

Examining Class Action Lawsuits Against Intermediate Care Facilities  
for Individuals with Intellectual Disabilities (ICF/IID)  
U.S. House Judiciary Committee  
Subcommittee on Constitution and Civil Justice  
March 6, 2018

Statement of Alison Barkoff  
On behalf of the Consortium for Citizens with Disabilities

Thank you, Committee Chairman Goodlatte and Ranking Minority Member Nadler and Subcommittee Chairman King and Ranking Minority Member Cohen, for the opportunity to participate in today's hearing. I am here today on behalf of the Consortium of Citizens with Disabilities (CCD). CCD is the largest coalition of national organizations working together to advocate for federal public policies that impact people with disabilities. CCD is comprised of more than 100 national organizations representing people with all types of disabilities, their families, and a wide range of service providers.

The focus of today's hearing is class action lawsuits involving individuals with intellectual and developmental disabilities (IDD) who reside in a particular type of institution that is funded by Medicaid called an Intermediate Care Facility for Individuals with Intellectual Disabilities, or an ICF. As a sister of an individual with an intellectual disability and a lawyer who has dedicated my career to helping people with disabilities and their families get the services and supports they need to live healthy, safe and meaningful lives, I am deeply committed to this issue. Our family was offered an immediate placement in ICF when my brother Evan was born, as is the law. And also consistent with the law, because we chose to keep him at home, we had to struggle to piece together informal services – through school, family and friends, and our religious community – until Evan rose to the top of a waitlist to receive community services at age 23. With community services, Evan has achieved what people told us was impossible – learning independent living skills, getting a job, and advocating for himself.

But my professional work has shown me that not everyone who wants to live in the community is as fortunate as Evan. People like the Wright brothers, whose family faced a decade of barriers trying to get them out of an institution and into a community placement. In a recent Congressional briefing their mother, Pam Wright, described what it was like as she would leave after visits: “[I]n the beginning, he would burst out crying, big tears rolling down his face as he rolled away in his wheelchair. After many months, maybe a year into this routine, [he] ceased the crying but would just look at us, his eyes following us for as long as he could.” As a result of a lawsuit that expanded community services, her two sons are now living together in an apartment near their family, with 24-7 supports to meet their complex medical needs. People like Brenda Boose, a single mother whose 15-year-old son with IDD and autism was number 1,025 on a waitlist for community services, with an estimated eight year wait for any help despite being considered having “urgent needs.” She had to quit her job to care for her son; sell her car to help pay for his services; and would call 911 in desperation as her only option to address a behavioral crisis. In a letter to the court seeking input on a settlement agreement to expand community services in Virginia, she begged the judge to approve it, saying: “We need help and the waiver provides that help. I don’t know how long we will have to wait, but I do know, Judge Gibney that I have days that I’m desperate for help and more of those days are coming in our future.” After getting input from hundreds of individuals with a range of views, the court approved a settlement to expand a wide range of community services to thousands more Virginians like Ms. Boose. People like Earl H., a young man with significant medical needs, who had no choice but to leave his family’s home and enter an institution when he aged-out of community services for medically complex children when he turned 21. As the result of lawsuit expanding community services in Illinois, he is now back living and receiving services in the community nearby his family.

In my experience, IDD stakeholders share many of the same goals, including those of us on today’s panel. We all want people with IDD to be safe; free from harm, abuse, neglect and exploitation; and free from stereotypes and discrimination. We all recognize that long term services and supports must be provided at a level adequate to meet each person’s needs and consistent with their preferences – whether those services are delivered in an ICF, a group home or one’s own or family’s home. We know that public resources, particularly Medicaid, are often

stretched too thin to do this well. And I think we all agree that people with IDD should have the opportunity to live a full life, while experiencing love and joy and maximizing their potential, regardless of where they live or receive services.

We also share concerns about the well-documented shortfalls in the IDD system. We have seen abuse and neglect in both institutions and community settings, and seen vulnerable individuals harmed by inattention and lack of access to care across a range of settings. We have seen isolated people – many of whom do not have the benefit of caring family members to advocate on their behalf – miss the opportunity to live the life they might choose because they have no voice. We also know, first hand and from decades of experience, that sometimes executive officials are not responsive to these systemic problems, legislatures do not appropriate sufficient funds to address these deficiencies, and litigation – often class action litigation – is the only alternative that individuals with IDD, their families and their advocates have to right these wrongs. Yet despite our shared interests and concerns, we do not always agree about how best to address these and other problems in the IDD system, including how best to respond to tragic events that sometimes occur, especially when these systems are not monitored adequately.

