STATE OF NORTH CAROLINA	IN THE GENERAL COURT OF JUSTICE
	SUPERIOR COURT DIVISION
WAKE COUNTY	17 CVS 6357

SAMANTHA R., by her Guardian, TIM R., MARIE K., by her guardian, EMPOWERING LIVES GUARDIANSHIP SERVICES, LLC CONNIE M., by her guardian CHARLOTTE R., JONATHAN D., by his guardian MICHAEL D., MITCHELL T., by his guardian, BETSY S., and DISABILITY RIGHTS NORTH CAROLINA,	)	
Plaintiffs,	)	**RESPONSE TO DEFENDANTS' MOTION TO STAY ENFORCEMENT OF ORDER ENTERED NOV. 2, 2022**
v.	)	
STATE OF NORTH CAROLINA, NORTH CAROLINA DEPARTMENT OF HEALTH AND HUMAN SERVICES, and KODY KINSLEY, in his official capacity as Secretary of the North Carolina Department of Health and Human Services,	)	
Defendants.	)	

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INTRODUCTION

A stay of the Court's injunctive Order is not warranted and would be deeply counterproductive. In the nearly three years since the Court's Order declaring Defendants to be in violation of the Persons with Disabilities Protection Act, Defendants have failed to show a serious intent to implement a comprehensive and effective remedy. Each stage of this case has produced only new and increasingly strident insistence on the state's prerogatives. In the meantime, thousands of people with intellectual and developmental disabilities (I/DD) are made to wait.

As the Court previously determined, Defendants have failed to produce the remedy that they promised after the Court's February 2020 ruling finding them in violation of the rights of North Carolinians with I/DD. The February 2020 ruling itself was based on Defendants' decades of failed promises to address the growing harms to people with I/DD. Defendants, in their Motion and supporting brief, continue to argue that progress toward serving people with I/DD is too hard to achieve on a ten-year timetable, while insisting that they are working on the *Olmstead* plan that the Court already determined is inadequate. (Defendants' Memorandum in Support of Motion to Stay Enforcement (Defs.' Br.) pp. 9-10.) A stay is not warranted and would in fact merely reinforce the state's continuing resistance to accountability; Defendants'

arguments about their inability to implement the relief required by the Court's November 2, 2022 Order is merely a repeat of the same refrain offered at every stage of this litigation.

STATEMENT OF THE CASE

Plaintiffs filed this action on May 24, 2017. On February 4, 2020, the Court granted Plaintiffs' Motion for Partial Summary Judgment on their First Claim for Relief, finding that Defendants are in violation of the rights of thousands of North Carolinians with I/DD who are subject to unnecessary institutionalization and risk of institutionalization. On the same day, the Court denied Defendants' Motion for Summary Judgment. Defendants requested and received approximately two years to develop an *Olmstead* plan to bring them into compliance with the Integration Mandate of Chapter 168A of the North Carolina General Statutes. After briefing and consideration of Defendants' published *Olmstead* Plan, the Court determined that Defendants have failed to produce a plan that would address Defendants' ongoing violation of the rights of people with I/DD. On November 2, 2022, after providing the parties opportunities for input, the Court entered an Order providing for injunctive relief.

On November 30, 2022, Defendants filed a Notice of Appeal and the instant Motion to Stay Enforcement. Defendants seek to stay Benchmarks 1 and 2 of the Order, namely the requirement to provide community-based alternatives to those who wish to leave institutional settings, and the requirement to eliminate the waiting list for Innovations Waiver services over ten years.

ARGUMENT

I. The Denial of a Stay is Within the Court's Discretion and Is Warranted Because of Defendants' Longstanding Failure to Fix the Problem or Accept Accountability, and the Ongoing Serious Harms to People with I/DD.

The Rules of Civil Procedure give the Court wide discretion regarding a motion to stay the effects of an injunction:

> When an appeal is taken from an interlocutory or final judgment granting, dissolving, or denying an injunction, the court in its discretion may suspend, modify, restore, or grant an injunction during the pendency of the appeal upon such terms as to bond or otherwise as it considers proper for the security of the rights of the adverse party.

N.C. Gen. Stat. § 1A-1, Rule 62(c). The denial of a motion to stay is reviewed under an abuse of discretion standard and will not be disturbed unless it is "manifestly unsupported by reason or is so arbitrary that it could not have been the result of a reasoned decision." *N. Iredell Neighbors for Rural Life v. Iredell Cty.*, 196 N.C. App. 68, 78, 674 S.E.2d 436, 443 (2009) (quoting *Long v. Harris*, 137 N.C. App. 461, 464-65, 528 S.E.2d 633, 635 (2000) (citation omitted)).

The lives and rights of people with I/DD will continue to be limited and impaired by a stay. Defendants remain in violation of the rights of thousands of North Carolinians with disabilities. The record in this case is replete with Defendants' admissions regarding their continued overreliance on institutions and failure to serve people with I/DD. *See Order,* p. 2 (finding that North Carolina is over-reliant on institutions for people with I/DD and that Defendants do not have in place adequate community-based services for all individuals with I/DD who prefer a community-based setting to institutionalization).

The ongoing harm to North Carolinians with I/DD is beyond dispute. *See infra*, Sections III.B and C. Moreover, institutionalization "perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life." *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 600 (1999). Rather than inherent inability, the difference between those who are institutionalized or at risk and those who are not is the availability of community-based services. (*See* **Attachment 1**: Excerpt from Deposition of Deborah Goda (Goda Dep.) pp. 61:16-62:1; 62:25-63:4) (noting that individuals in institutions generally have the same level of support needs as those in the community). For those without adequate services, the risk of

institutionalization is ever-present: "Because our state lacks robust community-based behavioral healthcare services, more people go into crisis for otherwise manageable conditions." (Dep. Ex. 29: *DHHS Strategic Plan*, p. 5.)

Plaintiffs respectfully submit that the Court's discretion should be exercised in support of holding Defendants accountable. Defendants' Motion to Stay should be denied.

II. Since the State's Appeal Will Not Change the Need for a Remedy, a Stay is Merely Delay for its Own Sake.

Defendants' have failed to provide people with I/DD with adequate community-based services. *Order*, p. 2. During the course of this litigation, the problem has only worsened, with the waiting list ballooning from 10,000 to over 16,000. The record in this case supports beyond any doubt the Court's determination in February 2020 that Defendants are in violation of the rights of North Carolinians with I/DD – a determination that Defendants did not appeal at the time it was issued.

Defendants also admit that they need to do all that is required by the November 2022 Order: help people transition to the community if they so choose, address the waiting list for services, and fix the DSP shortage. (Defs.' Br. pp. 9-10.)

A stay allows the Defendants to continue to acknowledge the problem without solving it. Defendants admit they have known that the State has over relied on institutional care for decades yet failed to provide adequate home and community-based services. In all that time Defendants failed to move from describing the problem to implementing a remedy, including throughout the *Olmstead* planning process, which did not produce a remedy for people with I/DD. A stay simply buys even more time without a remedy being in place.

III. Defendants' Arguments for a Stay Are Identical to Arguments they Have Made for Years and Reflect a Continued Insistence that Plaintiffs and the Court

Should Just Leave the State Alone to Carry Out its (Chronically Non-Specific) Plans.

