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IN THE SUPREME COURT OF THE STATE OF DELAWARE

EDWARD and PAMELA PRUNCKUN, as parents and legal guardians of ROBERT PRUNCKUN, Appellants Below, Appellants, v. DELAWARE DEPARTMENT OF HEALTH AND SOCIAL SERVICES, Appellee Below, Appellee.	No. 93, 2018 On appeal from the Superior Court of the State of Delaware, C.A. No. N16A-05-010 FWW

APPELLANTS' REPLY BRIEF

ECKERT SEAMANS CHERIN
& MELLOTT, LLC
Francis G.X. Pileggi (DE No. 2624)
Brian D. Ahern (DE No. 3924)
222 Delaware Avenue, 7th Floor
Wilmington, DE 19801
302-574-7400
fpileggi@eckertseamans.com
bahern@eckertseamans.com

Attorneys for Appellants Below/Appellants – Edward and Pamela Prunckun, as parents and legal guardians of Robert Prunckun

Of Counsel:
Michael P. Flammia, Esquire
ECKERT SEAMANS CHERIN
& MELLOTT, LLC
Two International Place, 16th Floor
Boston, MA 02110-2602
mflammia@eckertseamans.com

Christopher E. Torkelson, Esquire
ECKERT SEAMANS CHERIN
& MELLOTT, LLC
P.O. Box 5404
Princeton, NJ 08543
ctorkelson@eckertseamans.com

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Appellants hereby reply to the Answering Brief ("Opposition" or "Opp.") of the Department of Health and Social Services ("DHSS").

I. Appellants Were Denied A Fair Hearing On The Central Issue.

A. The Appropriateness of Graduated Electronic Decelerator ("GED") as a Treatment Modality for Appellants Is the Central Issue.

In its Opposition, DHSS states that "this case is solely about the use of the GED, and changes to federal and state rules that have altered the appropriateness of GED as a treatment modality." Opp., p.8. Indeed, "the appropriateness of GED as a treatment modality" for these Appellants is the central issue of the case. Similarly, the central error in this case below was the Hearing Officer's ("HO") decision to allow DHSS to define "appropriateness of GED as a treatment modality" without any evidential support, while prohibiting Appellants from presenting any evidence on the same issue.

When DHSS instructed JRC in October 2013 to stop providing aversive treatment to Appellants, it terminated a covered Medicaid service and triggered Appellants' constitutional, statutory and regulatory rights to due process, specifically a fair evidentiary hearing, to address the basis for DHSS' action. DHSS repeatedly has admitted that the basis for its action was an alleged change in

[1] *See* Reply Brief in companion case.

"the appropriateness of GED as a treatment modality." At every stage in this case, DHSS has cited its concern about the "appropriateness of GED as a treatment modality" *without ever presenting any factual supporting evidence*. At the same time, DHSS has fought to preclude Appellants from presenting any countervailing evidence on this central issue. This is why the hearing below was fundamentally unfair, and why the decisions below erred in accepting DHSS' premise regarding "the appropriateness of GED as a treatment modality" as fact without evidence.

B. A Recent Massachusetts State Court Decision Is Directly Relevant to the Appropriateness of GED as a Treatment Modality.

In its Statement of Facts, DHSS improperly makes numerous assertions regarding the "appropriateness of GED as a treatment modality" without any supporting citations to the record. Of course, this is because DHSS presented no such evidence below or in its Appendix, and because the HO did not allow Appellants to present any countervailing evidence on that issue. However, in a case decided after Appellants filed their Opening Briefs in this appeal, a Massachusetts court made numerous findings, based on a full evidentiary record, that directly rebut DHSS' unsupported assertions.