In light of this, I understand that the Committee is considering whether to change the rules that apply to every other type of class action lawsuit only for cases involving people with IDD in ICFs. I would urge this Committee not to move forward with this approach. ***Creating special rules that limit class actions involving people with IDD in ICFs is unnecessary, unfair, discriminatory and potentially dangerous.*** It won't do anything to address the real problems and could even make them worse.

If the primary concern behind this proposal is the trend of reduced reliance on institutional care, it is important to recognize that the vast majority of this change has not occurred as a result of litigation. Instead, it has been based on service demands by people with disabilities and their families and through state policy and legislative decisions about how to best meet the needs of people with IDD. The census in costly ICFs has dramatically decreased and the demand for more cost-effective community services has exponentially increased, resulting in state executive and legislative officials gradually reallocating state resources. Courts have repeatedly and

appropriately deferred to those state executive and legislative decisions about how best to use their limited resources. Changing the rules governing class actions would not change this trend.

To the extent that litigation to enforce the Constitution and federal law has motivated systems change, current federal rules governing class actions provide extensive opportunities for people with IDD and their families to have their voices heard, to shape the goals of these lawsuits, and to influence the remedies they seek. People with IDD are one of the most vulnerable populations, experiencing among the highest rates of abuse and neglect across all settings. Establishing additional hurdles or procedural barriers to bringing class action lawsuits on behalf of people with IDD would unfairly – and dangerously – limit their ability, as well as that of their families, to enforce and protect their rights. Proposed changes would impede their ability to remedy a wide range of constitutional, human and civil rights violations in both ICFs and in community settings. Lawsuits seeking improved conditions – addressing health, safety and medical issues – in ICFs, just like those seeking community alternatives to ICFs, would be subject to a range of procedural challenges and legal obstacles that would at least delay, if not entirely frustrate, efforts to improve services for individuals with IDD in ICFs. ***This proposal would increase the risk of harm to people with IDD, regardless of setting, by reducing protections ensuring their health and safety, access to needed medical and habilitative services, and the right to be free from abuse, neglect and other harms.*** That is why groups like the American Bar Association and CCD have vigorously and consistently opposed these types of proposals. See June 15, 2011 Letter from the American Bar Association Regarding Opposition to H.R. 2032 (attached as Exhibit 1) and November 8, 2012 Letter from Consortium for Citizens with Disabilities and 31 national disability organizations (attached as Exhibit 2).

### **Changes in States' IDD Service Systems Have Primarily Been Driven by the Desires of People with IDD and Their Families and State Decisions About How to Best Allocate Limited Resources**

Over the last several decades, there have been significant changes in the state systems that provide services to people with IDD. To frame today's conversation, those changes have been driven primarily by factors completely independent of lawsuits: the desires of people with IDD

and their families; an increase in research and knowledge about the ability of people with IDD to live quality lives in the community; an emerging professional consensus; significantly enhanced community services and supports for all individuals with IDD, particularly those with complex needs; and decisions by state executive officials and legislatures about how to best allocate limited resources to meet the needs and preferences of people with IDD. Class action lawsuits have always been a last resort, when people with IDD have been harmed by the very systems that are intended to serve them and have no effective alternative to prevent that harm.

Over the last fifty years, persons with IDD and their families have increasingly advocated for more and better community-based services as an alternative to care in institutions. For decades, the only choice for families was to institutionalize their son or daughter, often at a very young age, or to care for their child on their own at home with little to no assistance. The 1975 passage of the federal law giving students with disabilities a right to receive a public education, now called the Individuals with Disabilities Education Act (IDEA), made it possible for more children with IDD to grow up at home with their families, attend public school, and participate in their communities alongside their neighbors and peers without disabilities. Yet states continued to provide substantial funding for state institutions, making few investments in community-based care, despite the desire of families to stay together. In 1981, these families successfully convinced President Regan to allow Medicaid not only to fund institutions, but to also pay for services to allow their loved ones to remain in their homes and in the community. Since then, the federal government has offered states the option to provide Medicaid-funded community services as an alternative to individuals who meet an institutional level-of-care and otherwise could be placed in an ICF. By the mid-1990s, every state in the nation had chosen to offer community services as an alternative to ICFs. *See Declaration of Nancy Thaler at 6-7 (Attached as Exhibit 3).*

