IN THE UNITED STATES DISTRICT COURT
FOR THE DISTRICT OF PUERTO RICO

UNITED STATES OF AMERICA, Plaintiff, v. THE COMMONWEALTH OF PUERTO RICO, *et al*., Defendants.	)	Civ. No. 99 - 1435 (GAG/MEL)

UNITED STATES' RESPONSE TO THE COURT'S ORDER AND THE COMMONWEALTH'S RESPONSE REGARDING INSTITUTIONALIZATION AND THE UNITED STATES' COMMENTS ON THE COMMONWEALTH'S PLAN FOR OPENING NEW COMMUNITY HOMES

On June 4, 2020, the Commonwealth moved participant JPL from a substitute home in the community to the Shalom Institution. As a result of this, on June 19, 2020, the Court issued an order prohibiting the Commonwealth from institutionalizing more participants and directing the Commonwealth to develop and implement a plan "for community homes that can effectively address the needs of all participants, including those who need around the clock attention and care," like participant JPL, specifying that the plan must "address the immediate transfer of institutionalized participants back to community homes." Order Regarding Participant Re-Institutionalization & *Olmstead*, ECF No. 2900, at 2-3 (hereinafter, "Institutionalization Order").

On June 29, 2020, the Commonwealth filed a response, challenging the Court's order. Commonwealth Resp. to Order, ECF No. 2920. On July 2, 2020, the Court directed the United States to respond to the Commonwealth's filing. Order, ECF No. 2926, (emphasizing that "the Court highlights that as of January 2019 there have been 11 institutionalizations").

Several weeks later, also per the Institutionalization Order, the Commonwealth filed its "Plan for New Community Homes." Commonwealth Mot. Submitting Plan for New Community Homes, July 21, 2020, ECF No. 2961 (Spanish version); Commonwealth Mot. Submitting Translation of the Plan, July 23, 2020, ECF No. 2970 (English translation). On July 22, 2020, the Court ordered the United States to file comments on the plan. Order, ECF No. 2965.

Given that all of the filings and orders referenced above relate to the same topic, as well as to the same incident – the transfer of participant JPL from the community to an institution – the United States submits in the instant document both its response to the Commonwealth's *Olmstead* filing and its comments about the Commonwealth's plan for new community homes.

As set forth below, the Court's concern about the placement of JPL (and others) in the Shalom Institution is well-placed (*see* §§ I and II), the Commonwealth's community homes plan is insufficient and inappropriate (*see* § III), and the Commonwealth misapplies the Supreme Court's *Olmstead* opinion in ways that disadvantage participants in this case (*see* § IV).

I. The Institutionalization of Participant JPL

The record shows that the Commonwealth violated this Court's orders in institutionalizing JPL.

A. Background

On June 5, 2020, the office of the Joint Compliance Coordinator (JCC) sent the Commonwealth an "urgent request for information" regarding the transfer of participant JPL from his substitute home in the community to Shalom – one of three private institutions for people with developmental disabilities. JCC Info. Req. from Margarita Mercado-Echegaray to Laura Sola Palacios. The JCC asked for an explanation as to why the transfer "is not a violation of the Commonwealth's duties on community placements and expansion of provider services in the community under the [Joint Compliance Action Plan] JCAP." *Id*. at 1.

Shortly thereafter, as referenced above, the Court issued an order stating that it was "seriously troubled" by the recent transfer of participants to institutions, like the transfer of JPL to Shalom. Institutionalization Order at 1. The Court referenced that the central focus of the JCAP was to transition participants "from institutions to integrated community settings, not the other way around." *Id*. As with the JCC's request for information, the Court's reference here is supported by numerous provisions in the JCAP, discussed below, that mandate utilization and expansion of community services. The Court concluded that the "placement or re-placement of participants in institutions rather than in a community setting constitutes a major setback in terms of compliance with the mandates of the JCAP." *Id*. at 2. The Court also noted that "there still exists a very concerning deficiency in the number of available homes for participants as required by the JCAP." *Id*.

In response, the Commonwealth asserted that JLP is not appropriate for community services because he is "65 years old, partially verbal, has severe intellectual disability, and suffers from multiple diagnosed health conditions … [has had] multiple hospitalizations … is currently bed-ridden and requires 24-hour nursing care, including assistance to change positions to avoid pressure areas and ulcers." Commonwealth Resp. at 4.

The Commonwealth identifies virtually no steps that it took to find an alternative community setting or service to meet JPL's needs around the time of his last hospitalization. The Commonwealth's filing suggests that it did exactly the opposite of what it is required to do under the JCAP, and, instead, almost immediately set out to find a non-community setting for JPL. *See Id*. at 4 (reporting that DSPDI temporarily arranged for daily visits from nursing personnel at his substitute home and, "*simultaneously*, began the process of identifying a facility where he could receive the level of care that his current medical conditions require") (emphasis added). Indeed, within just 17 days of his last hospitalization, the Commonwealth had transferred JPL to an institutional facility. *See Id*. (reporting that on June 2, 2020, JPL was transferred to the Shalom Institution, which the Commonwealth had determined was the appropriate placement). The Commonwealth attached to its filing a memorandum from the DSPDI Compliance Officer that confirmed, with some additional details, that the Commonwealth proceeded with haste to place JPL in an institutional facility instead of exploring expansion of community services to meet his needs. *Id*., ECF No. 2920-1, Ex. 1.