In recent years, JRC, its clients (the "JRC Clients"), and their parents and guardians (the "JRC Parents") (together, the "JRC Appellants") have been involved in litigation against the Massachusetts Department of Developmental Services ("MA DDS"). MA DDS had sought to prohibit JRC from using

aversives, including the GED, to treat JRC clients with severe and treatment refractory self-injurious behavior ("SIB") and aggressive behavior ("AB"). On June 20, 2018, the Bristol County Probate and Family Court (the "Massachusetts Court") issued its decision in that litigation. *Judge Rotenberg Educ. Ctr., Inc., et al. v. Comm'r of the Dep't of Dev. Servs., et al.*, No. 86E-0018-GI (Mass. Prob. Ct. June 20, 2018) (Order and opinion attached hereto as Ex. "A") (the "2018 Decision"). Although not binding on this Court, the Massachusetts decision is directly relevant to this case because it considered substantial factual and expert testimony and exhibits, all of which were subject to rules of evidence and cross-examination of witnesses, and made findings directly rebutting DHSS' unsupported statements.

The case originated in 1986, when the JRC Appellants filed a civil rights lawsuit against the Commonwealth of Massachusetts (the "State") in response to the State's attempt to prohibit JRC from providing critical aversive treatment that had been the only treatment that effectively prevented the JRC Clients from engaging in severe SIB and AB. After holding a preliminary injunction hearing, the Massachusetts Court found that there was no medical evidence for the State's prohibition of aversive treatment, State officials had acted in bad faith, and there was every likelihood that the JRC Appellants would prevail on their claims. Accordingly, the Massachusetts Court enjoined the State from prohibiting JRC

from providing aversive treatment to the JRC Clients. The parties then executed a Settlement Agreement, which was adopted by the Court and entered as the Consent Decree in 1987 (the "Consent Decree"), which allowed the use of aversive treatment at JRC if approved on an individual basis by the Massachusetts Court. The Consent Decree also required the State to regulate JRC in good faith. Since 1987, the Massachusetts Court has approved hundreds of Applied Behavior Analysis ("ABA") treatment plans that include aversives such as the GED. After scrutinizing the clinical information on an individualized, client-by-client basis, the Massachusetts Courts have found that the treatment plans have saved JRC Clients from the intense pain, permanent injury, disfigurement, and potentially death, caused by their previously untreatable behavior disorders.

In 2013, the State filed a motion to vacate the Consent Decree, arguing that aversives such as the GED are no longer needed or part of the standard of care, i.e., that they are no longer "appropriate." After forty-four full days of trial, where twenty-seven witnesses, including five medical and psychological expert witnesses called by the State and six such experts called by the JRC Appellants testified, the Massachusetts Court issued its order denying the State's motion. Its 50-page decision found that the GED effectively treated the severe behaviors of JRC Clients (2018 Decision, at 37-38); that psychotropic medications and Positive Behavior Supports ("PBS") are not effective alternatives for the severe, refractory

behaviors of the JRC Clients (*Id*. at 41, 49); and that the State had failed to prove that aversives, including the GED, are not within the standard of care. *Id*. at 49. The Massachusetts Court further found that State officials had acted in bad faith and had ignored medical opinions and scientific support for the need for aversives, such as the GED, for some dangerous forms of behavior disorders. *Id*. at 14-17, 40-43, 48-49.

Turning back to this appeal, DHSS' Opposition repeatedly asserts that the applicable standard of care has changed. Thus, DHSS states "[o]ver time . . . accepted treatment modalities . . . change" (Opp., p. 11) and "[p]ractice standards for the treatment of aggressive behavior and self-injurious behavior have evolved to reject devices that use pain and fear to coerce desirable behavior, in favor of treatment modalities that use positive support to mold behavior.' Opp., pp. 11-12. DHSS' premise is unsound. First, DHSS cites no authority or evidence for these statements. Second, DHSS ignores the undisputed fact that Appellants' behavioral treatment plans at JRC have always been based on positive ABA procedures. A20; A22. Third, the Massachusetts decision, considering a wealth of evidence, explicitly rejected these same contentions.