The arguments offered in support of the stay the Defendants seek are merely a continuation of the same posture the state has taken for many years: that Plaintiffs (and the Court) are moving too fast, and Defendants alone are entitled to judge what is the right pace. Given that the pace so far has moved in reverse, with increased waiting lists and less reliable services, what Defendants are really arguing is that they get to decide *if*, not just when, to correct the deficiencies that are causing the ongoing deprivation of the rights of people with I/DD. They now insist that most of the remedy must wait until some undetermined point in the future when the community service system and housing crisis are fixed in some unspecified way. Defendants are proficient at identifying barriers and offering explanations as to the ways that the system is broken but have steadfastly refused to reckon with the reality that carrying on business as usual is not sufficient – particularly considering the existence of judicial orders requiring change. The Court allowed Defendants years to come up with their own effective plan. They did not. The Court should reject Defendants' demand for endless patience.

A. <u>In Arguing Benchmarks 1 and 2 Cannot Be Achieved, Defendants Reject the Benchmarks They Proposed, and Do Not Offer Any New Alternative Benchmarks or Accountability Measures.</u>

The Court can modify an injunction pending appeal. N.C. Gen. Stat. § 1A-1, Rule 62(c). But Defendants did not ask the Court to reduce Benchmarks 1 and 2 to "achievable" levels. Instead, Defendants complain, page after page, about how bad they have let things get. They note that there are still not enough Direct Support Professionals, or community services more generally. (Defs.' Br. pp. 9-10.) Providers are not prepared. More plans are being developed. More time (of unspecified length) is needed. (*Id*. at pp. 9-11, 16-18.)

However, the benchmarks in the Order are not a surprise to Defendants. In response to Plaintiffs' proposed injunctive order which initially proposed that 500 people with I/DD should be diverted or transitioned in the first year, Defendants proposed to transition or divert 100 people in the first year; Defendants' figure was agreed to by Plaintiffs and included in the Order as the first year of Benchmark 1. Similarly, Plaintiffs proposed a 10% reduction in the Registry of Unmet need in the first year of the injunction. Defendants, in response, adopted the same number, but proposed language to permit them to count essentially anyone with I/DD receiving community-based services. Plaintiffs submitted, and the Court ordered, a compromise version that allows Defendants to count people who remain on the waiting list but otherwise have their needs met to the same degree they would on the Innovations Waiver. *Order*, p. 8.

Having considered and agreed with the figures in the Order, Defendants cannot now credibly claim that the benchmarks are not achievable.

Defendants state no reason for stay of reporting requirements other than their connection to Benchmarks 1 and 2. The data required by the order is data the Defendants should be collecting already. Defendants' request to be free from reporting requirements suggests that they simply wish to be free from oversight, and not that the requirements themselves are onerous.

A wholesale stay of Benchmarks 1 and 2 is not warranted.

B. Defendants' Failure to Comply with Benchmark 1 Will Keep People Institutionalized (Or at Risk for Institutionalization) Against Their Will for the Duration of the Appeal.

Benchmark 1 requires the state to help people leave or avoid institutional settings *if they want to*. *Order*, p. 7. We know – and Defendants admit - that some people want to leave. *Order*, p. 2; (Am. Comp. ¶ 44; Ans. ¶ 44.) Some people with I/DD are in Adult Care Homes (ACHs) that provide no support. Some are in ICFs of poorer quality. (**Attachment 2**: Excerpt from Deposition of Natasha Ashmont (Ashmont Dep.) p. 87, ll. 2-17.) It is also established that there

are individuals with I/DD living in the community who are at risk of placement in an institution. Leaving an institution or avoiding institutionalization (diversion) requires the provision of services in the community. (*Id*. at p. 16:8-14; **Attachment 3**: Excerpt from Deposition of David Richard (Richard Dep.) p. 186:9-29 (agreeing the barrier in addressing the desire for discharge is availability of community-based services)).

Benchmark 1 requires the State to assist 100 people with I/DD who want to live in the community transition from – or avoid being confined to – institutional settings before January 1, 2024. *Order*, p. 5. If Defendants are granted a stay, there will be 100 people who are placed in institutional settings or who will be forced to continue to wait to get out for the first year of the appeals process.

The six LME/MCOs supervised by Defendant DHHS would each have to transition – or divert from institutionalization - about 1.4 people per month for Defendants to comply with the first year of Benchmark 1. Only 25 percent of those 100 (or about 4 per MCO per year) must be transitioned out of current institutional settings; the remainder can be those who receive services to avoid becoming institutionalized. These are very modest figures, particularly relative to thousands institutionalized and the thousands at risk.

Each LME/MCO has an *Olmstead* coordinator whose job is to help people transition from – or avoid – institutionalization. It is also the job of the LME/MCOs to ensure that there are adequate providers. This is a core function of managed care. *See* 42 C.F.R. § 438.206(b)(1) (requiring MCO contracts to ensure adequate providers to supply services for all services and beneficiaries in the MCO's catchment area). A stay will do nothing to ensure the LME/MCOs carry out their functions, or that the State finally holds them accountable for doing so. A stay

would merely allow the *status quo* to continue, robbing people with I/DD of the opportunity to live as they choose.

Without a hint of irony, Defendants quote Plaintiffs' expert, Dr. Michael Kendrick's deposition testimony from four years ago about the need to *have a plan* and not move too quickly on systems changes. (Defs.' Br. p. 8.) Defendants have made this argument before. And each time it is accompanied by no evidence of progress or plans for a pace that Defendants believe would be appropriate. Here, it is coupled with the complaint that complying with the Order will interfere with the State's implementation of its *Olmstead* Plan – the same plan that the Court previously determined was insufficient to remedy the violations in this case. Notably, Defendants point to nothing in the *Olmstead* Plan that would be disrupted in any way.

C. Defendants' Request to Stay Benchmark 2 (the Innovations Waiver Waitlist Provision) Seeks an Indefinite Delay that Harms People Who Have Already Waited a Decade or More.

Defendants agree that the Registry of Unmet Needs is too long, is growing, and must be addressed. (Defs.' Br. pp. 16-18.) But not yet, although they don't say how long would be enough.

Defendants contend that they must be allowed first to build up the community service system and fix the housing crisis before additional services are added. (*Id*.) They, again, offer no timeline for this nebulous idea. It should be noted that at no point have Defendants proffered any evidence of how the housing crisis affects people waiting for services, many of whom live with family members who need the help that Waiver services provide to enable the individual *to stay in their home*. (*See,* **Attachment 4**: Excerpt from Deposition of John Agosta (Agosta Dep.) p. 178:23-24 (noting that half of community-based service recipients nationally reside with family)).

The Court's Order requires that Defendants reduce the waiting list by approximately 1,650 people by July 1, 2023, and by about the same number in future years. The number on the waiting list may increase, but the Order also permits Defendants to obtain "credit" for serving people on the waiting list through I/DD services other than the Innovations Waiver. *Order*, p. 8. Defendants have touted the benefits of the new 1915(i) option,[1] but are unwilling to project that it will meet the needs of an adequate number of those on the waiting list to satisfy the Order. There is still time for Defendants to add more Waiver slots if they believe the 1915(i) services will not fully support enough people in 2023 to reach the reduction required by the Order.

Ultimately, however, Defendants' continuing protests about the difficulties of addressing the waiting list have done nothing to reduce the waiting list. More services are needed – either through additional waiver slots or comparable services.

Defendants' argument about the DSP shortage is problematic on several levels, not the least of which is that it is simply a restatement of a longstanding problem for which Defendants have not implemented the known solutions – accountability for LME/MCOs to pay people enough to do the work, and a credentialling process to professionalize the workforce. *See Order*, p. 3 (citing Technical Assistance Collaborative Report making these recommendations). Yet Defendants' other argument is that they are expanding services by requesting more Waiver slots and making services available under the 1915(i) option. Thus, Defendants are saying that the Court will absolutely crash the service system if there is no stay, but also claim inconsistently that they are ramping up access *to the very same services*.