Families' and individuals' strong preference for community services is also apparent through the significant number and length of waitlists across the country. Under Medicaid law, states that include ICFs in their Medicaid programs must promptly place in an ICF anyone who qualifies and chooses such placement. But if there is insufficient funding for community alternatives, as there often is given the demand, states can create waitlists for people who need that same ICF

level-of-care but who prefer to receive services in the community. Today almost 200,000 individuals are estimated to be waiting for community services.<sup>i</sup> Under Medicaid law, all of these individuals on waitlists could immediately get ICF services if they demanded it. But they instead choose to wait for community services – often struggling for years with no services or very limited supports.

As the demand for community services has significantly increased, the demand for ICFs has drastically decreased. From 1992 to 2010, there was a 948% growth in the number of people receiving community services, while the number of residents in any type of ICF decreased by almost 40% during the same time period.<sup>ii</sup> The use of state-operated ICFs to provide residential supports to people with IDD reached its peak in the 1960s, when at one point nearly 200,000 children and adults with IDD lived in institutions. Since that time, the vast majority of people with IDD have chosen to move out of ICFs and into the community. By 2015, just over 21,000 people were living in state-operated ICFs. *See* Thaler Dec. at 7-8. As the census and demand for institutional care has decreased, the cost of ICF care has sky-rocketed – often exceeding \$200,000 per person per year. At the same time, the need and preference for community services has increased, while the cost of such care is fraction (about one-third nationally) of placement in an ICF.

Not surprisingly, governors and state legislatures have chosen to reduce, consolidate or eliminate their state-operated ICFs and expand home and community based services, in order to allocate limited state funds to assist as many people with disabilities as possible. Courts have appropriately deferred to these state executive and legislative judgments. For example, Massachusetts Governor Mitt Romney and the Massachusetts legislature developed a phase down plan for a number of state-operated ICFs. The First Circuit Court of Appeals refused to intervene and overturn these executive and legislative decisions at the request of families who wished to remain at their current ICF rather than transfer to another ICF. *Ricci v. Patrick*, 544 F.3d 8 (1<sup>st</sup> Cir. 2008).<sup>iii</sup> A similar decision was recently issued in Virginia, where a court made clear that the decision to close state-operated ICFs lies solely in the hands of the state legislature. *See United States v. Virginia* Order Approving Consent Decree at 8-9.<sup>iv</sup> (“Decisions [about facility closures] lie in the hands of the Virginia General Assembly . . . The Court recognizes that

the Virginia Department of Behavioral Health and Developmental Services is trying to move away from a care model with Training Centers, but the ultimate decision whether to close any Training Center lies not with the Department, but with the legislature.”).

As a result of the preferences of individuals with IDD and their families, the professional consensus in favor of community living, and the significant cost differentials between ICF and community care, thirteen states and the District of Columbia have closed all, and many more have closed most, of their state-operated ICFs (most states continue to offer the ICF benefit through smaller private facilities). *See* Thaler Dec. at 8-9. No change in class action procedures or erecting barriers to class action litigation will alter this trend.

Due to the comprehensive development of community-based systems over the past several decades, even individuals with very significant support needs can live safe, healthy and rich lives in the community with appropriate services and supports. National data shows that many individuals in the community have the same complex medical conditions, the same severity of disability, and the same behavioral issues as do individuals in institutions. Each of the more than 700,000 individuals who received Medicaid-funded community services in 2015 had disabilities severe enough to be eligible for an ICF level of care.<sup>v</sup> However, these individuals and their families instead chose to have them remain with their families in their communities with access to needed services and supports. Community providers have expanded services for people with more complex medical and behavioral needs, have created specialty medical homes for those with more complex physical and nursing needs, and developed best practices for serving all persons with IDD. These state systems and local providers are successfully serving individuals with the most severe or complex needs in community settings, including those who are non-verbal and need complete assistance with functions such as eating and bathing; individuals with complex medical conditions such as those requiring feeding tubes, ventilators and tracheostomy care; and those with challenging behaviors such as self-injurious behavior or compulsive overeating. *See* Thaler Dec. at 7-8.