B. <u>JCAP Requirements</u>

There are a number of important JCAP requirements that apply in the current situation with JPL, but the Commonwealth's response at ECF No. 2920, indicates that it did not comply with any of them.

First, the Commonwealth is required to expand community capacity to meet the needs of participants like JPL, but there is nothing in the Commonwealth's filing that indicates that the Commonwealth did so. *See* JCAP § III.2 ("the Commonwealth will develop and implement effective measures to expand available residential and other provider capacity in the community such that the community capacity will be sufficient to enable the Commonwealth to provide the [] participants with adequate and appropriate protections, supports, and services to meet their individualized needs and ensure their health, safety, and welfare … to improve outcomes for participants day-to-day"). Indeed, in the DSPDI memorandum, the Commonwealth admitted that "the DSPDI has no community or substitute home[s] that offer twenty-four nursing or medical care" and that "the kind of specialized care that is medically required to treat his existing condition, can not be found in a community or substitute home" in the Commonwealth's system.

Commonwealth Resp. Ex. 1, at 5. In effect, the Commonwealth ignored JCAP § III.2, failed to expand community capacity to meet JPL's needs, and instead, immediately proceeded to institutionalize JPL at Shalom.

That same JCAP provision specifies that expansion measures are to include "effective ongoing outreach efforts to regularly increase the number of high-quality prospective residential providers available and able to adequately and appropriately meet the needs of [] participants." JCAP § III.2. There is nothing in the Commonwealth's filing that informs the Court that it took *any* steps to expand community capacity by conducting effective outreach efforts to find alternate community providers that could meet JPL's needs. Quite rightly, the JCC asked the Commonwealth for an explanation about "what community placements were considered and why a community placement was not chosen." JCC Info. Req., June 5, 2020, at 1.

Second, the JCAP requires *active* engagement by the Commonwealth's Clinical Evaluation Unit [CEEC, per the Spanish acronym] to help meet the participants' needs. *See* JCAP § III.5.C (the Commonwealth's [CEEC] is to "regularly re-evaluate [] participants … regularly review the adequacy and appropriateness of the course of health care and mental health care [] participants are receiving through their primary care community physicians … [and] whenever necessary, [the CEEC] will promptly raise red flags and actively advocate on behalf of the [] participants when the assessments, diagnoses, treatments, and/or follow-up monitoring they are receiving through their primary care community physicians do not meet the individualized needs of the participants and/or comport with generally accepted practice").

Once again, there is scant evidence in its filed papers that the Commonwealth complied with these essential JCAP provisions requiring active CEEC engagement: although there was reference to a "case discussion," Commonwealth Resp. Ex. 1, at 4, there was no mention of a formal evaluation or re-evaluation of JPL by the CEEC; there was no mention of a review of the adequacy of care provided to JPL by the community primary care physician; and there was no reference to the CEEC raising red flags or actively advocating on behalf of JPL to remain in the community with additional services and supports.

Third, the JCAP requires the CEEC to take mobile action to help address the needs of a participant in decline or crisis – onsite and face-to-face. *See* JCAP § III.5.C (the Commonwealth's CEEC will "serve as a mobile crisis team, providing prompt, flexible, mobile expert support and advice to the community homes and [day programs] in special situations, such as health care and/or mental health care emergencies, crisis interventions, and transitions"). The JCAP further specifies that the CEEC's mobile crisis team is to "*deliver* comprehensive, individualized, and flexible treatment and supports to participants *where they live and work*." *Id.* § III.5.D (emphasis added). The mobile crisis team component is to be "multi-disciplinary" and is to include a nurse and/or mental health clinicians and mobile crisis team services are to be "*highly individualized and customized* to address the *constantly changing needs* of the participant over time." *Id.* (emphasis added). Mobile crisis services are to include crisis services, case management, nursing services, mental health services, and other supports and services critical to a participant's *ability to live successfully in the community*" and they are to be "*available 24 hours per day and seven days per week*." *Id.* (emphasis added).

Again, it appears that the Commonwealth simply ignored the JCAP by failing to provide mobile services and supports for JPL throughout his decline, or even after he returned home from the hospital. There is no reference in the Commonwealth's filings to the CEEC or to any other Commonwealth entity providing mobile crisis services to JPL onsite and face-to-face. There is the brief mention of a "case discussion" (referenced above) and there is a cursory reference to

Dr. Cubano (a CEEC psychiatrist) suggesting a medication modification, Commonwealth Resp. Ex. 1, at 2, but nothing to clarify that these were mobile interventions, as required by the JCAP.

Fourth, and perhaps most importantly, there are detailed JCAP provisions requiring the Commonwealth to identify participants with high risks and to then provide them with tailored and, if needed, intensive services and supports to meet their needs. *See* JCAP § III.5.H (the Commonwealth is to "develop and implement a protocol to gather information from various sites and sources regarding the health care and mental health care needs of the [] participants in order to identify 'at-risk' participants who may require heightened and enhanced attention and focus"). The JCAP then goes on to detail certain characteristics of participants that need to be included in this "at-risk" group.