[1] The 1915(i) option is a set of services that have not yet gone into effect but will provide some level of access to services for those who are otherwise qualified for Medicaid.

Allowing the waiting list to grow simply compounds a problem that has been allowed to worsen for years. A stay would be directly harmful to thousands of people who will wait even longer than they already have.

IV. The Order Provides Time for Needed Long-Term Reforms; Plaintiffs Propose One Modification to the Order to Facilitate Sustainable Progress.

Contrary to Defendants' argument, the Court's Order does not threaten anyone's ability to choose to remain in an institutional setting, although a modification of the Order may now be needed to undo harm caused by Defendants' repeated public insistence to the contrary.

A. The Order Provided a Means for Defendants to Carefully Reduce Reliance on Institutional Settings Over Time Through Voluntary Transitions.

The Court's Order specifies that all decisions about seeking and using community-based alternatives must be based on informed choice. *Order*, p. 7. No one living in any institutional setting can be required to leave that setting against their will. *Id*. The Order also allows a six-year period for Defendants to prepare to end new *long-term* admissions. *Id*. at p. 6. The cessation of long-term admissions is meant to avoid simply re-filling beds as people are transitioned out voluntarily – creating an endless loop of over-reliance on institutions and an ongoing need for intervention. Limiting new admissions is already the approach Defendants are promoting regarding Developmental Centers, requiring new admittees to agree that their stay is short term.

The Order expressly does not require the elimination of institutions but provides a means to avoid the continued and indefinite overreliance on institutions as long-term or permanent placements. Defendants have agreed that there is a need for reform to address overreliance on private ICFs. *See infra,* Section IV.B. The November 2, 2022 Order merely requires the implementation of reforms that *Defendants* have proposed in the past.

B. Defendants Previously Expressed the Need and Desire to Reform the ICF System by Improving Quality, Converting Some Providers to Community-Based, and Addressing "Cherry Picking."

There are about 300 private ICFs in North Carolina, each housing anywhere from 6 to 125 people, although most are six-bed facilities. Private ICFs house most of those with I/DD who are currently institutionalized. *Order*, p. 2. The record in this case shows that Defendants' own leadership, staff, and retained expert believe that there are serious concerns regarding how – and to what extent - private ICFs are used in North Carolina.

Defendants' Rule 30(b)(6) designee testified that the trend in earlier decades was to move people from state-operated facilities (DD Centers) to "community" ICFs, but that "a community ICF shouldn't be the end point" and that the state should "work on getting them to a less restrictive setting." (Ashmont Dep. p. 84:22-23; 85:6-7) Instead of private ICFs being one step on a path toward integration, people tended to remain in them and not move to other, fully integrated settings. (*Id*. at pp. 84:14-85:13.) In addition, the intent of moving people from DD Centers to community ICFs was to serve those with the highest (often complex medical) needs in a relatively smaller setting (as compared to the state institutions). However, many ICF operators "cherry pick" those with less acute needs and receive the same payment as they would for serving those with higher needs. (*Id*. at 86:23-87:1.) While some ICFs may serve those with more complex needs, that is not the general rule. (*See* Goda Dep., pp. 60:18-25) ("people that we're serving in the community [are] very similar to the people that we are serving in the ICFs, which leads to my wanting additional slots, so I can bring them to the community.")

Defendants have expressed the desire to reduce reliance on ICFs by ensuring that they are serving only those with the highest needs. According to Defendants' representative, "if we had a little revamping of the community ICFs they could potentially be serving the higher needs

individual." (Ashmont Dep. p. 85:19-21.) "I think it's a bigger issue that we have so many ICFs. The quality varies and staff turnover is high and how do we address all of that." (*Id*. p. 86:18-20.)

Regarding quality and the need for change, Defendants representative testified as follows:

> **Q.** And you mentioned politely, I think, the variety of quality of ICF.
> **A.** Um-hm. Yes.
> **Q.** Is it fair to say that some [are] not that good?
> **A.** Yes.
> **Q.** And some of them don't really provide the kind of habilitation and support like we really want for folks?[2]
> **A.** Not optimally, yes.
> **Q.** All right.
> **A.** They have lots of layers of oversight. Complaints are made. They have lots of investigations. It's not like they're out there completely on their own. But as far as outcomes for individuals, I think we can do better there.

(*Id*. at p. 87:2-17.)

The State's Medicaid Director testified that there is not sufficient mobility for people with I/DD to move from ICFs to a community-based setting. (Richard Dep. p. 179:14-24.) At his 2018 deposition, he said that Defendant DHHS was having conversations about the prospect of moving some private ICF beds to community-based, using the example of a converting services in a ten-bed ICF to community-based services through waiver slots. (*Id*. p. 180:16-181:18.) He also indicated shifting ICF providers to a community-based model was being done elsewhere and could be accomplished in North Carolina through policy changes and community and stakeholder engagement – a process that is necessary to build trust and assure providers and the community that adequate support for those changes will be in place. (Richard Dep. p. 182:2-184:10.) The Order specifically allowed for this type of transition and affords Defendants the opportunity to use this approach to meet Benchmark 1: "Transitions may include the conversion

[2] Defendants admit that, in the absence of appropriate habilitation and ongoing support, individuals with I/DD are vulnerable to needless dependence and institutionalization. Am. Comp. ¶ 25; Ans. ¶ 25.

of the service model of a resident's institutional setting provider to a community-based setting provider." *Order,* p. 6.

This is consistent with Defendants' retained expert, Dr. John Agosta, who had previously provided a blueprint for reducing North Carolina's reliance on institutions, which included reducing reliance on private ICF providers. One feature of that shift was "to help providers decide to begin to offer services as waiver services as opposed to ICF/IID services. But also it was to help individuals – to create pathways for people to decide they would like to go to an optional alternative of some kind." (*Id*., p.142:6-10.)

The six-year period before the 2028 cessation of admissions was to provide an opportunity for Defendants to do what they have said they want to do – reduce reliance on ICFs while ensuring that they provide high quality services.

C. Defendants Have Abandoned Their Prior Convictions Rather Than Undertake Needed Work to Transform a System That Is Failing So Many People.

Defendants *could* have begun working on ways to spend the next six years helping providers evolve their models – which Defendant DHHS was already discussing in 2018. (Richard Dep. pp. 180:16-181:18.) They could have said publicly what they had said repeatedly in depositions:

- Some ICFs are not serving the habilitative needs of residents with I/DD. (Ashmont Dep. p. 87:8-11.)
- We simply have too many ICFs and we keep those beds full because we lack community services for people who want to leave. (*Id*. at p. 86:18-19.)
- Those excess beds are being filled by ICF operators who cherry pick those who are easier to serve – and would be easier to serve in the community. (*Id*. at p. 86:23-87:1.)
- Some ICFs are poor quality. (*Id*. at p. 87:2-17.)
- Defendant DHHS has previously pursued discussions of transitioning some ICFs to settings that are considered community based. (Richard Dep. pp. 180:16-181:18.)

Instead, Defendants have offered a full-throated defense of the *status quo*. Instead of calming community concerns, they have actively inflamed fears by telling the I/DD community that the Court's Order will result in sudden closure of ICFs and people being put out on the streets and made homeless. Instead of addressing the needs of *all* of those with the most at stake, Defendants have elevated the voices of those with an understandable interest in keeping things as they are - all in defense of their resistance to the Court's Order.

a. Defendants Have Raised and Amplified Fears Among Families About Loved Ones Being Made Homeless by the Court's Order, In Reckless Disregard for the Consequences.