In the 2018 Decision, after listening to extensive testimony and examining hundreds of trial exhibits, the Massachusetts Court found that MA DDS had failed to prove that "there is now a professional consensus that the . . . aversive treatment

used at JRC does not conform to the accepted standard of care for treating individuals with intellectual and developmental disabilities". 2018 Decision, at 49. The Court also found that current scientific literature describes devices such as the GED as "'an effective and efficient means of significantly reducing . . . [SIB]'". *Id*. at 40. The Court further found that: (1) the testimony of witnesses (including the testimony of MA DDS' lay and expert witnesses and the testimony of JRC Parents and former JRC Clients) and the clinical data admitted at the evidentiary hearing demonstrated that the GED treatment used at JRC has been effective at treating the SIB and AB of JRC Clients (*Id*. at 33, 37-38); (2) there was no evidence that psychotropic drugs – which have serious side effects, including, for example, stroke, bradycardia, tardive dyskinesia, tremor, and cognitive, neurological, and motor impairment – would be more effective than the GED treatment used at JRC for any of the JRC Clients currently receiving such treatment (*Id*. at 34-35, 49); and (3) "DDS did not offer credible evidence at the hearing that PBS can effectively treat some or all of JRC's clients". *Id*. at 41. These factual findings not only rebut the unsupported assertions in DHSS' Opposition, they also contradict DHSS' basic premise that the GED is no longer an appropriate treatment modality.

Similarly, DHSS' assertion (again without any citation or authority) that "the relevant federal and state standards have evolved in response to clinical practice"

(Opp., p. 12) is belied by the evidence regarding clinical standards for individuals such as Appellants. The Massachusetts Court found that JRC treats an extraordinarily difficult-to-treat client population. As the Court explained, "[u]nquestionably, many of JRC's … [clients] engage in many severe problematic behaviors, including aggressive behaviors, self-injurious behaviors, and destructive behaviors". *Id*. at 32. JRC Parents testified credibly that their children had to be restrained or heavily sedated at their prior programs, that their children had been terminated from prior programs because of their unmanageable behaviors, and that JRC was the only program willing to accept their children. *Id*. These experiences mirror those of the Appellants in this case. A19-22.

By accepting DHSS' assertion that aversives in general, or the GED in particular, is no longer an appropriate treatment modality, the HO and Court below in this appeal accepted a narrow and incomplete picture of the available evidence. Significantly, even witnesses testifying for MA DDS in Massachusetts admitted the value of the GED. MA DDS witness Dr. Philip Levendusky, an Associate Professor of Psychology in the Department of Psychiatry at Harvard Medical School, acknowledged that "there are many examples where the GED has had a significant positive impact on a JRC client". *Id*. at 10, 38. MA DDS expert witness and psychiatrist Dr. Edwin Mikkelsen admitted that, "in many cases, there was a rapid deceleration in self-injurious behaviors after use of the GED, with the

problematic behaviors decreasing from hundreds per day to zero in a very short period of time". *Id*. at 33, 38. Dr. Susan Shnidman, a MA DDS witness and an independent licensed psychologist who is paid by MA DDS to review JRC treatment plans, testified that the behaviors of many JRC clients improved after GED treatment. *Id*. at 37. Dr. Jennifer Zarcone, another MA DDS expert witness and a senior behavior analyst and supervising psychologist at Kennedy Krieger Institute, confirmed that GED treatment rapidly decreased SIB. *Id*. at 38. The State's own literature review concluded that "'[a]versives are effective in reducing severe . . . [SIB] quickly'", and that aversive treatment "may be successful in maintaining reduced rates of severe problem behaviors for as long as five years". *Id*. An analysis of clinical data for 189 JRC Clients, including Appellants in this appeal, also showed decreases in the average monthly occurrence of health dangerous and aggressive behaviors, from hundreds of such behaviors before GED treatment, to near zero occurrences after the start of GED treatment. *Id*.

In its October 2013 letters to JRC, DHSS not only instructed JRC to cease the use of aversives, it also instructed JRC to develop entirely new "positive behavioral support" plans for treatment of Appellants' severe forms of SIB and AB. A14-17. In its Opposition, DHSS asserts without any citation that "other providers employ positive behavior support techniques to manage unwanted behaviors." Opp., p. 10. When presented with evidence and testimony on the

effectiveness of PBS, however, the Massachusetts Court disagreed, finding that MA DDS "did not offer credible evidence at the hearing that PBS can effectively treat some or all of JRC's clients". 2018 Decision, at 41. The Court also found that PBS "is more accurately described as a philosophy . . . than as a sub-discipline" of psychology. *Id*. In contrast, the Court found that ABA treatment, which is the treatment used by JRC with Appellants, including the GED, "is a sub-discipline in the field of psychology", is a subject that is taught in many undergraduate, graduate, and doctoral level degree programs, and is a field that is licensed by the majority of U.S. states. *Id*. Notably, Appellants' own treatment records confirm that intensive positive-only techniques were unsuccessful in treating their dangerous and self-destructive behaviors. A19-21.