Per the JCAP, this priority at risk group is to consist, at least, of those participants who: have a seizure disorder; are non-ambulatory; have developed or are at risk of developing a bowel impaction or bowel obstruction; have developed or are at risk of developing a decubitus ulcer or skin breakdown; and/or are at risk of choking and/or aspirating, have dysphagia, difficulty swallowing, chewing, or retaining food or liquids, have had aspiration pneumonia or other recurrent pneumonias, cannot feed themselves, or currently use a feeding tube.

Based on the Commonwealth's own submission, JPL fits into almost all of these high-risk groups. *See, e.g.*, Commonwealth Resp. Ex. 1, at 1, 2, and 4 (JPL has "epilepsy," which is a seizure disorder; JPL "remains bedridden," so he is non-ambulatory; JPL has a "diagnosis of constipation," so he is at risk of a bowel impaction or a bowel obstruction; JPL "requires constant assistance in the changing of positions to prevent the formation of pressure areas," so he is at risk of developing a decubitus ulcer or skin breakdown; JPL was diagnosed with "pneumonia" and with "bronchopneumonia," so he has had recurrent pneumonias).

Far from being an outlier and an unexpectedly difficult case, JPL's profile fits squarely within the agreed-upon parameters of the JCAP. JPL is exactly the type of participant who was to be covered by the provisions in JCAP § III.5, especially JCAP §§ III.5.H-L. *See also* JCAP § III.5.I (for these at-risk participants, the Commonwealth is to work with the participants' community doctors to help them "promptly develop and implement tailored and intensive protections, supports, and services … that meet the participants' individualized needs." The intent is that the Commonwealth will "prompt these community doctors to develop and implement strategies to provide proactive health care and mental health care such that participant seizures, bowel impactions and obstructions, aspiration and aspiration pneumonia, decubitus ulcers and skin breakdown, and the adverse consequences of other at-risk conditions including mental illness will be minimized or eliminated)"; and JCAP § III.5.J (the Commonwealth is to thereafter, and on a regular basis, compile incident, outcome, and intervention and/or treatment information and data for each at-risk participant and then analyze, share, and utilize this information and data to help develop and implement remedies to address the individualized needs of each participant).

To summarize, the overarching JCAP obligation for at-risk participants, as well as for all others, is that the Commonwealth implement individualized plans and monitor the participants to ensure that services are effective such that all participants receive all necessary services in a timely manner. *See* JCAP § III.5.G (the Commonwealth is to "ensure that each [] participant's health care and mental health care plan and/or treatments are implemented properly, day-to-day, to meet each participant's individualized health care and mental health care needs" … the Commonwealth shall "ensure that each [] participant receives necessary health care and mental health care services in a timely manner, whenever necessary, to evaluate and/or treat each participant's health care and mental health care problems" … the Commonwealth is to "develop and implement an expanded system to regularly monitor each [] participant's health and mental health status and progress to prompt changes, whenever warranted, in each participant's health care and/or mental health care plan and/or treatments").[1]

The Commonwealth failed to do that here when it rushed JPL to an institutional setting without first trying to develop appropriate community capacity. *See* Institutionalization Order at 1-2 (requiring the Commonwealth to meet the needs of participants, even those with complex conditions like JPL, in integrated community settings). In light of the above, the Commonwealth's disregard for central components of the JCAP – a document it helped draft and that the parties jointly filed with this Court – and its institutionalization of JPL are unacceptable.

II. Shalom's Service Deficiencies Indicate That It Cannot Ensure Participants' Well-Being

The Commonwealth asserts that JPL "needed to receive specialized care" at the Shalom Institution so that he might access the "level of care required to *ensure his health and well-being*, instead of a community home placement." Commonwealth Resp., Ex. 1, at 5 and 7 (stressing that "transferring [JPL] into an institution, rather than a community home, is the most appropriate course of action to *ensure the safety and well-being of the participant*") (emphasis added). The Commonwealth is proceeding on a risky assumption, as the premise that Shalom

---

[1] There are similar provisions in the Community-Based Service Plan (CBSP). As summarized in the JCAP, the CBSP requires the Commonwealth to "ensure that each participant's individualized plan is appropriate and implemented fully to meet the ongoing needs of each participant; provide the type, quantity, duration, and level of support in the community for each participant according to the participant's individualized needs, capabilities, and desires." JCAP at 3. The CBSP also requires the Commonwealth to "provide clinical services that attend to personal objectives regarding community integration, mental health, behavioral considerations, physical health considerations, and other individualized clinical needs." *Id.*

can ensure a participant's health, safety, and well-being is in serious doubt. This is evident from the Commonwealth's own documents.

Based on documents and data provided by the Commonwealth, at least 20 participants died while a resident of Shalom during a three-year span from mid-January 2017 through mid-January 2020. Commonwealth "Lists of Deceased in DSPDI," 2017, 2018, and 2019; subsequent mortality submissions. It appears that more participants died at Shalom during this time period than at any other residential location for people with developmental disabilities in Puerto Rico. *Id*. The death rate, figuring the total number of deaths per resident census, has been far greater at Shalom than in community homes in Puerto Rico; as the Court may recall, the United States has raised mortality issues at various status hearings and conferences. Even compared to the other two private institutions, Shalom stands out – from January 1, 2017 through July 1, 2019, Shalom accounted for 13 of the 17 total deaths (over 75 percent) at the three private institutions in Puerto Rico for individuals with developmental disabilities. *Id*. As discussed below, these deaths are associated with lapses in basic health protections.