Defendants have made numerous public statements that either imply or state outright that implementation of the Court's Order would result in the sudden closure of private ICFs and even the specter of people being made homeless. *See*, *e.g.*, Taylor Knopf and Rose Hoban, *Judges' order gives NC 10 years to provide more at-home disability services*, North Carolina Health News, https://www.northcarolinahealthnews.org/2022/11/07/judges-order-gives-nc-10-years-to-provide-more-at-home-disability-services/?utm_source=iContact&utm_medium=email&utm_campaign=north-carolina-health-news&utm_content=November+7%2C+2022.

These statements have been echoed and amplified by ICF operators, apparently in coordination with Defendant DHHS. For example, one operator wrote to families with loved ones in the ICF's facility about the Order:

> We are writing to let you know about a problem that could potentially cause your loved one to lose their ICF group home placement.
> . . .
> Our company and all the ICF community group home companies across North Carolina are working very hard with Secretary Kinsley and Assistant Secretary Dave Richard to encourage them to appeal this order. We are encouraging you to write to him as well.
>
> Contact Dave Richard Here: [email address omitted]

(**Attachment 5**: Letter from GHA Autism Supports, November 14, 2022) (emphasis in original). Defendants have submitted a selection of emails received from providers and family members of ICF residents that appear to be an answer to these calls for support. (Defs.' Br. pp. 12-14.) These statements are from facility operators and family members who fear a change in the *status quo* based on the characterization of the Order as a demand for closures, as opposed to a chance for long-discussed reforms.

Defendants' embracing and amplification of fears run counter to their obligations, as articulated by the United States Department of Justice (DOJ). Recognizing that individuals or their guardians may have previously been dissuaded from pursuing greater integration, the DOJ directed that States "take affirmative steps to remedy this history of segregation and prejudice in order to ensure that individuals have an opportunity to make an informed choice." U.S. Dept. of Justice, Statement of the Department of Justice on Enforcement of the Integration Mandate of Title II of the Americans with Disabilities Act and *Olmstead v. L.C.*, June 20, 2011 ("DOJ Guidance") p. 4.

Defendants could have responded with assurances that:

- The six-year period would provide enough time to ensure continuity of services.
- ICFs and ACHs must give notice of discharge. N.C. Gen. Stat. § 122C-63 (60 days' notice required to discharge from I/DD facility) and § 131D-21(17) (ACHs must provide 30 days' notice).
- They would be actively working to ensure appropriate services will remain in place, as required under state law. *See* N.C. Gen. Stat. § 122C-63(f) ("The Secretary is responsible for coordinative and financial assistance to the [LME/MCO] in the performing of its duties to coordinate placement so as to assure continuity of care and for assuring a continuity of care placement beyond the operator's 60-day obligation period.")
- The state would continue to pay for ICF services for short term admissions and respite, as permitted by the Order.

It was unnecessary for family members to be placed in fear and was unconscionable for Defendants to use that fear rather than allay it. While Defendants

insist that they want to respect the "choice" of those with family members in ICFs, they are actively avoiding the requirement to provide real choice for those who want to leave – like Samantha and her family, who placed her in a DD Center not by choice, but because they had *no* choice. The 16,000 on the waiting list for services also have no choice but to continue to wait.

Plaintiffs wholeheartedly disagree with Defendants' characterization of the Order and the notion of inevitable negative consequences. Defendants have an obligation to address barriers, including guardian concerns. DOJ Guidance, p. 4. Instead, they have exacerbated those concerns.[3]

b. Defendants' Deference to the Concerns of Private Facility Operators Is Improper and Violates Clear Statutory Duties to People with I/DD.

Defendants' argument is premised in significant part on concerns for providers' ability to carry on business as usual:

> Like any business, ICFs and ACHs have a business model that depends on maximizing utilization of capacity, either by adding new residents when beds are empty and/or providing services to existing residents. The Cessation requirement directly undermines the viability of those business plans.

(Defs.' Br. p. 11.) The phrase "maximizing utilization of capacity" is chilling because it really means keeping more people institutionalized to make sure institutions make enough money to maintain capacity, perpetuating the cycle of overreliance on institutions. Instead of engaging in efforts to resolve family and provider concerns consistent with the rights of those who would

[3] Members of the disability community have also called on Defendants to act rather than pursue delay. *See*, *e.g.*, Bill Donohue, *If I Had a Hammer*, https://journalnow.com/opinion/columnists/bill-donohue-if-i-had-a-hammer/article_5b8f3aa4-6b4f-11ed-b2aa-03c88bddb61e.html; and Ray Hemachandra, *A Letter About IDD Advocacy in North Carolina*, December 14, 2022, https://rayhemachandra.com/2022/12/14/iddletter/?fbclid=IwAR0Vy0vwoY1TZD0j5FxPR8_Uc2gRmsvdg7ky_Y_TeMpCkAb6uZS44nyKXD4.

choose to live outside institutional settings, Defendants have decided to focus on supporting the "business plans" of ICFs and ACHs. However, DHHS' obligation is to people with disabilities, and not to the providers of services. *See Cedarbrook Residential Ctr., Inc. v. N.C. HHS*, No. 36A22, 2022 N.C. LEXIS 1101, at *63 (Dec. 16, 2022) ("A careful analysis of the statutory provisions [governing adult care homes] . . . indicates that those provisions are intended to protect the *residents* of adult care facilities rather than the facility owners or operators.")

Defendants also argue that "DHHS is concerned that ICFs and ACHs, recognizing that no new admissions will be permitted starting in 2028, may close their doors earlier than this, which may result in current residents being forced out and having no place to live." *Id*. As noted above, closures and homelessness would not be an act of God or a natural disaster; they would be a product of Defendant DHHS' failure to carry out its statutory function.

A misguided idea of Defendant DHHS's role has been a chronic impairment to achieving compliance. Historically, the state has lacked the political and executive will to effectuate needed reforms. (Deposition of Holly Riddle, p. 120:14-25; Deposition of Trish Farnham, p. 25:17-19.) Defendants' submissions in support of their Motion to Stay simply confirms the institutional bias in the current system and suggests that it remains deeply engrained.

D. Plaintiffs Believe It Would Benefit the Disability Community and the Ultimate Aims of this Action to Modify the Injunction and Require Collaborative Resolution of Issues Surrounding Private ICFs.

Plaintiffs have never requested closure of institutions generally, or private ICFs specifically, because this case is about giving people with I/DD an option to choose community placement if that's what they want. However, Defendant DHHS's response to the Order has created fear in the disability community, and divided those who urgently need change from those who are concerned about change. For this reason, Plaintiffs believe – and previously proposed to

the Defendants -- that the Order may be modified to ensure that reform in the private ICF context happens with full transparency and engagement of all stakeholders.

As noted above, Defendants' previous position has been that (1) there are too many ICFs and (2) some tend to "cherry pick" and serve those without high needs and (3) some are not high quality. *See*, *supra*, Section IV.B. Consequently, there is significant basis for Defendants to actively and urgently engage in addressing the known deficits in the ICF system. To address the quality and overreliance issues – while respecting the concerns of those whose family members are residing in ICFs they like – Plaintiffs proposed that the parties actively engage the community in discussions designed to develop sustainable, consensus solutions.