In its Opposition, DHSS suggests that the GED presents certain risks. Opp., p. 10. However, when presented with evidence on that issue, the Massachusetts Court found that, other than temporary pain, there was no evidence of physical or psychological side effects from GED treatment when used according to JRC's policies and protocols. 2018 Decision, at 35.

DHSS mischaracterizes the GED as a form of prohibited corporal punishment for supposedly minor behaviors. Opp., p. 14.[2] To the contrary, the

[2] Had DHSS permitted the introduction of competent evidence below, Appellants would have shown, as documented in Ashlee's treatment records, that "[g]etting out of his seat without permission proved to be a direct antecedent and the initial

Massachusetts Court found that aversives such as the GED are a generally accepted form of ABA treatment that is scientifically proven to be an effective and efficient means of significantly reducing severe behavioral problems. 2018 Decision, at 40. The Massachusetts Court further found that one national expert and four other MA DDS psychologists admitted that aversive interventions should be an available treatment option, including one who stated: "'Failing to use these [physical] aversive procedures that research has shown to be effective in suppressing self-destructive behavior that have not responded to positive reinforcement, extinction, or less intrusive intervention is unethical because doing so withholds potentially effective treatment and risks maintaining a dangerous state.'" *Id*. at 40, 41-42. Yet another psychologist formerly employed by MA DDS testified that the GED "was an accepted tool in the field of psychology", and that, as MA DDS' representative on JRC's Human Rights Committee, he approved GED treatment plans and "would not have done so if there were less restrictive,

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behavior in a chain of dangerous behaviors" after which Ashlee "[o]n almost every occasion" became "aggressive" including by "charg[ing] at staff, bit[ing] them, [and] sometimes kick[ing] them …." A1225. The use of aversive treatment in the scenario criticized by DHSS, if it occurred, was thus part of a carefully developed treatment plan to decelerate Ashlee's aggressive behaviors based on well-accepted ABA principals. *See also* A1592 ("It is clear that antecedents and consequences play at least a small part in the duration, frequency, and severity of [Robert's] behaviors" and noting that "[a]wareness and manipulation of antecedents and consequences helps in changing [Robert's] avoidance behavior and his conditioned response to stressors.").

effective alternatives". *Id*. at 40. Further, the Court found that the Behavior Analyst Certification Board and the American Psychological Association, two national professional organizations, allow the use of aversive interventions when other treatments are ineffective. *Id*. at 43.

DHSS disingenuously suggests that JRC's provider contract requiring it to comply with "all other applicable standards" somehow created a contractual prohibition on the use of the GED. Opp., p. 16. As already discussed at length, DHSS' characterization of the applicable standard of care is not in any way supported by any evidence, and is directly contradicted by the specific evidential findings made by the Massachusetts Court. Even more importantly, however, JRC's provider contract explicitly allowed the use of the GED as part of Appellants' court-ordered treatment plans. A134; A720-733.

DHSS' attempt to establish the standard of care through uncited legal briefing cannot be countenanced. "It is settled law in Delaware that the standard of care applicable to a [medical] professional can be established only through expert testimony." *Stayton v. Clariant Corp.*, No. 468, 2013, 2014 WL 28726, at *3 (Del. 2014); 18 *Del. C.* §6854. Delaware law also recognizes that the applicable standard of care is a "question of fact" which depends on the unique circumstances of every case. *See Shapira v. Christiana Care Health Services, Inc.*, 99 A.3d 217, 222 (Del. 2014). In the Medicaid context, Delaware law also "requires that the

administrative decision-maker (here, DHSS) give 'substantial weight' to the opinions of treating physicians; that DHSS generally should give less probative weight to the opinion of a physician who has never examined the patient; that DHSS should explain its reasons for rejecting any expert evidence; and that DHSS should not substitute its expertise for the competent medical evidence." *Urban v. Meconi*, 930 A.2d 860, 865 (Del. 2007) (internal footnotes omitted).