At least nine Shalom participants have died since the beginning of last year. *See* various Commonwealth Emails and Mortality and Morbidity Reports (participant initials and number, with date of death): NGM #992 (Apr. 11, 2020); MMV #18 (Mar. 22 or 23, 2020); CGA #96 (Mar. 13, 2020); NEGS #668 (Jan. 22, 2020); REPM #989 (Dec. 4, 2019); CQO #788 (Oct. 7, 2019); RFL #491 (Aug. 9, 2019); JASC #626 (June 30, 2019); and NDM #810 (June 2, 2019).

The individual death reports from the Commonwealth's quasi-independent Mortality Review Committee (MRC) raise serious concerns about deficiencies and substandard care at Shalom. We have set forth below pertinent excerpts from recent MRC reports that highlight these failures and demonstrate that Shalom cannot ensure the health, safety, and well-being of the participants living there.

- For NEGS #668, the MRC concluded on March 11, 2020, that at Shalom, there was a "[l]ack of follow-up of vital signs" after a low blood pressure reading "should have triggered a suspicion that something was occurring that required further investigation. This event recurred two days later, but more pronounced, resulting in the cascade of events which most probably resulted in the demise." MRC Rep. #668, at 7-8. The MRC also found "unsupervised use of potent sleep aids." *Id.* at 8.

- For NDM #810, the MRC found on November 15, 2019, that Shalom had failed to properly prevent the negative progression of pressure ulcers; this is *basic care*. The MRC found that Shalom failed to "remedy the situation causing the multitude of ulcerations. This could have been arrested or slowed by paying careful attention to the bedding used, special cushioning, and regular turning of [the] patient. Ultimately the overwhelming sepsis which ensued caused the demise of the participant." MRC Rep. #810, at 12. The MRC also found "Malnutrition" as there was "no nutritional plan for the participant, and, there was a laboratory [test result] … which shows that the participant was under nourished." *Id.* The MRC also found that Shalom missed anemia, which "became symptomatic. The bleeding source should have been sought to prevent the anemia." *Id.* Finally, the MRC concluded that NDM was subjected to polypharmacy, where the participant was receiving "many medications which were not supported by recent diagnoses." *Id.*

- For REPM #989, the MRC found on February 20, 2020, that Shalom allowed use of "polypharmacy of psychotropic medication without diagnoses to justify their application." MRC Rep. #989, at 6. The MRC concluded that the "combined effect" of the polypharmacy caused the participant to have negative side effects, including "confusion, weakness, unsteadiness, hypotension, dizziness, drowsiness, extreme drowsiness, and others." *Id.* The MRC also implied that Shalom repeatedly failed to take proper action in response to blood test results that revealed that REPM suffered from reduced blood flow to the kidneys due to heart failure or dehydration and that this failure to recognize and treat "reduced filtering by the kidneys caused the medication levels to increase causing the drop in blood pressure which occurred [on] November 11, 2019 … The participant was not as fortunate on December/04/2019 when she was discovered without vital signs." *Id.* at 7.

- For JASC #626, the MRC reported on December 2, 2019, that this Shalom participant had been hospitalized for a few days, presenting with respiratory difficulty, but then stressed disapprovingly that "**[t]here is no documented evidence in the record of this event**" from January 2017. MRC Rep. #626, at 5 (emphasis in original). There was a similar failure at Shalom in September 2018, with the MRC finding that "**[t]here does not appear to be a medication notation in the September 2018 kardex, neither are there nursing notes in the days post hospitalization**." *Id.* at 6 (emphasis in original). The MRC also found that the "medical record did not reflect nursing progress notes from January to May 2019." *Id.* at 8. The MRC found that there was "no evidence found of documents or nursing progress notes evidencing follow-up or studies done" post-gastroenterologist consult, even though the participant had experienced respiratory difficulty, gastrointestinal bleeding, a urinary tract infection, chronic gastritis, as well as, presenting in several different months, "coffee-ground" or "coffee-brown" emesis, which typically indicates that there is blood in the vomit. *Id*. at 5-6. As for the root cause analysis, the MRC concluded that there was a "[f]ailure to Follow-up. Discharge orders were not followed resulting in avoidable hospitalizations and increased morbidity for the participant." *Id*. at 9. The MRC concluded that there were multiple hospitalizations for the same problem, "secondary to non-completion of treatment, and lack of follow-up, resulting in increased morbidity adding to the burden which resulted in the participant[‘s] demise." *Id*. The MRC found that Shalom's "failure to consult with specialists resulted in the referrals to the hospital … Had the specialists been consulted the health problems could have been treated and resolved obviating the need to hospitalize." *Id*. Finally, the MRC concluded that JASC was receiving "many medications which were not supported by recent diagnoses." *Id*. at 10.