Specifically, on November 18, 2022, Plaintiffs proposed to Defendants that the 2028 cessation on new long-term admissions be replaced by a provision requiring the parties to actively engage with the community to address the issue of quality and integration of private ICFs. (**Attachment 6**: Email from Counsel for Plaintiffs to Counsel for Defendants, dated November 18, 2022.) This proposal was the result of Defendants' repeated statements that the cessation on admissions was the sole basis upon which they were considering an appeal – an appeal that threatened to inject further delay in a case that is all about the State's failure to take timely action on a known cause of deeply consequential harm to thousands of people.

Having heard nothing, counsel for Plaintiffs sent a draft motion to stay to counsel for Defendants on November 29, 2022, proposing to agree on a substitute term in lieu of an appeal. (Defs.' Exhibit D filed November 30, 2022.) During a call later that day, Defendants reporting their intent to appeal, which they did the next day. Defendants never engaged in a substantive discussion of the proposal referenced in this section.

Plaintiffs' proposal was designed to address the fears of those families who like their loved one's ICF placement, while requiring Defendants and providers to engage with the community and with Plaintiffs in addressing issues of quality and over-reliance.

There need not be an all-or-nothing approach based on pitting groups with different desires against each other. A stay is not needed to enable Defendants to engage in the needed reforms over the next six years. However, it is apparent that Defendants' success in stoking fear will impair its own ability to carry out the reforms it has advocated for in the past.

Rule 62(c), under which Defendants have sought a stay, permits the Court to modify its own Order pending appeal. To allay community fears and facilitate needed reforms, and consistent with the previous proposal to Defendants, Plaintiffs suggest that the Court modify the Order pursuant to Rule 62, replacing the following provision of the Order:

- After January 1, 2028, Defendants shall ensure a cessation on new admissions to institutional settings. This cessation on new admissions does not apply to or bar the use of institutional settings for respite or short-term stabilization.

with:

- After January 1, 2028, Defendants shall ensure a cessation on new admissions of people with I/DD to public ICFs and Adult Care Homes. This cessation on new admissions does not apply to or bar the use of institutional settings for respite or short-term stabilization.
- With regard to private ICFs, the Parties are directed to develop a plan to ensure compliance with *Olmstead* principles and informed choice. The Parties are directed to engage in good faith efforts to ensure that those who choose to remain in or enter congregate settings such as private ICFs or group homes have access to settings that are high quality, as integrated into the community as possible, and offer the greatest degree of individual independence as possible. The Parties are directed to include all interested parties in developing a sustainable plan for compliance with *Olmstead* principles and informed choice, including but not limited to: individuals with I/DD; providers of ICF, group home, or community-based services; interested family members; advocates for the integration of individuals with I/DD in the community; and state and local agency staff. By January 1, 2024, the Parties shall report to the Court on the status of their efforts to develop a joint proposal consistent with this provision. The Court will make such further orders as appropriate.

Defendants have unwisely, and improperly, chosen to support the *status quo* rather than engage in the hard work of transforming the I/DD system. Permitting the *status quo* to continue during appeal sends a signal that those with the most influence over Defendants will prevail even against the agency's own better judgment. A stay would be counterproductive. The above modification would require reforms to proceed.

CONCLUSION

The Court has permitted Defendants time to address the urgent needs identified in this case. The response has been to continue to admire the problem – engaging in an ongoing reflection but failing to get past the barriers and difficulties of operating a system that Defendants are specifically charged with operating. In the meantime, the waiting has continued, and the list of those waiting has grown. Defendants' Motion to Stay is a continuation of the State's refusal to accept accountability and take effective action and should be denied.

Plaintiffs respectfully request that the Court deny Defendants' Motion to Stay, or limit the relief provided pursuant to Rule 62(c) to the modification proposed above. Delay regarding the other provisions of the Order would perpetuate the harms that the Order sought to end.

This 17th day of January, 2023.

DISABILITY RIGHTS NORTH CAROLINA

Lisa Grafstein
North Carolina Bar No. 22076
lisa.grafstein@disabilityrightsnc.org

Emma Kinyanjui
North Carolina Bar No. 31450
emma.kinyanjui@disabilityrightsnc.org
3724 National Drive, Suite 100
Raleigh, North Carolina 27612
Telephone: (919) 856-2195
Facsimile: (919) 856-2244

LAW OFFICE OF JERRY HARTMAN
By: Jerry Hartman
3607 Whispering Lane
Falls Church, VA 22041
ghartmanlaw@gmail.com

ATTORNEYS FOR PLAINTIFFS

CERTIFICATE OF SERVICE

This is to certify that the undersigned has served a copy of the foregoing **Response to Defendants' Motion to Stay** on Defendants by email to counsel for the Defendants as follows:

Michael T. Wood
mwood@ncdoj.gov
N.C. Department of Justice
Post Office Box 629
Raleigh, North Carolina 27602

This 17th day of January, 2023.

DISABILITY RIGHTS NORTH CAROLINA

Lisa Grafstein
North Carolina Bar No. 22076
lisa.grafstein@disabilityrightsnc.org
3724 National Drive, Suite 100
Raleigh, North Carolina 27612
Telephone: (919) 856-2195
Facsimile: (919) 856-2244

Attachment 1

STATE OF NORTH CAROLINA — IN THE GENERAL COURT OF JUSTICE
SUPERIOR COURT DIVISION
WAKE COUNTY — 17 CVS 6357

SAMANTHA R., by her Guardian, TIM R., MARIE K., by her guardian, EMPOWERING LIVES GUARDIANSHIP SERVICES, LLC, CONNIE M., by her guardian CHARLOTTE R., JONATHAN D., by his guardian MICHAEL D., MITCHELL T., by his guardian, BETSEY S., MICHAEL A., and DISABILITY RIGHTS NORTH CAROLINA,

Plaintiffs,

vs.

STATE OF NORTH CAROLINA, NORTH CAROLINA DEPARTMENT OF HEALTH AND HUMAN SERVICES, and MANDY COHEN, in her official capacity as Secretary of the North Carolina Department of Health and Human Services,

Defendants.

TELEPHONIC DEPOSITION OF DEBORAH GODA

(Taken by the Plaintiffs)

Raleigh, North Carolina

Wednesday, March 20, 2019

Reported in Stenotype by
Lynn A. Ruggiro, Court Reporter
Transcript produced by computer-aided transcription

Q. So, yeah, so the question was, I'm sorry, what was being tracked is the clinical needs with people with an I/DD right now, that's only being done in the individual files, so there's not a system of tracking the overall needs, and so what I was asking if you agree that the lack of that data affects your opinion on whether the system is adequate in regards to being able to support people in the community?

A. I don't know that that will change my opinion, because the individuals who are in the institutions, putting aside the specialty programs --

Q. Okay.

A. -- it's the same level of care. It's the same continuum of needs.

Q. Okay.

A. So what's in the ICF, I believe that that data would confirm --

Q. Okay.

A. -- the opinion that I have, which is people that we're serving in the community, very similar to the people that we are serving in the ICFs, which leads to my wanting additional slots, so I can bring them to the community.

Q. Is there a review of individual files to confirm that? You said you believe that the needs in the ICF are the same as the needs in the community.

A. It's the same level of care.

Q. Same level of care, but does that go as to the capacity of the community or -- or to discharge in the community? Like if I haven't assessed the needs of the individuals in, how do you design a plan to transition them out?

A. Well, I think then we're looking at individuals, and I think at that point in time, we're -- they're looking at individual charts to determine the needs of that specific individual. But we're either talking about the system as a whole or we're talking about an individual. As far as the system as a whole, every person who comes on to Innovations has to meet the same of level of care as the ICF facility, so they have to have the disability, they have to have the functional limitations that are required. They have to have a need for active treatment.