The outcomes for individuals with IDD receiving community-based services are overwhelmingly positive. Two of the leading research organizations on people with IDD – the Association of

University Centers on Disabilities (AUCD) and the American Association on Intellectual and Developmental Disabilities (AAIDD) – recently published a white paper, “Community Living and Participation for People with Intellectual and Developmental Disabilities: What the Research Tells Us.”<sup>vi</sup> The National Council on Disability also recently published a report, “Home and Community-Based Services: Creating Systems for Success at Home, at Work and in the Community,” examining outcomes from community services.<sup>vii</sup> Both reports found decades of research demonstrating that people with IDD have happier, healthier, and more independent lives when they live in smaller, community-based residences. Given the opportunity to live and receive services in family homes, supported apartments, or other integrated settings, individuals with disabilities and their families/caregivers reported increased satisfaction in their day-to-day life. They had more individual choice and autonomy, greater opportunities for community participation, and broadened social networks. These community experiences also resulted in individual improvements in adaptive behavior and independent living skills. *Accord Illinois League of Advocates for the Developmentally Disabled v. Illinois*, 803 F.3d 872, 874 (7<sup>th</sup> Cir. 2015) (describing evidence and academic studies supporting positive outcomes in the community). With a well-planned and implemented transition, the likelihood of experiencing positive outcomes increases. What these positive outcomes mean in the day-to-day lives of people who have transitioned to the community is reflected in the stories attached to my testimony – the basic but important things in life like choosing what to eat, when to go to sleep, having visitors, or choosing to go to the library or a park when you want. *See Stories of Changed Lives: What’s Possible* (Attached as Exhibit 4).

### **Lawsuits Involving People with IDD In Or At Risk of Entering ICFs Have Addressed a Broad Range of Constitutional and Civil Rights Violations and are Necessary to Address Systemic Problems**

As noted above, many of the enhancements in IDD services systems have occurred based on the demand by people with IDD and their families and state planning and resource decisions. Yet class action lawsuits also have played a pivotal role in addressing a wide range of constitutional, human and civil rights violations experienced by people with IDD when other types of advocacy cannot address these wrongs. In many of these cases, litigation has been brought to address

neglect or sub-standard conditions in ICFs, as well requiring public agencies to provide alternatives in the community.

The vast majority of early class action litigation on behalf of people with IDD focused on remedying shameful, inhumane and unconstitutional institutional conditions in infamous institutions like Willowbrook in New York, Pennhurst in Pennsylvania, and Belchertown in Massachusetts. The abuse and neglect exposed by these cases led to a public outcry and a push for community alternatives for people with IDD. These early cases used the Due Process Clause Fourteenth Amendment and the Eight Amendment’s prohibition against cruel and unusual punishment to combat squalid, abuse conditions impacting thousands of individuals. Class action status allowed this group of individuals and their families to enforce the right to safe conditions of confinement, freedom from bodily restraints, and access to habilitation recognized by the Supreme Court in *Youngberg v Romeo*, 457 U.S. 307 (1982), on behalf of everyone impacted. Congress also responded to the particular vulnerability of people in state-operated facilities by passing the Civil Rights of Institutionalized People Act (CRIPA), which authorized the Department of Justice to challenge unconstitutional conditions in state-operated institutions.

Unfortunately, abuse and neglect in institutions is not just a sad chapter from the past. Recent incidents include abuse in a large public ICF in Texas, where residents were forced into a “fight club,”<sup>viii</sup> to hundreds of incidents of sexual assaults, physical abuse and neglect at an ICF in Colorado.<sup>ix</sup> DOJ continues to use its authority under CRIPA to address inadequate care, abuse, and other harms in institutions, including, for example, unconstitutional conditions and inadequate care in all of the thirteen state-operated ICFs in Texas.<sup>x</sup>

Similarly, private class action lawsuits continue to address these types of issues, particularly those brought by the Protection and Advocacy (P&A) Systems. P&As in each state address institutional practices that amount to abuse and neglect, as defined by Congress in the Developmental Disabilities Assistance and Bill of Rights Act, 42 U.S.C. § 15002 (mandating quality assurance activities, including legal advocacy, to ensure that people with IDD, among other things, do “not experience abuse, neglect, sexual or financial exploitation, or violation of legal or human rights” and “will not be subject to the inappropriate use of restraints or

seclusion”). P&As across the country have numerous investigations, individual cases, and class actions relating to abuse, neglect, exploitation, inadequate care, and illegal restraints in a range of institutional settings, including public and private ICFs, nursing homes, psychiatric hospitals, jails and prisons.