- For RFL #491, the MRC reported on December 12, 2019, that the Shalom "Primary MD/Internist could have [] dealt with the participant[‘s] altered HDL, LDL levels which most probably contributed to the participant[‘s] demise." MRC Rep. #491, at 7. The MRC added that "[o]ptimization of medications … could have improved the participant[‘s] cholesterol/HDL/LDL profiles quite possibly improving his chances of surviving a myocardial infarct." *Id*. at 8. The MRC concludes that the order at Shalom for "PRN restraints should not have been allowed" as they are "legally forbidden and when used result in unnecessary morbidity." *Id*. The MRC also found that there was a "[f]ailure to consult with specialists. Gastroenterology should have been consulted … [and] A Pulmonologist should have been consulted to assess if any damages to the lungs had resulted from the aspirations and to follow the participant'[s] progress." MRC Rep. #491, at 7. The MRC recommended that Shalom personnel should "[c]onsult specialists in all instances as this will reduce the need to hospitalize[] [the participants] and [will] improve the services of the institution." *Id*. at 8.

- For CQO #788, the MRC reported on February 2, 2020, that, although the actions of Shalom staff did not contribute to his death, there was no record at Shalom of CQO's medical history and physical examination, the diagnoses on his chart were not updated or substantiated, CQO was taking medications "whose utility had not been updated or had been continued unnecessarily," laboratories "should have been performed periodically," and even though CQO was non-ambulatory, there were no Position Change sheets in his record for several months at Shalom prior to his death. MRC Rep. #788, at 3, 4, and 7.

In light of these concerning events regarding the well-being of participants at Shalom, the Commonwealth's decision to institutionalize JPL in this setting is all the more problematic.

III. The Commonwealth's Plan for Opening New Community Homes Is Inappropriate and Insufficient

As referenced above, given the Court's concerns about recent transfers to private institutional settings, including the transition of JPL to Shalom, the Court, in its Institutionalization Order, directed the Commonwealth to develop and implement a plan for community homes that "can effectively address the needs of all participants, including those who need around the clock attention and care as does participant [JPL]." Institutionalization Order at 2. The Court specified that this plan "must include the opening of new homes" and "must address the immediate transfer of institutionalized participants back to community homes." *Id.* at 2, 3. As referenced above, the Court ordered the United States to file comments on the plan after it was filed. Order, July 22, 2020, ECF No. 2965.

The Commonwealth filed its "Plan for New Community Homes" in late July. There is language in the Commonwealth's plan, primarily in the introductory sections, with which we agree. But those statements of principle are not matched by the detailed operational aspects of the plan, which are incomplete and misguided in many key respects, and certainly are inconsistent with the earlier principled statements. As such, the United States cannot endorse the Commonwealth's plan. The areas of agreement and disagreement are detailed below.

Areas of Agreement. The United States agrees with the over-arching statements in the plan, set forth immediately below, that speak to the importance of ensuring participants' overall well-being and dignity, the need to deliver quality services, the importance of community integration and social opportunities, and the need to overcome obstacles and challenges that confront participants in general society.

- The Commonwealth asserts that it is "committed to providing quality services aimed at promoting the overall well-being of each of its participants."

- The Commonwealth states that it wants to provide people with ID with "social opportunities for their development … [with an aim] to promote an image focused on their skills, humanism and nobility."

- The Commonwealth seeks to "establish the necessary support so that the process of social integration for the participant with [ID] has positive results." The Commonwealth states that "it is important to emphasize that in order to advance in social integration the service program to be offered must be linked with the community's activities. It is imperative to keep in mind that the services should be integrated with the issues concerning society in order to promote the connection between the person and his/her community."

- To promote social inclusion, the Commonwealth recognizes that "[i]nclusion can be measured from the participation and access that allows [participants] to break the physical barriers that make difficult social integration."

- The Commonwealth states that "[w]ithout participation and inclusion in society it is not possible to decipher quality of life, whose main indicator is participation of the population with ID in the society with equal rights."

- The Commonwealth seeks to promote participants' emotional well-being, close relationships and "feeling loved," material well-being, personal development, physical well-being, self-determination, and social inclusion, while protecting their rights.

- The Commonwealth asserts that it will "highlight [participants'] human condition and dignity, safeguard human and civil rights, and promote opportunities for equality in the community through a support system based on the population's needs throughout its life cycle."

- The Commonwealth states that "many obstacles are generated by the very society which is designed to facilitate the functioning of an average individual," whereas, with the "current social structure, the limitations of the population with ID are accentuated and the possibility of developing an independent life continues to be a challenge that demands great attention."

Commonwealth Plan at 4, 5, 6, 9, 10, and 12.

The Commonwealth's plan also includes language that stresses the need for adequate community health care services, even for those with complex conditions, so as to safeguard their health and well-being. The United States supports that position, as well as the specific statements in the Commonwealth's plan, set forth immediately below.

- To promote physical well-being, the Commonwealth highlights the need for "health care (preventive, general, home …)."

- The Commonwealth "affirms that [DSPDI] shall foster quality service and … safeguard[] the health and integral well-being of the population with [ID] in Puerto Rico."

- The Commonwealth pledges to provide services "in a dignified manner" where "regardless of how compromised a person's clinical and medical condition is, [staff] never cease in their efforts to offer quality of life to their residents."

Commonwealth Plan at 8, 9, and 26.

The Commonwealth's plan also promotes services and supports that will help participants achieve greater autonomy and independence in the community. The United States supports that position, as well as the specific statements in the plan, set forth immediately below.

- The Commonwealth strives to give "value to [participants'] capabilities, creating opportunities by promoting autonomy and self-determination."

- The Commonwealth pledges to direct its "efforts, through coordinated actions, to the full development of [participants'] personal capacities and social skills in order to achieve greater autonomy and independence, which will allow an optimal level of functioning in society."