Q. Okay.

A. So we're looking at individuals who are at the same level of care, who have the same type of

support needs. Now, I may need some more -- I may need more assistance with bathing than Neal does, but Neal can't be left alone in the kitchen because he doesn't know how to operate the stove. So once you get down to granular, then you're looking at the person by person, but when we're talking about data systems as a whole, we would be looking at overarching to see this is where the support needs are of the whole of our ICF population, that data isn't necessarily going to drill down and tell me what one person needs within the community.

Q. Okay.

A. At that point, I'm looking at that person's chart, looking at their support system, talking with their staff and their family versus trying to do an overarching programmatic change.

Q. So you don't need --

A. I will need it when we get there.

Q. Oh, when do we get there, what is that? When you said, "When we get there," what is "get there"?

A. What I'm saying is that is as far as talking about where we are at the -- at where we are now in the community, I have what I -- I have the data on those individuals. If we have the data on

the folks in the ICFs, I think we're going to see that they look pretty much the same as the folks that are in the community, but I need more slots to bring those folks over here.

Q. Can we take a break?

A. Sure.

(Recess taken)

BY MR. KINYANJUI:

Q. Ms. Goda, is there anything that you'd like to change or add to your earlier testimony?

A. No, ma'am.

Q. Okay. All right.

So Dave Richard testified that the department has always been under-resourced when it comes to management of the MCO contracts and that there have been concerns around the lack of competition and in defining expectations for the MCOs to meet in terms of outcomes. Would you agree with that concern?

MR. McHENRY: Objection to the characterization.

Q. You can answer.

A. I can use more staff. I think competition is something that's going to be solved with transformation.

Attachment 2

STATE OF NORTH CAROLINA IN THE GENERAL COURT OF JUSTICE
SUPERIOR COURT DIVISION
WAKE COUNTY 17 CVS 6357

SAMANTHA R., by her Guardian, TIM R., MARIE K., by her guardian, EMPOWERING LIVES GUARDIANSHIP SERVICES, LLC, CONNIE M., by her guardian CHARLOTTE R., JONATHAN D., by his guardian MICHAEL D., MITCHELL T., by his guardian, BETSY S., MICHAEL A., and DISABILITY RIGHTS NORTH CAROLINA,

Plaintiffs,

VS.

STATE OF NORTH CAROLINA, NORTH CAROLINA DEPARTMENT OF HEALTH AND HUMAN SERVICES, and MANDY COHEN, in her official capacity as Secretary of the North Carolina Department of Health and Human Services,

Defendants.

DEPOSITION OF NATASHA ASHMONT

At Raleigh, North Carolina
August 22nd, 2018
10:02 a.m.
Reported by: Leslie Christian

best fit for folks but for some it is. It's a very -- it's much more structured than a lot of our community settings, and some individuals respond well to that and don't handle the lack of structure well.

So I think that community ICFs and the ICF model has its benefits that the interdisciplinary team, everything under the umbrella, can be really good or it can be really bad.

I think that for a lot of people what that should yield is higher levels of communication among all the team members. I think that that's always a good thing for an individual.

Q. And I appreciate you kind of giving me your personal perspective on it as well. In terms of the department's view is that -- is moving people from the DD centers to private ITFs an appropriate solution to the issue of deinstitutionalizing --

A. At all levels. I think throughput at all levels is an issue.

Q. Throughput?

A. Throughput. Yeah. I think if we moved somebody to a community ICF, that shouldn't be the end point either. So I think that they should have the same transition planning standards that we have at the developmental center.

I think that -- I would say that we've discussed with DMH kind of just the quality of the homes and making sure that the ICFs are still working that active treatment component and that the MCOs are following up to make sure that the individuals who are there are there and they're still planning to work on getting them to a less restricted setting, that that's not the end game for that person.

Q. That's a conversation you've been having?

A. Yes.

Q. So the private ICF is not the end of the story? Shouldn't be?

A. Shouldn't be.

Q. And you said there's conversations now about talking to the MCOs about that fact?

A. Um-hm. I think the MCOs are aware of it. I think just from a cost standpoint it's to their benefit to not utilize the ICFs. But I think that there are -- I mean, if we had a little revamping of the community ICFs they could potentially be serving the higher needs individual.

As it stands currently, I mean, the beds are full. They get to pick who are admitted. Usually if they have an opening, as a quality provider they're going to get multiple referrals. And when you have the

same rate for each individual in the home there's not a lot of incentive to serve those higher needs individuals. So then our folks kind of jump in our door when they could have been met in the community had the criteria been a little bit different.

So that's a much, much more involved discussion on how we hold -- you know, how we have the oversight and get involved in that level of care inside homes.

Q. And that's outside your purview?

A. It's outside my purview currently other than we're having the conversations and that we need -- we're having them specifically around the bed transfer homes with the idea being that they were designed to help us move individuals out of the facilities. And if they're not doing that then what do we need to do differently.

But I think it's a bigger issue that we have so many ICFs. The quality varies and staff turnover is high and how do we address all of that. It's a big system kind of issue that I think is not going to be solved today in this conversation.

Q. Have you heard the phrase "cherry picking"?

A. Yes.

Q. Is that kind of what you're talking about?

A. Yes.

Q. And you mentioned politely, I think, the variety of quality of ICF.

A. Um-hm. Yes.

Q. Is it fair to say that some is not that good?

A. Yes.

Q. And some of them don't really provide the kind of habilitation and support like we really want for folks?

A. Not optimally, yes.

Q. All right.

A. They have lots of layers of oversight. Complaints are made. They have lots of investigations. It's not like they're out there completely on their own. But as far as outcomes for individuals, I think we can do better there.

Q. Anything else you would like to add about what's being done to advance the institutionalization with regard to the DD centers?

A. I'm sure there is but not that I can think of at this time.

Q. Are you familiar -- you know a little bit about the innovations waiver, I assume?

A. Yes.

Attachment 3

APPEARANCES

ON BEHALF OF THE PLAINTIFF:

Lisa Grafstein, Esquire
Emma Kinyanjui, Esquire
Disability Rights North Carolina
3724 National Drive, Suite 100
Raleigh, North Carolina 27612
(919) 856-2195
Lisa.grafstein@disabilityrightsnc.org
Emma.kinyanjui@disabilityrightsnc.org

ON BEHALF OF THE DEFENDANT:

Michael T. Wood, Esquire
Neal McHenry, Esquire
North Carolina Depart of Justice
114 West Edenton Street
Raleigh, North Carolina 27603
(919) 716-0168
Mwood@ncdoj.gov
Nmchenry@ncdoj.gov

ALSO PRESENT:
Dylan Hix, Legal Intern
Emily Sorge, Legal Intern

DEPOSITION OF DAVID RICHARD, a witness called on behalf of Plaintiff, before Lauren M. McIntee, Registered Professional Reporter, Certified Realtime Reporter, and Notary Public, in and for the State of North Carolina, at the offices of the North Carolina Department of Health and Human Services, Division of Medical Assistance, 1985 Umstead Drive, Raleigh, North Carolina 27603 on Friday, July 27, 2018, commencing at 9:02 a.m.

support around -- around what's happening, that they with their mental health needs and somebody with developmental disabilities is going to need those long-term supports. So the direct support professionals have become a much more important component of that as well as the technology opportunities that might exist.

Q. Okay. And just -- you said ACT team, which is an acronym, A-C-T?

A. Yes, correct.

Q. Okay.

A. Sorry.

Q. No, it's not you. Just want to make sure we keep the record clear.

I wonder if you -- we could talk a little bit about sort of mobility between settings for folks with IDD. You know, the ability to opt to go to a group home instead of an ICF or the ability to, you know, have your own apartment or ability to choose whatever setting you want. I want -- I want to find out sort of your take on, do you think there's currently sort of sufficient mobility in the system for people to sort of make those choices on any given day?