Likewise, contrary to DHSS' claims, federal Medicaid law and regulations simply do not establish the medical standard of care. *See* 42 U.S.C. §18122(1), (2)(A) ("…[A]any guideline or other standard under any Federal health care provision [including specifically Medicaid] shall not be construed to establish the standard of care or duty of care owed by a health care provider to a patient …."). Federal law prohibits the promulgation of regulations that adversely affect patient access to appropriate treatments or interfere with the physician-patient relationship or provision of needed medical care or services. *See* 42 U.S.C. §18114 ("…[HHS] shall not promulgate any regulation that * * * creates any unreasonable barriers to the ability of individuals to obtain appropriate medical care … [or] limits the availability of health care treatment for the full duration of a patient's medical needs.").

In sum, DHSS' fundamental premise that changes in federal and state policy have changed the "appropriateness" of the GED as part of the applicable standard

of care has been thoroughly discredited by the Massachusetts Court, and is contrary to the principles of governing law. DHSS has done everything in its power to discount and preclude the wealth of evidence proffered by the Appellants in this case – the very information that the Massachusetts Court found credible and relied upon in finding that aversive treatments remain within the standard of care – in order to preserve a policy decision that ignores Appellants' constitutional and statutory rights to person-centered planning and services that advance the fundamental goals of the HCBS Waiver.

II. DHSS Failed To Provide Appellants With Due Process.

A. Appellants Are Entitled to Challenge DHSS' Action to Terminate Aversive Treatment Services.

DHSS' Opposition intentionally blurs the chronology of events in order to create the false impression that its decision to terminate Appellants' aversive treatment services was not targeted and was the consequence of a change in federal and state law. In fact, the chronology conclusively proves otherwise.

On October 8 and October 11, 2013, DHSS sent two letters addressed to JRC—*not to the Appellants or their parents/guardians*—demanding the discontinuation of aversive services then being provided to Appellants pursuant to the Medicaid HCBS Waiver. Only after sending its October 2013 letters to JRC did DHSS meet with the guardians and provide them with copies of the October 2013 letters to JRC. At no point did DHSS provide Appellants themselves with any written description of its proposed action; the legal, clinical and/or other grounds for its proposed action; or a notice advising Appellants of their rights to a fair hearing. DHSS provided no professional or clinical basis or opinion in support of its directives to JRC, nor did DHSS claim that the health, safety or welfare of Appellants was in any way in danger or at risk.

On November 27, 2013, Appellants submitted a timely fair hearing request, thereby invoking their federally-conferred rights to participate in pre-termination administrative proceedings related to DHSS' proposed discontinuance of aversive

services pursuant to the HCBS Waiver. Aversive treatment services had been part of Appellants' court-ordered treatment plans for nearly ten years. They were explicitly allowed as a term of JRC's provider contract, and they were (and had been) covered services under Delaware's then-current HCBS Waiver. Moreover, Delaware's October 2013 instructions to JRC did not apply to any other Delaware Medicaid recipients, for the simple reason that Appellants were the only two recipients who were receiving aversive treatment services under Delaware's HCBS Waiver

The "HCB Settings Rule" that DHSS has repeatedly cited as the "changed" federal law that prohibited aversives was not published in its final form until January 16, 2014, and was not effective until March 17, 2014. See 79 Fed. Reg. 3032 (Jan. 16, 2014). Similarly, Delaware's revised HCBS Waiver did not become effective until July 1, 2014. Notably, DHSS did not provide Appellants with specific notice regarding the proposed change to the HCBS Waiver that would prohibit aversives, and DHSS submitted the HCBS Waiver application to CMS for approval *prior* to the purported period for public comment. *See* 17 Del. Reg. Regs. 1180 (Jun. 1, 2014). In short, the regulatory changes cited by DHSS were *post hoc* changes made after Appellants had asserted their rights to a fair hearing.