As these institutional conditions cases progressed, it also became evident that hundreds, if not thousands, of individuals across the country did not want, and were not best served by, ICFs. Congress responded by enacting the Americans with Disabilities Act (ADA) in 1990 to prohibit discrimination against people with disabilities. Based upon testimony at numerous public hearings, Congress explicitly found that people with disabilities experience unnecessary segregation, isolation, exclusion and institutionalization and that “such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem.” 42 U.S.C. § 12101.

In 1999, the Supreme Court in *Olmstead v. L.C.* affirmed that unjustified segregation constitutes prohibited discrimination under the ADA. 527 U.S. 581. The Supreme Court recognized that segregation of people with disabilities perpetuates unjustified assumptions that institutionalized persons “are incapable or unworthy of participating in community life” and that institutional confinement “severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.” *Id.* at 600-01. Thus, the Supreme Court held that states must develop and provide community services to allow all individuals who are “qualified” and “do not oppose” the opportunity for community living. *Id.* *Olmstead* cases have carefully implemented these requirements, ensuring that all people in institutions are evaluated for community services and that they and their representatives are given enough information to make an informed decision about the options. These cases do not seek to close facilities or eliminate all institutional services as an option, but instead leave these policy decisions to residents, guardians, and state officials, as detailed above.

The ADA and *Olmstead* have given people with disabilities an important legal tool, particularly in class actions, to make systemic changes to ensure that people with disabilities have a real and

meaningful option to receive services in integrated settings in the community. Cases brought under the ADA challenge a lack of available community services and structural barriers for people who are in institutional settings, but would prefer to live in the community. These cases typically involve people who are in, or at serious risk of, entering segregated settings due to a lack of adequate community services. The remedy sought in these lawsuits is an expansion of critical community services – medical, behavioral, crisis, nursing, and residential and day services and supports – and the removal of systemic barriers, such as lack of adequate transition planning or funding incentives, that prevent people from accessing community services.

Systemic problems – be it around abuse and neglect, inadequate care in an institution, or insufficient community services – cannot be adequately or effectively addressed through individual cases. Class actions are best suited to promote these reforms for a broad group of vulnerable individuals impacted by these same deficiencies. The implementation of class action remedies include a range of oversight and protections for the people impacted. These cases typically are overseen by a court; include a court monitor or independent reviewer with expertise in designing and implementing IDD services; involve the active engagement of stakeholders and affected entities like providers, professionals, counties, and facility staff; and are frequently adjusted to account for changes in local situations, funding, and improved practices.

Significantly, this long history of successful class actions that have both improved conditions in public institutions and ICFs, and expanded community alternatives to these facilities, have achieved their goals and balanced their remedies under current class actions procedures.

### **Current Class Action and Intervention Rules Already Provide People with IDD in ICFs and Their Representatives Protections and a Voice in Litigation**

There is no need or justification to limit or alter the current rules for litigation of class actions involving people with IDD, particularly given the critical role class actions play in protecting this vulnerable population as described above. The existing rules already provide for numerous protections and opportunities for people with differing views to be heard and to impact the litigation. The rules governing class actions are already structured to protect and balance the rights of all parties and any others who may have a stake in the outcome of the litigation process.

Those protections are complemented by federal rules on intervention, which already give individuals or groups with significant interests in the litigation the opportunity to join the case. In addition, even those who do not seek party status can participate in, and seek to influence the course of, cases through the submission of ‘friend of the court’ briefs. Creating an exception to long-standing class action rules, and placing limits on a small subset of class actions involving a small subset of people with disabilities – those with IDD in ICFs – is unnecessary and unfair. Even worse, the proposal would also limit the rights and protections for people with IDD in a range of cases seeking to address harms in ICFs, from those involving systemic abuse, inadequate treatment, or unnecessary institutionalization.