A. There's some ability, but it's not sufficient.

Q. Okay. All right. What are the barriers, do

you think? Same stuff?

A. It's going to come back to funding, is one of the -- I think the highest level barrier. Is the -- you know, moving from an ICF, again, it does happen. I'm well aware of examples, but moving from an ICF to a -- say a -- somebody supporting what the waiver slot requires, if there's a waiver slot.

Q. Okay.

A. And if the waiver slot's not available, then that delay that approach.

Now, there are, you know, MFP slots available that -- that help that effort. And there are some emergency slots available to do that, but -- but it really requires a more significant amount of -- of waiver slots.

Q. Okay. I'm going to -- in addition to sort of -- so there's -- there's additional resources. Is there sort of any way to redeploy some current resources in -- in the sense that, is there money in the system where we can reduce reliance, for example, on -- and I don't want to pick on DD centers, but you know, if we're spending too much in institutional settings, is there a way to reconfigure that over time, and has that been part of the discussion?

A. It's been -- it's been discussed for a long

time and continues to be discussed. And I think -- I think there are -- there are particularly difficult challenges in redeploying DD center dollars, but not impossible. And I think that there has been a -- a -- there's been a lot of conversation about that. Figuring the challenges around that are -- are difficult.

I think easier is that -- I think more people are -- at least there's more conversation about converting ICF community beds and then allowing that to -- to be supported by, you know, somehow figuring out the waiver slots. So if somebody was no longer going to, you know, we're on a ten-bed ICF, that the dollars are easier to convert to waiver slots that way than it would be in a state facility.

Q. Okay.

A. So I think -- I think those types of conversations are happening. They're happening at the LME level right now with -- with providers.

Q. Okay. So let's talk about both of those. In terms of, you know, do you --

(Phone ringing.)

BY MS. GRAFSTEIN:

Q. Do you need to get that?

A. I do not.

Q. Okay.

A. Actually, I'd be glad not to get it.

Q. In terms of converting sort of the ICF providers, what -- what incentives or what needs to happen to make that not just sort of a one-off here or there somebody doing it, but more of a systemic approach to that?

A. I think there is a one-off component of that. I think somebody has to go first, right. You have to have people willing to -- to do that. There is the, also the -- the, you know, the how -- how do you -- right way to say this is right now with a -- because in ICF you have a certificate of deed that essentially gives you a right to get funding for -- from the state for it, that we have to figure out how to -- how to -- to a provider that's willing to make that change, that that isn't a barrier for them.

So, you know, essentially I don't want to say -- I will say that there has to be some ability for people to -- to feel confident that that funding will stay once it happens. And then -- and then I think it's the regulatory environment that people have to feel comfortable that if they're going to take support people in a -- in a community setting with significant needs, there are risks for a provider in doing that.

And -- and I'd say we all -- I'd say we all

contribute to this, is that there -- my assumption is -- and I think you do everything to avoid that, but if people leave from higher regulated settings to less regulated settings, at some point in time something negative will happen to someone. And if the response from the community is, oh, gee, then we've got a highly -- we've got to create more regulation or you penalize the provider for that, then people won't take that risk anymore.

And I think -- I think we have a very risk-averse provider system at this time because they -- I think many of -- many have taken chances and felt they were penalized for it. We have to figure that out.

Q. Who is going to figure that out?

A. I'd say -- I mean, what I think is the state along with the broader stakeholder community, including people like Disability Rights and all of the advocacy and provider groups. Because it does take, I think, some trust that people are going to try to do the best they can, but understand that there are -- there are risks of doing that.

Q. Are there states where that's happened and they've done it well or they've done it badly and we can learn from it?

A. I think -- I think there are lot of examples

of -- of poor implementation. And -- and I think there are good examples of states. I mean, you know this as well as anybody, is that there -- you know, that -- that there are many states who have downsized their state facilities to very small numbers and have created community settings. I think many of them have done well. Some of them have -- have, I think, done it on the cheap, and that has caused problems for people. But, yeah, I think there are good examples that we can -- we can pull from.

Q. Okay. I'm going to ask you to name names, so are there --

A. I'm not going to name names.

Q. So let's -- we can just talk about the ones you think have done it well. How is that? Is that a --

A. Well, I think -- what I'd say -- and let me also clarify, is that so since I've been in the Medicaid role, I've been less involved and paying attention to detail around the disability community. But one state that I think had done well for years is Maryland and Pennsylvania have, I think, demonstrated really good, solid plans on how to support people in communities. And we can learn from them.

Q. Okay. And when you say "support people in the communities," you mean sort of less reliance --

A. Yes.

Q. -- on those facilities?

A. Correct.

Q. Okay. All right. I know that there are some states where they've actually closed their state-operated facilities?

A. That's right.

Q. And I don't know what the number is right now, but maybe you do?

A. I don't know, but it's relatively -- you know, it's probably in the teens at this point.

Q. Okay. All right. Well, I'm just going to touch the third rail. Has there been discussion about that?

A. There is -- there is not any active discussion inside of the department to eliminate developmental disabilities centers. There has been plenty of active discussion, and continues to be, inside of the department of how do we continue the approach of downsizing state facilities? The population of facilities are -- are older. People have lived there for a long time. I think there's a -- a value and compassion side of, we're not going to try to move people out that, you know, are much older, that are, you know, settled and -- and frankly, families have counted

on those for a long time.

But what we are -- we are absolutely committed to is to avoid unnecessary placement in a state facility. I think we've done a relatively good job of that over the past five years. And for any -- any individual that has an interest in leaving or family member that wants their family member to leave, that we will aggressively work with them to do so.

Q. There -- there are -- tell me if you disagree with this statement. There are currently people in DD centers who would like to be in the community?

A. I don't -- I don't know specifically of anyone, but again, I -- I would be shocked to find out that there weren't.

Q. Okay. All right. So that's likely?

A. Yes.

Q. Okay. And that's just, again, a question of finding the community placement for them essentially?

A. That's correct, yeah.

Q. So -- so that was the DD centers. In terms of the -- the conversion of ICFs, we talked a little bit about are there some other states that are doing that well, and maybe we can get some specifics if you know any. But what -- are there any -- other than what you've described, are there any other barriers to that

Attachment 4

NORTH CAROLINA	) IN THE GENERAL COURT OF JUSTICE
	) SUPERIOR COURT DIVISION
WAKE COUNTY	) 17 CVS 6357

SAMANTHA R., by her guardian, TIM R., MARIE K., by her guardian, EMPOWERING LIVES GUARDIANSHIP SERVICES, LLC, CONNIE M., by her guardian CHARLOTTE R., JONATHAN D., by his guardian, MICHAEL D., MITCHELL T., by his guardian, BETSY S., MICHAEL A., and DISABILITY RIGHTS NORTH CAROLINA,

Plaintiffs,

vs.

STATE OF NORTH CAROLINA, THE NORTH CAROLINA DEPARTMENT OF HEALTH AND HUMAN SERVICES, and MANDY COHEN, in her official capacity as Secretary of the North Carolina Department of Health and Human Services,

Defendants.

DEPOSITION OF JOHN MICHAEL AGOSTA, Ph.D.

(Taken by Plaintiffs)

Raleigh, North Carolina

Tuesday, March 26, 2019

Reported by
Cathleen M. Clack
Transcript produced by computer-aided transcription

other people moved in, which is a possibility.