Rather than merely anticipating a change in law, DHSS instructed JRC to change Appellants' long-term, court-ordered treatment plans (and DHSS changed

its own Waiver) in blind reliance upon the 2012 McGreal Letter that was directed to another region of CMS regarding another state's (Massachusetts) Medicaid waiver, and was thus inapplicable to Delaware's Waiver. DHSS never considered or permitted Appellants (or JRC) an opportunity to respond to all relevant issues raised by its October 2013 action, including the potential impact upon Appellants, or to correct DHSS' uninformed misperceptions. *See Goldberg v. Kelly*, 397 U.S. 254, 268 (1970) ("[Due process] rights are important in cases such as those before us, where recipients have challenged proposed terminations as resting on incorrect or misleading factual premises or on misapplication of rules or policies to the facts of particular cases.").

B. DHSS' Failed to Provide Appellants Adequate Notice.

1. The October 2013 Letters were inadequate, and sent to JRC.

DHSS' October 2013 letters infringed Beneficiaries' due process rights because, *inter alia*, they: were sent to JRC, rather than being addressed or sent to Appellants, who only received them after the fact; failed to advise Appellants of their rights to an evidentiary fair hearing and to continuing medical assistance pending such a hearing; and failed to provide any medical, clinical or other factual basis for DHSS' demands that JRC "discontinue the use of aversive procedures" in Appellants' treatment plans and "develop a new positive behavioral support plan

for both men[.]" *See, e.g.*, 42 C.F.R. §§431.206; 431.210; DSSM §§5000 (defining "adequate notice"); 5001; 5200; 5300.

Significantly, "adequate notice" is required even when "changes in either state or federal laws … require automatic adjustments for [benefits rendered to certain] classes of individuals." DSSM §5302(K) (requiring such "mass change notices [to] be adequate and timely" and include statements regarding the state's intended action, the reasons for the intended action, the specific change in law, and "[c]ircumstances under which a hearing may be obtained and assistance continued[.]"). Medicaid law also clearly entitles Appellants to timely, adequate and meaningful notice of DHSS' proposed termination even if – as DHSS also incorrectly claims – no hearing right also exists. *See* 42 C.F.R. §431.210(d) (adequate notice must be provided in all cases where a state takes adverse action against a beneficiary and "[i]n cases of an action based on a change in law, [it must also state] the circumstances under which a hearing will be granted[.]"). Thus, even if alleged "changes in … state or federal laws" did occur which had the effect of legally prohibiting aversives, DHSS still clearly violated Appellants' procedural due process rights to "adequate notice."

2. The Fair Hearing Summary was inadequate and misleading.

Likewise, the "Fair Hearing Summary" eventually produced by DHSS (after it was requested by Appellants) was both untimely and inadequate. The sole

purpose of such a summary is to promote due process through the full disclosure of the factual and legal grounds supporting a proposed action by the State, meaning "enough information for [an] appellant to prepare his or her case" for an ultimate evidentiary fair hearing. *See* DSSM §5312, §2. Contrary to that core purpose and explicit DHSS regulations, however, the hearing summary produced in this case, *inter alia*: falsely denied that DHSS had taken any "action" with respect to Beneficiaries' Medicaid benefits that would entitle Beneficiaries to a fair hearing;[3] falsely suggested that adequate notice had been provided to Appellants on October 8, 2013; falsely indicated that Appellants medical assistance benefits would continue pending the resolution of the administrative proceedings[4]; claimed that DHSS had factual and/or documentary evidence in support of its positions but yet improperly failed to identify or produce any such factual information (and, to date,

[3] *See* 42 C.F.R. §431.201 (broadly defining "[a]ction" as "a termination, suspension, or reduction of Medicaid eligibility or covered services."). *See also* 42 U.S.C. §1396a(a)(3) (requiring each state to provide a fair hearing "to any individual whose claim for medical assistance … is denied"); 42 C.F.R. §431.200 (hearing required where a state agency "takes action … to suspend, terminate, or reduce [Medicaid] services" that are provided).