- The Commonwealth reports that it seeks to "facilitate active participation in the community, access to employment in certain modalities and the development of autonomy" and that it is "focused on highlighting the capabilities and skills of the person with [ID]."

Commonwealth Plan at 4, 5, and 10.

Consistent with stressing the importance of independence, autonomy, and self-determination, the Commonwealth specifically embraces the concept of Person-Centered Planning, which has long been a generally accepted standard across the United States and is included in CBSP § II.A.1. Person-Centered Planning places the interests of the person with disabilities at the fore and then develops and implements a plan to build an array of services and supports around the person in the community according to the person's needs and preferences.

The United States supports Person-Centered Planning, as well as the specific statements in the Commonwealth's plan, set forth immediately below.

- The Commonwealth asserts that "when we speak of independent living, we are referring to the person deciding about those situations that concern, worry and interest him/her. Issues related to their expectations and desires. In other words, that the person takes control of his/her own life."
- The Commonwealth endorses "Person-Centered Plans (PCP) according to real capabilities and growth potential."
- The Commonwealth's plan presents quality of life as "a concept identified with a movement in progress, innovation and change in professional practices and services that fosters person-centered actions."
- As part of promoting personal development, the Commonwealth emphasizes "participation in [participants'] own PCP." To promote self-determination, the Commonwealth stresses the importance of a "personal life project … choosing and having options [with] goals and values, preferences and personal interests … [a]utonomy as a fundamental right … [that] allows [participants] to organize their lives on matters that interest them."
- The Commonwealth states that it wants to "support [participants'] life projects … to their singular desire of happiness."

Commonwealth Plan at 4, 6, 9, and 10.

In the context of JPL's recent transfer determination, however, there was no emphasis on the importance of community integration and social opportunities, no emphasis on the need to overcome obstacles and challenges to meet JPL's needs in the community, no emphasis on the need to provide him with adequate and proactive health care in the community even with his complex conditions, no emphasis on the need to promote JPL's autonomy and independence, and no emphasis on the need to engage in a Person-Centered Planning process where self-determination was valued, JPL's needs and preferences were a priority, and services were built around him in the community.

As referenced, the Commonwealth's positive principled statements, set forth above, did not then become incorporated into a worthy community homes plan. Overall, the operational aspects of the plan conflict with established, evidence-based practice models in the DD field. We set forth a few examples of this below.

Areas of Disagreement. The Commonwealth seeks to segregate participants by age and by disability level "according to their essential characteristics and functioning levels." Commonwealth Plan at 6. The Commonwealth reports that its plan strives to place people with ID into community homes "with as much homogeneity as possible" and that the plan overall is guided by focusing on functional differences, "the different stages of development, and the differences in cognitive and adaptive abilities of the population with [ID] ascribed to the DSPDI." *Id*. at 5. The Commonwealth reports that its plan is "based on the analysis of statistical data … in regard to: the demographic universe and composition of the population, the scales of severity of [ID] and its inherent practical functioning." *Id*. The Commonwealth's plan seeks to create senior homes, transitional homes, and other stratified homes. *Id*. at 16-17.

This plan proposal is inconsistent with Person-Centered Planning because it segregates and stratifies participants based on their age and disability rather than their preference. In a Person-Centered Planning process, the person with a disability is the focus of planning, and that person, along with those who know him best, such as loved ones, are the primary authorities on his life direction.[2]

The Commonwealth's top-down approach of forcing people into residences with others who are of similar ages and/or have similar disability levels is inconsistent with the bottom-up

---

[2] *See generally* Angela Novak Amando, Ph.D. and Marijo McBride, E.Ed., *Increasing Person-Centered Thinking: Improving the Quality of Person-Centered Planning*, Inst. on Cmty. Integration, Univ. Affiliated Program, Univ. of Minn. (2001); Michael W. Smull and Helen Sanderson, *Essential Lifestyle Planning for Everyone*, The Learning Cmty. (2005).

Person-Centered Planning approach where the person-centered plan, based on the individual's needs and preferences, is a critical component in determining how and where a person receives appropriate services.

To put this in more concrete terms, participants should not have to leave their homes because they reach a certain age (age 50 or 60, per the Commonwealth's plan) or experience a health decline. As determined through Person-Centered Planning, a participant may want to stay in his current community home with his friends, and have services and supports provided there. That would be impossible if the Commonwealth's plan were implemented, because DSPDI officials would decide where participants live and with whom, based on segregating people by their perceived level of disability or age, and not on more individualized criteria. Instead, the Commonwealth's system should operate to *put the person first*. This construct – the Person-Centered Planning process – has been the generally accepted practice model throughout the country for decades and is a component of the CBSP.[3]

Unfortunately, the Commonwealth also seems to endorse the use of a "continuum" of services in a "step-down" model, with participants receiving services in "transitional homes" where they are to "develop and strengthen [their] personal and social skills" as a "transition step" towards eventual life in the community. Commonwealth Plan at 8-9. This step-down approach, through a continuum of services, was rejected by the DD field decades ago as unworkable and unnecessary. Instead, it is generally accepted that individuals can transition directly from an