Q. Was the purpose of Action Step 4 to help change the funding models so that some of the providers of private ICFs could move to a different setting?

A. That would -- that would definitely be part of it, is to -- is to help providers decide to begin to offer services as waiver services as opposed to ICF/IID services. But also it was to help individuals -- to create pathways for people to decide they would like to go to an optional alternative of some kind.

Q. Okay. And so apart from what we've looked at, do you have any other information about whether Action Step 4 was followed?

A. No.

Q. We're going to go to Action Step 5 on page 25.

Action Step 5 was, "Conduct a study of individual intellectual and other developmental disabilities residing in Skilled Nursing Facilities to determine if placement is appropriate."

Do you have any information about whether that was done?

A. No, I don't.

Q. Let's go ahead and go on to Action item 6. I think you referred to this one earlier, on page 27.

call out any particular state.

Q. Okay. Let me ask this way. Are you thinking of some other states?

A. Am I thinking of some other state?

Q. Yeah.

A. More than one.

Q. Okay. All right. We've talked a little bit about -- I think you've referred to them as legacy systems, like DD centers and ICFs.

Are there sort of fiscal consequences for continuing to rely on those kinds of legacy systems?

A. Fiscal consequences, what do you mean?

Q. Well, they cost money, right?

A. Yeah.

Q. Okay. So can you talk about what consequences there are for --

A. The math is what it is to the graphics that we provided to you. ICF/IIDs from state to state to state tend to cost more, on average, than home community-based waiver services.

But you've got to be careful with that because home and community-based waiver services, remember about half the people nationally live home with their moms and dads. So that's naturally going to be less expensive than any kind of out-of-home paid

Attachment 5

GHA AUTISM SUPPORTS

Administrative Office
213 North Second St.
PO Box 2487
Albemarle, NC 28002

P **704.982.9600**
F **704.982.8155**

Wilmington Services
PO Box 4122
Wilmington, NC 28406

P **910.769.1046**
F **910.399.1780**

CARF

November 14, 2022

Dear Family Members:

We are writing to let you know about a problem that could potentially cause your loved one to lose their ICF group home placement.

A court has issued an order in the Samantha R. Lawsuit which will harm community ICF group homes. We are concerned that this new order may force many ICF group homes to close. This would eliminate or change your choice of services.

We are asking families and guardians to be in touch with Dave Richard, Deputy Secretary of the Department of Health and Human Services and ask him to appeal the Samantha R. Order.

Disability Rights of North Carolina (DRNC) filed a class action lawsuit against the Department of Health and Human Services on behalf of Samantha R. and other individuals. The suit alleges that those individuals were discriminated against under state law because they were being served in a setting that was not the 'least restrictive environment'. The department was working with DRNC to resolve Samantha R.'s placement and the other issues in the lawsuit. The Lawsuit also alleges that Community ICF group homes are 'institutions' and are not appropriate places for individuals with Developmental Disabilities to live

The judge issued an order that surprised us. The judge issued an order that will require the state do three things.

- Increase the number of Innovations 'slots' and provide more services through the Innovations Waiver
- Eliminate the waiting list over a period of time by funding more community services
- **Stop admissions to the community group homes by the year 2028**

The first two items in the order we completely agree with. More community services are necessary. The State and the Legislature has been working toward this goal.

We strongly disagree with the third item. This section of the order will force community group homes to close.

We believe;

- Community ICF group homes are not institutions.
- People live in ICF community group home because they want to.
- ICF group homes are a very stable long term community option chosen by many residents, parents, and guardians as the best place to live
- Nobody should be forced to leave a community group home unless they want to.

We believe that when DRNC recommended this approach they did not understand how group homes are funded. Community ICF group homes depend on funding for at least six residents to have the budget necessary to operate the home. If a resident leaves a group home and we cannot place another person in the home, then we will not have enough money to operate the home and it will be forced to close.

Our fear is that if the State is required follow the judge's order which forces people to move out of community group homes and into other services, ICF community group homes will begin to close at an alarming rate.

Our company and all the ICF community group home companies across North Carolina are working very hard with Secretary Kinsley and Assistant Secretary Dave Richard to encourage them to appeal this order. We are encouraging you to write to him as well.

Contact Dave Richard Here: dave.richard@dhhs.nc.gov

We are encouraging you to attend a DRNC Town Hall meetings and speak up! DRNC is holding two town hall ZOOM meetings to discuss the new order. We are encouraging you to attend and express your opinion.

Register for the Town Hall here: https://disabilityrightsnc.org/event/25355/. The Town Hall is two 60-minute community conversations about the new ruling. Friday, November 18th, at Noon and 4 p.m.

Attachment 6

From:	Lisa Grafstein
To:	Wood, Michael
Cc:	Emma Kinyanjui
Subject:	Proposal
Date:	Friday, November 18, 2022 10:34:00 AM
Attachments:	drnc-responds-to-concerns-regarding-small-and-specialized-icfs.pdf image001.png

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Michael:

We wanted to reach out to you about some feedback we have been getting regarding Judge Baddour's Order, and some comments from Dave Richard in public forums. By and large, the provisions of the Order have been very well received, and we have been glad to hear Mr. Richard say that DHHS also agrees with the need to move forward on most of the provisions. The point of contention seems to be the cessation on long-term admissions to private ICFs in 2028. A few days ago, Mr. Richard indicated to a group of I/DD advocates that the state is considering an appeal based on this piece alone. We wanted to propose a solution that we think will address this concern and let us move forward in a way that meets everyone's needs.

In conversations with various stakeholders, it has become apparent that there is a concern about whether some smaller ICFs will close, even though there is a 6 year period with no limit on admissions and time to work on alternatives. We have explained that the Order does not allow for involuntary discharges and that we do not want people to be displaced against their will, but ICF providers are raising the concern among families that they will be forced to close and discharge people with nowhere to go. We have put out a response (attached) that sets out our views on this issue. We think there are alternatives, and time to address the concerns raised, but understand that people are looking for more assurances than that.

It is also apparent that there are wide differences in quality and integration among ICFs. The same is true for group homes, which are not covered by the Order; although they are supposed to be more integrated and allow for more independence, that is not always the case. We believe the focus should be on quality rather than on the label associated with a setting, and believe there are ways to improve integration and quality. In other words, we are less concerned with whether something is called an ICF or a group home; we want high quality services and better community integration. We think the state wants the same thing.

There is a way forward that can address concerns about admissions to ICFs and improve the quality of care and integration in the community. We could pause the provision about the cessation date. Over the course of the next year, DRNC and DHHS would convene stakeholders (including ICF providers) to identify ways to address quality and integration and make sure we are focused on the right outcomes. From there, we can see if there is a way forward. The work would ultimately take more than a year, but we think a year would be enough time to see if we are moving in the right direction. Obviously, this would be premised on the state deciding not to take an appeal. We can work out a way to preserve everyone's rights regarding the Order in the meantime.

We hope that this presents a way to address the concerns that have been raised, but we would welcome a conversation with you and anyone at DHHS who may want to develop this idea further.

Please let us know your thoughts. Emma and I will be happy to make ourselves available for a call or meeting.

Thank you!
Lisa

Disability Rights North Carolina

NC's protection and advocacy system, dedicated to advancing and defending the rights of people with disabilities

Lisa Grafstein
Litigation Counsel
Pronouns: She/her(s)
919-856-2195
877-235-4210
TTY callers, dial 711
919-856-2244 (fax)
lisa.grafstein@disabilityrightsnc.org

3724 National Drive Suite 100 | Raleigh, NC 27612
www.disabilityrightsnc.org | Support Our Work

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