Existing class action rules already require notice and an opportunity for input and objections, particularly before any remedies can move forward. Rule 23(e) requires any proposed settlement of class action litigation to undergo a rigorous review by the court, beginning with initial approval and concluding with a public fairness hearing. As part of this review process, the court approves a formal notice to all class members, other interested parties, and the general public. This notice provides information on the intended settlement agreement and how to get more information about its terms and impact. It also informs interested parties of the date of the fairness hearing and the process for offering written or oral comments. Before approving any settlement agreement, the court must consider these comments and issue a written decision describing why the proposed settlement is a fair and reasonable resolution of the case. It is not uncommon for individuals, parents and guardians with a wide range of views to make their voices heard during the fairness hearing process. Cases in Virginia, Illinois, Florida, Massachusetts, and New Mexico illustrate how this phase of class action litigation allows for objections to be considered, and how those objectors can impact the ultimate outcome of the litigation.

The federal rules currently distinguish between the Rule 23(b)(2) classes typically used in cases involving people with IDD, which seek systemic changes to defendants’ policies and practices (called declaratory and injunctive relief), and Rule 23(b)(3) classes, which are used in cases involving individual money damages. Damages class actions allow class members to “opt out” in order to pursue their own damages case; injunctive class actions do not because there is no

practical way to “opt out” of a broad change in a policy or practice a defendant puts in place to comply with the law. For example, a class action that seeks to increase staff or reduce restraints at an ICF consistent with the law could not practically exempt an individual from those remedies. Additionally, creating a special right to opt out in ICF cases is unnecessary because many cases already define the class to exclude people who oppose or are not qualified for community placement.

Existing rules also already allow for intervention of representatives of people in ICFs when appropriate. Specifically, Federal Rule of Civil Procedure 24 provides that a court must permit intervention in cases where others who did not initiate the lawsuit have a significant legal interest that would be affected by the case. Courts may also grant intervention under a more flexible standard in a broader class of cases under Rule 24. These existing intervention rules already provide an important avenue for families, providers, and others to request party status when they have a significant interest in the case and its outcome. As a party, intervenors can engage fully in all aspects of case, including any trial on the merits. Families and guardians of people in ICFs have successfully used existing intervention rules to join class action cases in Virginia, Pennsylvania, Illinois, and Ohio, including cases where the individual ICF residents may or may not have been members of the putative class. Through intervention, individuals in ICFs have impacted the terms of settlement agreements and the benefits they have received in cases, even when initiated by others with whom they may disagree. In Illinois, for example, the final settlement agreement not only included an expansion of community services but also included a commitment by the state to maintain ICFs in their Medicaid plan and to provide sufficient resources to people remaining in ICFs to meet their needs. Similarly, in Virginia, the district court required the parties to add to the settlement agreement focused on expanding community services provisions explicitly describing the intervenors’ right to placement in a state-operated ICF and requiring reporting to the court, independent reviewer, parties and intervenors any time an individual in the class experienced any critical incident of harm.

Given the myriad of substantive and procedural protections already built into existing rules on class certification and intervention and opportunities for participation, there is no need or justification for creating special rules for persons with IDD only in certain facilities. Placing

additional limits and procedural restrictions on the ability of this vulnerable population to assert their federal and constitutional rights, and to protect themselves from systemic harm, would only exacerbate the risks they face.

### **People with IDD, Families and Advocates Share Concerns About the Funding and Quality of Services, Regardless of Setting, That Would Be Undermined By Limiting Class Action Lawsuits**

Individuals with IDD, their families, professionals, and advocates of all persuasions share many of the same concerns about IDD service systems, none of which would be advanced — and some that would be hindered — by restricting the availability of class action lawsuits involving people in, or at risk of entering, ICFs. These cases are often the only vehicle for ensuring that minimal federal standards are met, that the rights and dignity of people with IDD are respected, and that the very lives and safety of vulnerable persons are protected.

Regardless of preferences for institutional or community services, individuals with IDD, their families, service providers, agencies and advocates all agree on the importance of the necessary investments to ensure quality services. Limited resources are a significant problem at the heart of the concerns being discussed today, often resulting in unfortunate divisions and adversarial positions as people with IDD and families press states to address growing needs and equitable allocations of available funding. But the common problem of inadequate services, regardless of setting, can provide a basis for diverse stakeholders to join together – rather than work against each other – in developing litigation solutions. For example, in a class action focused on expanding community services in Illinois, class members supporting community services and intervenors supporting ICFs worked together to ensure on-going funding for both types of programs when the state’s budget was frozen due to a budget impasse and other human service programs were being dismantled. To revise the class action rules would serve only to pit one group against another and would be counter-productive to achieving the common goal of better services for more people.