---

[3] Analogous to our discussion here, in its recent report, the Center for Developmental Disabilities Evaluation and Research (CDDER) correctly challenged the false assumption that it is proper to treat participants in stratified groupings all the same. *See* CDDER Rep., July 15, 2020, ECF No. 2942-1, at 14 (asserting that "people who are identified as having 'severe' IDD or 'profound' disabilities should not be automatically deemed unemployable and excluded from employability screening").

institutional setting to a truly integrated community setting, when supported by an appropriately individualized array of services and supports to meet their needs. There is no need, and no justifiable basis, for forcing people with disabilities to move from an institution to a quasi-institutional site then to a quasi-community site and then to a truly community site. The false assumption that the person needs to acquire skills at the various step levels before moving to the community has been discredited for years. *See generally Disability Advocates, Inc. v. Paterson*, 653 F. Supp. 2d 184, 251-54 (E.D.N.Y 2009) (summarizing evidence that this approach is unnecessary, ineffective, and largely abandoned) (vacated on other grounds).

Finally, there are no operational timetables and no deadlines set forth in the plan. An effectively working plan is one that includes and implements reasonably specific and measurable goals for addressing the unnecessary institutionalization by target dates. *Frederick L. v. Dep't of Pub. Welfare of Pa.*, 422 F.3d 151, 157-58 (3d Cir. 2005)). Such goals should be "not only measurable, but strategically tailored to make a significant impact in the lives of individuals with disabilities across the state." *Jensen v. Minn. Dep't of Human Servs.*, 138 F. Supp. 3d 1068, 1072 (D. Minn. 2015).

IV. United States' Response to the Commonwealth's Filing on the Court's Institutionalization Order

In its response to the Court's Institutionalization Order, the Commonwealth argues that the Supreme Court's decision in *Olmstead v. L.C.*, 527 U.S. 581 (1999) does "not prohibit the institutionalization or re-institutionalization of participants whom the DSPDI's clinical professionals have reasonably determined would not benefit from a community-based placement or require attention that cannot be properly given in such a setting." Commonwealth Resp. at 2. The Commonwealth then asserted that it "*takes issue*" with the Court and the way the Court's order "characterizes *Olmstead*." *Id*. at 3 (emphasis added). But the Commonwealth's filing makes clear that it is the Commonwealth that errs in applying *Olmstead* and the Americans with Disabilities Act (ADA), 42 U.S.C. §§ 12101 *et seq*., which *Olmstead* interpreted.

As set forth below, *Olmstead* and the ADA are centrally focused on promoting integrated community services for people with disabilities, not facilitating institutionalization and segregation of people with disabilities.

A. The ADA and Its "Integration Mandate"

In 1990, Congress enacted the ADA "to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities." 42 U.S.C. § 12101(b)(1). In passing this law, Congress recognized that "historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem." 42 U.S.C. § 12101(a)(2). For those reasons, Congress prohibited discrimination against individuals with disabilities by public entities: "[N]o qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity." 42 U.S.C. § 12132. As directed by Congress, the Attorney General issued regulations implementing Title II of the ADA, which are based on regulations issued under Section 504 of the Rehabilitation Act. *See* 42 U.S.C. § 12134(a); 28 C.F.R. § 35.190(a). The ADA's Title II regulations require public entities to "administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities." 28 C.F.R. § 35.130(d). The preamble discussion of the "integration regulation" explains that the "most integrated setting" is one that "enables individuals with disabilities to interact with nondisabled persons to the fullest extent possible …" 28 C.F.R. Pt. 35, App. A (2010).

B. The *Olmstead* Opinion

In *Olmstead*, the Supreme Court held that Title II of the ADA prohibits the unjustified segregation of individuals with disabilities. The Supreme Court explained that this holding "reflects two evident judgments." First, "institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life." Second, "confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment." *Id.* at 600-01.

For decades now, because of the ADA and *Olmstead*, jurisdictions all across the country have been working to move people with developmental disabilities and other disabilities from institutional settings to integrated community settings.

Indeed, the Commonwealth's decision to institutionalize participants is at odds with the fact that people with developmental disabilities, like JPL, with similar complex health conditions, have been living successfully in the community all across the country for decades. Longitudinal and other studies looking at data going back to the 1970s demonstrate that people with complex conditions can not only live successfully in the community, but they typically fare *better* than those who are institutionalized. *See, e.g.*, James W. Conroy & Valerie J. Bradley, *The Pennhurst Longitudinal Study: A Report of Five Years of Research and Analysis*, 187 (1985) (finding that "the people [with developmental disabilities] with the most severe impairments turn out to be among those who benefit the most from community placement").

C. The Commonwealth's Position Misconstrues *Olmstead*

In its filing, the Commonwealth does not acknowledge that the fact pattern in *Olmstead* is exactly the opposite of the situation that faced JPL and the other participants with developmental disabilities who have been institutionalized. In *Olmstead*, the State of Georgia refused to provide services enabling two women with disabilities who wanted to move *from an institution* to the community to do so; in the instant case, the Commonwealth insists on moving JPL and the other participants with disabilities from the community *to an institution*, without giving them the option to remain in the community if that placement is appropriate for them.