[4] In view of Appellants' timely challenge of DHSS' action and the terms of the Transition Agreements entered into between Appellants and DHSS, JRC has continued to provide services, including aversives, as required by the Appellants' court-ordered treatment plans. (Ashlee no longer receives GED applications.) Nearly five years later, DHSS still has not identified an appropriate alternate provider to which Appellants can safely be transitioned. JRC still has not received any payment from DHSS for the services it has continued to provide to Appellants, and DHSS has only offered to pay a reduced percentage of the costs of those services.

never has); and failed to identify any specific witnesses expected to testify on behalf of DHSS. As a whole, the Fair Hearing Summary, like the October 2013 Letters, offends due process because it unfairly and inadequately describes DHSS' actions. DHSS' *post hoc* regulatory action does not erase its failure to provide adequate notice and due process to Appellants.

III. DHSS' Prohibition of Aversives Undermines the HCBS Waiver.

DHSS acknowledges that "[t]he HCB Setting Rule defines person-centered planning requirements for persons in Medicaid-funded community settings under HCBS Waivers." Opp., p. 9. DHSS also asserts that it has made "no attempt to adjudicate the merits of individual recipients." Opp., p. 27. In fact, by adopting a *post hoc* regulatory prohibition that prohibits aversives as not "appropriate" or outside the standard of care, DHSS has done exactly what it disavows—it has adjudicated the merits of these individual Appellants. Worse, it has disregarded its mandate to employ a person-centered planning process.

DHSS would have this Court believe that its October 2013 action to terminate Appellants' covered Medicaid services was compelled by an explicit change in the federal law. But the federal law had not changed in October 2013. When the final HCB Settings Rule was published and effective the following year, it did not explicitly ban aversives. It only provided general descriptions of the types of community settings that were the goal and purpose of the Waiver. DHSS' assertion that the description of a setting as free "from coercion and restraint" equates to an absolute and inflexible ban that does not allow for consideration of individual (or person-centered) support needs is completely disingenuous. Despite the 2014 HCB Settings Rule, Delaware's HCBS Waiver still clearly permits the

use of restraints and restrictive interventions to ensure the health, safety and welfare of Waiver participants. *See* A57-62.

DHSS notes that Medicaid only imposes a "reasonableness" standard in determining the scope and extent of services to be provided under the waiver, and that its prohibition of aversives is somehow objectively reasonable. Opp., p. 39. Of course, DHSS has never provided any evidence that its prohibition is, in fact, reasonable, and the Massachusetts decision, based on actual evidence, proves otherwise. Specifically regarding Appellants, it is difficult to imagine how prohibiting aversives can be considered reasonable given the lack of effective alternative treatment and the findings in the record that the behavioral treatment with supplemental aversive interventions provided by JRC is "the most effective, least restrictive means currently available for treating [Appellants] without the risk of any significant adverse side effects." *See* A42-43; A204-256; *see also* A38-39; A161-202.

Contrary to DHSS' assertion, Appellants do not argue that providers or recipients should be allowed to override any safeguards mandated by Delaware's HCBS Waiver. Opp., p. 39. Appellants simply point out that, as discussed *supra*, federal Medicaid law does not permit the standard of care to be dictated by regulation. Moreover, DHSS' attempt to define the standard of care, or "the appropriateness of GED as a treatment modality," without evidentiary support is

discredited by the findings of the Massachusetts Court that actually considered the available evidence. As argued in the Opening Brief, the federal Medicaid rules are designed and intended to allow disabled Medicaid recipients access to non-institutional, community settings. By imposing a standard of care without any evidence or clinical support, DHSS has violated federal law, denied Appellants their rights to person-centered planning, and frustrated the goals and purposes of the Medicaid community settings waiver.

IV. Appellants Have Asserted Timely ADA Claims.

In its zeal to defend its deliberate indifference to Appellants' unique medical needs, and to avoid confronting the facially discriminatory impact of its action, DHSS dismisses Appellants' ADA claim as not having been properly preserved below. But DHSS, like the Court below, misses the point of Appellants' argument.

