$614
Day services	$10,478
Day service transportation	$5,745
Case management	$6,086
Other waiver services	$386
IO Waiver total avg cost	**$71,057**

Data Source: Gary Brown, CPA, Director, Brady Ware & Co.
Data as of 2011

The cost of waivers does not include such public benefits as:

- Nursing, therapy, and other services received through the individual Medicaid card
- Social Security Disability Income
- Food Stamps
- HUD benefits

The cost of these benefits should be included in any study analyzing and comparing the cost of Long-term Services & Supports. Public policy must be based on factual information if we are to ensure sustainability of care.

ICF residents are on average the most severe and profound individuals with I/DD. These individuals placed on the waiver will substantially drive up the average cost of care of waiver services provided above, increasing the disparity between the cost of the ICF Home model and the IO Waiver model.

Exhibit B

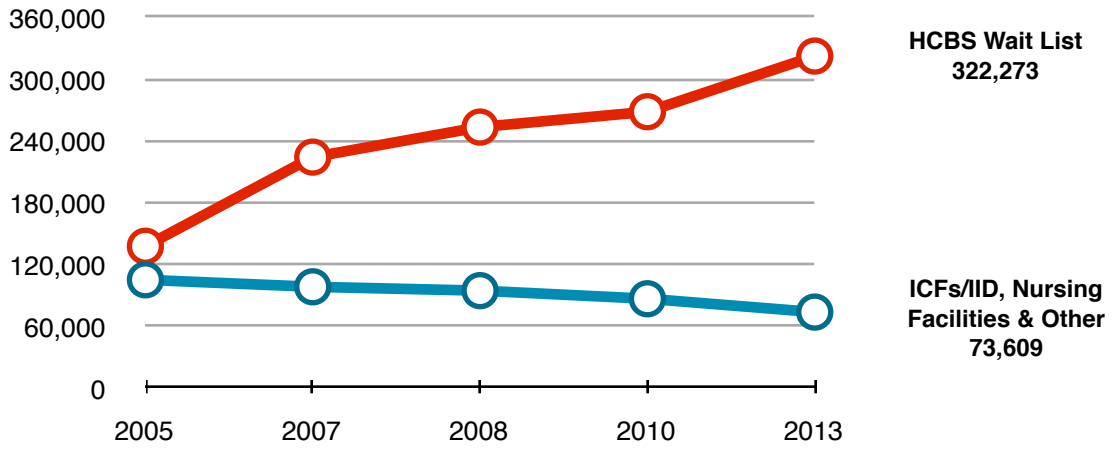
Speaking out for people with intellectual & developmental disabilities

Adverse Effect of Deinstitutionalization Policy on Home & Community Based Services Wait List

HHS' Administration on Community Living (ACL) and the Department of Justice (DOJ) have pursued a policy of "deinstitutionalization," driving individuals with severe and profound I/DD and complex medical and behavioral needs from large Medicaid-certified residential facilities, such as Intermediate Care Facilities for Individuals with Intellectual and Developmental Disabilities (ICFs/IID), into small group homes.

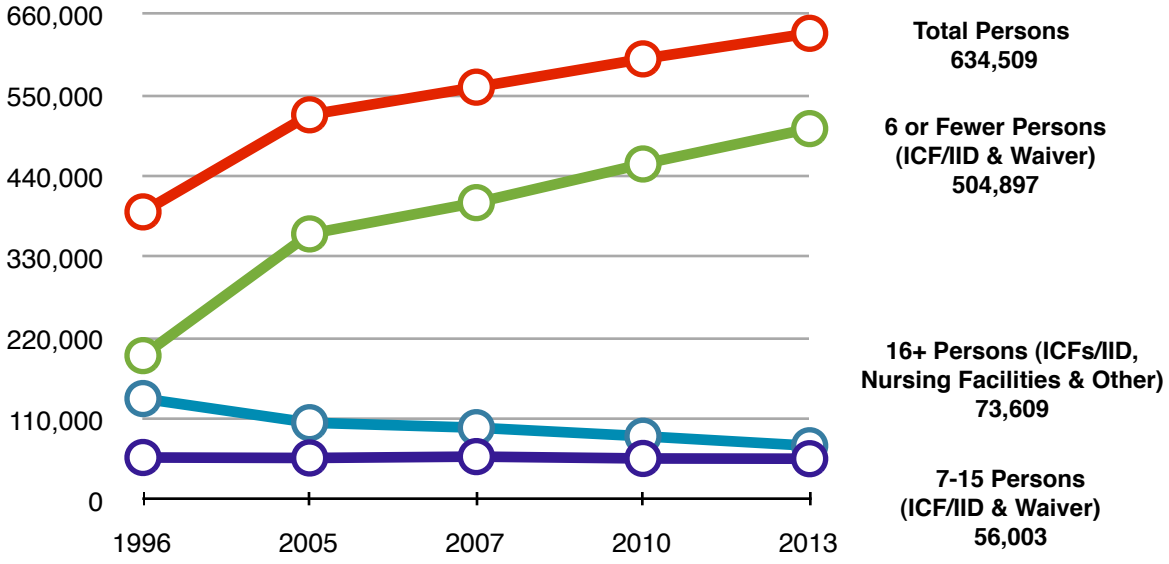
Instead of decreasing wait lists, this policy has contributed to nearly doubling their total size nationwide, stranding over 320,000 people because (1) too many resources are spent transferring happily-placed ICF/IID residents to community settings, rather than addressing the unmet needs of those on wait lists; (2) proper care for residents with complex needs who are transferred from ICF/IID homes is more costly in small community settings, crowding out those on wait lists from services.

Total Persons in ICFs/IID, Nursing Facilities & Other Homes of 16+ Beds vs. Total Persons on Home & Community Based Services (HCBS) State Wait Lists



Sources: United Cerebral Palsy Case for Inclusion and Coleman Institute and Dept. of Psychiatry, University of Colorado

# of Persons Served in Supervised Residential Setting by Setting Size



Source: Coleman Institute and Dept. of Psychiatry University of Colorado