When JPL and the others later institutionalized were living in the community, and as the Commonwealth contemplated how to serve them, they were already protected by the ADA as individuals who were at serious risk of institutionalization. This is not a novel assertion: every court of appeals to have addressed this issue has recognized that Title II of the ADA applies to persons with disabilities who are at serious risk of institutional placement. *See Steimel v. Wernert*, 823 F.3d 902, 911-12 (7th Cir. 2016) (rejecting the argument that the integration mandate applies only to people who have been institutionalized); *Davis v. Shah*, 821 F.3d 231, 263 (2d Cir. 2016) ("[A] plaintiff may state a valid claim for disability discrimination by demonstrating that the defendant's actions pose a serious risk of institutionalization for disabled persons"); *Pashby v. Delia*, 709 F.3d 307, 322 (4th Cir. 2013) (finding that individuals who must enter institutions to obtain needed services "may be able to raise [a] successful Title II … claim[] because they face a risk of institutionalization"); *M.R. v. Dreyfus*, 697 F.3d 706, 734 (9th Cir. 2012) ("An ADA plaintiff need not show that institutionalization is 'inevitable' or that she has 'no choice' but to submit to institutional care in order to state a violation of the integration mandate. Rather, a plaintiff need only show that the challenged state action creates a serious risk of institutionalization"); *Fisher v. Oklahoma Health Care Auth.*, 335 F.3d 1175, 1181-82 (10th Cir. 2003) (rejecting the argument that individuals with disabilities who "stand imperiled with segregation may not bring a challenge to state policy under the ADA's integration regulation without first submitting to institutionalization").

As these courts concluded, the ADA's integration mandate would be meaningless if people with disabilities, like JPL and the others, were required to segregate themselves by entering an institution before they could challenge an allegedly discriminatory law, policy, or action that threatens to unnecessarily force them into an institution.

The Commonwealth further misconstrues *Olmstead*, arguing that it may rely solely on the determinations of its treatment professionals to institutionalize JPL and the other participants, Commonwealth Resp. at 3, and cites to the recommendation of the treatment physician and to the conclusions of "DSPDI professional staff" that JPL had to relinquish his life in the community and become institutionalized in order to access needed health care and other services. *Id*. at 4. *See also* Commonwealth Mot., July 21, 2020, ECF No. 2961, at 1 (asserting that institutional placements are appropriate in large measure because "all cases [have] been justified based on the reasonable assessment of the DSPDI's clinical professionals").

But courts have repeatedly held that, in determining whether an individual can appropriately receive services in the community, the determinations of the state's treatment professionals are not controlling. *See United States v. Mississippi*, 400 F. Supp. 3d 546, 551 (S.D. Miss. 2019) (finding that, if establishing a case required reliance on the government's own treatment professionals, jurisdictions could circumscribe the requirements of Title II of the ADA). *See also Disability Advocates, Inc. v. Paterson*, 653 F. Supp. 2d at 258-59 (vacated on other grounds) (finding that plaintiffs need not provide determinations from state treatment professionals to demonstrate that they are qualified for community placement and noting that holding otherwise would "eviscerate the integration mandate"); *Long v. Benson*, No. 4:08cv26, 2008 WL 4571904, at *2 (N.D. Fla. Oct. 14, 2008) (noting that the right to receive services in the community would become illusory if the state could deny the right by refusing to acknowledge the appropriateness of community placement); *Joseph S. v. Hogan*, 561 F. Supp. 2d 280, 290-91 (E.D.N.Y 2008) (rejecting the argument that the state's treatment professionals must be the ones to make an appropriate determination); *Day v. District of Columbia*, 894 F. Supp. 2d 1, 23-24 (D.D.C 2012) (recognizing that plaintiffs need not prove the public entity's treatment professionals have determined eligibility for community services and noting that "lower courts have universally rejected the absolutist interpretation proposed by defendants"); *Frederick L. v. Dep't of Pub. Welfare of Pa.*, 157 F. Supp. 2d at 540 (finding that states cannot avoid the integration mandate by failing to make recommendations or community placement).

Instead, an individual participant may rely on a variety of forms of evidence to establish that an integrated setting is appropriate. Accordingly, contrary to its assertions, the Commonwealth failed to act in accord with *Olmstead* when it rushed JPL to an institution based solely on what its treatment professionals said, without considering any evidence from JPL or others.

V. Conclusion

The United States asks that the Court take note of the United States' response to the Court's order and to reject the arguments set forth in the Commonwealth's motion on institutionalization and *Olmstead*, and to take note of the United States' comments on the Commonwealth's plan for opening new community homes.

Respectfully submitted,

FOR THE UNITED STATES:

STEVEN H. ROSENBAUM
Chief
Special Litigation Section

BENJAMIN O. TAYLOE, JR.
Deputy Chief
Special Litigation Section

/s/ Richard J. Farano
RICHARD J. FARANO
District of Columbia Bar No. 424225
Senior Trial Attorney
United States Department of Justice
Civil Rights Division - Special Litigation Section
4 Constitution Square
150 M Street, NE – Suite 10.133
Washington, DC 20530
Telephone: (202) 307-3116
richard.farano@usdoj.gov

CERTIFICATE OF SERVICE

I hereby certify that on August 14, 2020, I electronically filed the foregoing document with the Clerk of the Court using the CM/ECF system, which sent notification of such filing to all counsel of record.

/s/ Richard J. Farano
RICHARD J. FARANO
Senior Trial Attorney
United States Department of Justice