Simply put, despite raising their ADA claims in their initial fair hearing demand, Appellants were not allowed to present arguments or evidence in support of their claims at the fair hearing. The thrust of the ADA claim is that prior to their admission to JRC, Appellants were unable to live in integrated, community settings. As a result, Appellants were perpetually isolated and institutionalized away from the community via locked, segregated rooms, paralyzing dosages of psychotropic medication, massive amounts of restraint and other attempted treatments or interventions that still left both men's health and safety at risk. Given their clinical history, the complete overhaul of Appellants' long-term, medically necessary treatment plans at JRC and cessation of aversive treatment is likely to again lead to their restraint, isolation, segregation and institutionalization.

In its Opposition, DHSS notes that "HCBS waivers allow states to offer services and supports to individuals who . . . have disabilities and live in a community setting in lieu of institutionalization." Opp., p. 9. Significantly, even Delaware officials have concluded that, "in the absence of home and community

based services" that are provided by JRC, both Appellants "would require the level of care required in an [institution]." A1233; A1412. Access to these community settings is exactly what JRC's intensive behavioral treatment program (including positive interventions supplemented with aversive treatment) does for these Appellants.

DHSS has argued that the "GED is not reflective of the characteristics of community settings" (parroting the 2012 McGreal Letter). Opp., p. 11. And yet the GED is precisely what has allowed Appellants to escape their prior institutional settings, so that they now live in a single-family home setting that allows them to engage in a true community. Denying Appellants the treatment that enabled their community placements would also deny them access to the settings that DHSS and the HCBS Waiver purport to advocate. That denial of access is the discriminatory effect of DHSS' action in this case.

Appellants asserted their ADA claims in their fair hearing demand. However, the HO unfairly restricted the scope of the fair hearing to a single legal issue regarding whether aversives are "covered services" and prohibited any evidence regarding the medical necessity of the treatment. The evidence and arguments prohibited by the HO included why this treatment is so critical to Appellants and how its withdrawal would impact their lives, including their ability to access community waiver services available to other disabled Medicaid

recipients with less severe behavioral support needs. Appellants did not fail to raise the issue; they were improperly precluded from pursuing the issue through the introduction of supporting evidence and arguments at the so-called fair hearing.

Appellants' rights under the ADA are federal in nature, and DHSS bears a continuing obligation to comply with Title II of the ADA and its integration mandate. *See* 42 U.S.C. §12132; 28 C.F.R. §35.130(d); *see also Olmstead* v. *L.C.*, 527 U.S. 581, 597, 600-601 (1999) (holding that unjustified isolation constitutes "discrimination based on disability" prohibited by Title II and the integration mandate). In addition to its obligations under the ADA, the Medicaid Act obligates DHSS to "administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities," and to "make reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability …." 28 C.F.R. §35.130(b)(7), (d); 42 C.F.R. §431.205(f).

Even though the HO erred in failing to address or even allow evidence regarding Appellants' ADA claims, this Court has the power to "decide all relevant questions and all other matters involved" with this appeal. 31 *Del. C.* §520. This Court should not repeat the error of the Court below by equating the HO's refusal to allow Appellants to present arguments or evidence in support of their ADA claims with a supposed failure to raise those claims at all.

CONCLUSION

Wherefore, for the foregoing reasons, the Court should reverse the Superior Court's ruling and order the administrative Final Decision to be reversed and vacated, and enter judgment for Appellants, as requested in Appellants' Opening Briefs.

ECKERT SEAMANS CHERIN & MELLOTT, LLC

By: */s/ Brian D. Ahern*
Francis G.X. Pileggi (DE No. 2624)
Brian D. Ahern (DE No. 3924)
222 Delaware Avenue, 7th Floor
Wilmington, DE 19801
302-574-7400
fpileggi@eckertseamans.com
bahern@eckertseamans.com

Attorneys for Appellants Below/Appellants – Edward and Pamela Prunckun, as parents and legal guardians of Robert Prunckun

Of Counsel:
Michael P. Flammia, Esquire
ECKERT SEAMANS CHERIN & MELLOTT, LLC
Two International Place, 16th Floor
Boston, MA 02110-2602
mflammia@eckertseamans.com

Christopher E. Torkelson, Esquire
ECKERT SEAMANS CHERIN & MELLOTT, LLC
P.O. Box 5404
Princeton, NJ 08543
ctorkelson@eckertseamans.com

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