Diverse IDD stakeholders also agree that there is a need to improve the capacity of state systems to provide services to people with the most significant disabilities and support needs. At the state level, strategies are being developed to expand the expertise of medical professionals and the capacity of providers who serve with people with IDD and particularly those with the most complex needs. People who receive services in the community, as well as families whose loved ones receive care in ICFs, have contributed to new and better approaches to meeting these challenges. Their contributions have informed the remedies included in many class action lawsuits, where there has been a particular focus on expanding services for people with the most significant medical and behavioral support needs.

Finally, people with IDD, families, and advocates share a concern about the potential for abuse, neglect or harm in any setting. People with IDD are uniquely vulnerable, and safeguards to protect them from harm are critical, regardless of whether they are in an ICF, group home, or their family home. This is another important area where stakeholders have worked together to develop robust oversight mechanisms as part of litigation. Resolution of class action lawsuits regularly include requirements for the development of oversight systems for services provided by states in ICFs and by private providers in the community; the reporting any incidents of abuse, neglect or inadequate care; and a system for addressing quality issues at particular facilities or with certain providers, as well as systemic problems causing quality gaps. Limiting the ability to bring class action lawsuits would undermine this important tool for combatting abuse, neglect or harm of people with IDD in a range of settings.

## **Conclusion**

You have heard today about the challenges that people with IDD and their families face in getting the services necessary to for them to live a healthy, safe, and meaningful life. Class action lawsuits have been a critical tool to address abuse, neglect, inadequate services, and a lack of community options when other types of advocacy have failed. It is unnecessary, and could be harmful, to limit the ability of people with IDD to enforcing their rights using class actions. Existing federal rules governing class actions and intervention already carefully balance diverse interests and ensure that all persons impacted by the case have a voice in the litigation and

remedy. I urge this subcommittee to abandon these efforts and instead work together with your colleagues to take steps to address the real problems, including under-funding of IDD services, at the heart of today's hearing.

---

<sup>i</sup> In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends 2015, University of Minnesota National Information Systems Project (2017) (“2017 RISP”), at 69, available at [https://risp.umn.edu/sites/risp.umn.edu/files/2018-02/2015\\_RISP-WEB.pdf](https://risp.umn.edu/sites/risp.umn.edu/files/2018-02/2015_RISP-WEB.pdf).

<sup>ii</sup> In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends Through 2013, University of Minnesota National Information Systems Project (2016), at 3, available at <https://risp.umn.edu/media/download/cms/media/risp/RISP2013.FIN.Web.pdf>.

<sup>iii</sup> Significantly, the *Ricci* case involved both a class of families demanding institutional improvements, like more staff and better buildings, as well as a class of families advocating for community alternatives. Both classes co-existed under the current class certification rules, despite their differences in proposed remedies to acknowledged institutional deficiencies at five ICFs.

<sup>iv</sup> Available at

[https://www.justice.gov/sites/default/files/crt/legacy/2012/09/05/va\\_orderapprovingdecree\\_8-23-12.pdf](https://www.justice.gov/sites/default/files/crt/legacy/2012/09/05/va_orderapprovingdecree_8-23-12.pdf)

<sup>v</sup> 2017 RISP, *supra* at n.1 at 72 Table 2.2.

<sup>vi</sup> Available at <https://aaidd.org/docs/default-source/policy/community-living-and-participation-for-people-with-intellectual-and-developmental-disabilities-nbsp-what-the-research-tells-us.pdf?sfvrsn=0>

<sup>vii</sup> Available at [https://ncd.gov/rawmedia\\_repository/HCBS%20Report\\_FINAL.pdf](https://ncd.gov/rawmedia_repository/HCBS%20Report_FINAL.pdf)

<sup>viii</sup> See <http://www.cnn.com/2009/CRIME/03/10/texas.school.fight.club/index.html>

<sup>ix</sup> See <https://www.denverpost.com/2016/12/09/pueblo-regional-center-disabled-neglect-abuse-complaints/>

<sup>x</sup> Available at

[https://www.justice.gov/sites/default/files/crt/legacy/2010/12/15/TexasStateSchools\\_findlet\\_12-1-08.pdf](https://www.justice.gov/sites/default/files/crt/legacy/2010/12/15/TexasStateSchools_findlet_12-1-08.pdf)