

# JCC SEMI-ANNUAL REPORT UNITED STATES V. PUERTO RICO 99-1435 (SCC) MARCH 2022

Joint Compliance Coordinator Team



# **Certification**

I, Alfredo Castellanos, Esq., in my independent capacity as Joint Compliance Coordinator ("JCC" and/or "Federal Monitor") hereby certify that the present March 2022 Semi-annual Report has been prepared by the undersigned discharging my duty to evaluate the Commonwealth of Puerto Rico's ("Commonwealth") progress in complying with existing consent decrees and other court orders in this case and, when warranted, to recommend action plans that if adopted and implemented, will help the Commonwealth to ultimately accomplish sustainable compliance. The present Semi-annual Report was prepared with the input and contributions of the following party-stipulated experts, subject-matter experts, and JCC team experts (collectively referred to as "Experts"):

- Ms. Emily Lauer and her team of experts at the University of Massachusetts/CDDER;
- Dr. Serena Lowe (AnereS Strategies, LLC); and
- Dr. Roberto Blanco, M.D. (affiliated with the University of North Carolina (Chapel Hill), currently on temporary leave).

The following members of the JCC Team contributed to this Report:

- Dr. Dimaris García, Psy. D. (Psychologist and JCC Team Expert);
- Dr. Carmelo Rodríguez, Psy. D. (Psychologist and JCC Team Expert);
- Ms. Diana Alcaraz, Esq./CPA (Court-appointed Special Investigator and Legal Advisor to the JCC);
- Mr. Salvador M. Carrión, Esq. (Legal Advisor to the JCC);
- Ms. Tirsa Sosa, MSW (Social Worker and Ex-Director of the Bayamón CTS/Daily Center).
- Ms. Jeannie Castillo (Administrative Assistant/ Expert Liaison with Participants); and
- Mr. Javier González (Executive Director of the Office of the JCC and Monitor in Management).

Alfredo Castellanos, Esq. JCC/Federal Monitor



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"The JCAP constitutes the culmination of months of intense discussion, review and evaluations between the United States Department of Justice, the Commonwealth Department of Health, and the Court Monitor..., the Court now expects the Commonwealth to fully and readily comply with the JCAP".

- Hon. Gustavo A. Gelpí Order Adopting the Joint Compliance Action Plan. August 19, 2011

## I. Introduction

The Federal Monitor's Office is pleased to submit its seventh Semi-annual Report ("Report") to the Court, the United States, the Commonwealth and its Division of Services for Adults with Intellectual Disabilities ("DSPDI") on the Commonwealth's compliance with existing orders in this case and with the party-stipulated Benchmarks, which is a working document prepared by the Parties to help us evaluate the Commonwealth's progress and compliance with the Joint Compliance Action Plan ("JCAP", also referred to as "Consent Decree") and the Benchmarks. The present Report covers the period of July 1, 2021 to December 31, 2021.

From the outset, the JCC wants to acknowledge that the Commonwealth of Puerto Rico, through its Department of Health and the DSPDI, has **significantly progressed** in many Benchmark areas when compared to the JCC's September 2021 Report.

The JCC would like to commend the efforts of the DSPDI's Compliance Officer, Mr. David Rodríguez Burns, Esq., for the manner in which he has diligently organized and furnished the information that the Office of the JCC requested for the present Report. The JCC would also like to commend the efforts of the Auxiliary Secretary of Family Health, Integrated Services and Health Promotion of the Puerto Rico Health Department, Dr. Marilú Cintrón Casado, who has continued to maintain constructive communication with the Federal Monitor's Office, particularly after the change of the DSPDI's previous Director. The efforts of these two officials have positively impacted the DSPDI's progress over the past six months.

Finally, we would also like to recognize the positive and constructive working environment created by the Governor of Puerto Rico, Hon. Pedro Pierluisi and his Secretary of Health Carlos R. Mellado; without their direction, none of the progress in recent months would have been possible.

Consistent with the directives of the Court, after receiving input from USDOJ and, for the first time ever since the undersigned has been Monitor in the present Consent Decree, receiving written comments from the Commonwealth, the Office of the JCC has adopted a constructive modification to our previous



assessment approach.<sup>1</sup> First, we are going to focus on all of the non-outcome Benchmark provisions; these are generally process-oriented items that are more easily achieved as compared to the outcome Benchmark provisions (such as those requiring the Commonwealth to meet individualized participant needs). There are 57 non-outcome and 49 outcome provisions in the Benchmarks.

The undersigned opines that with the above approach, the Commonwealth will make significant progress in achieving compliance with the vast majority of non-outcome provisions and that this will generate positive results that we expect will carry over to our review of the outcome provisions in our next Report.

In addition to evaluating progress on compliance, the JCC proposes that a six-month action plan be developed within 45 days in collaboration with the DSPDI to outline specific review activities and the provision of technical assistance ("TA") by the appointed Experts in a number of mutually-agreed upon priority areas. The primary purpose of the above six-month plan is to establish a productive mechanism for assisting the Commonwealth in reaching higher compliance levels in both outcome and non-outcome measures in a more expeditious manner to improve the safety and well-being of participants.

## Six-Month Work Plan

As mentioned above, in addition to assessing and work upon progress on compliance, the JCC recommends the adoption of a six-month work plan that outlines priority areas mutually agreed to with the DSPDI and in alignment with priorities set forth during the last Status Conference by the United States Department of Justice ("USDOJ"), with specific deadlines, to allow the Experts to conduct indepth reviews and to provide technical assistance in a number of critical areas to assist the DSPDI reach compliance as they relate to outcome Benchmarks.

In order to work in a more efficient and productive manner, the JCC Office and the Experts met with the DSPDI to identify priority areas (which will cover a broad number of Benchmarks). Identified key priority areas include:

- High Risk Population and Polypharmacy;
- Independent Living;
- De-Institutionalization; and
- Employment/Job Placement.

Our intention is not to diminish the importance of other areas, but rather to put a clear focus on certain important and time-sensitive areas that both the DSPDI and the Experts agree are vital to continual progress and where compliance has remained elusive. This work plan will emphasize core opportunities to advance the DSPDI's consented objectives and to significantly accelerate compliance with party-

<sup>&</sup>lt;sup>1</sup> One of the main reasons for the above modification is because after approximately 23 years of following the same evaluation and assessment methods to ascertain the DSPDI's progress, the JCC felt compelled to recommend the creation of a new sixmonth work plan that has proven to generate better results in other jurisdictions in the United States.



stipulated Benchmarks, the JCAP and existing court orders. In each of these areas, a strong focus on strategies to enhance capacity building, provider transformation, and participant health optimization will be emphasized within the TA that will be furnished.

Based on the prior experience of the Experts and the obstacles that the DSPDI has confronted in reaching compliance with the Agreement, the JCC and all named Experts are of the opinion that this is the most effective way to assist the Commonwealth in reaching compliance in these very important areas.

If the Commonwealth works diligently to address any outstanding issues identified during the review and uses the Experts' technical assistance, the JCC is confident that the DSPDI will be able to make prompt and significant progress towards compliance. After the initial six-month work plan is complete, and if significant compliance levels are reached, the undersigned intends to recommend that the same method that was used in the initial six-month plan be incorporated as a joint working method with the DSPDI in other outcome areas until all sections of the Benchmarks and the JCAP are fully addressed. Once worked upon, a meticulous Benchmark-per-Benchmark compliance assessment will be conducted to see if the Commonwealth has reached compliance, partial compliance or no compliance, as done in the past.

It is imperative to mention that the JCC will ensure that nothing in the work plan puts unreasonable expectations on the Commonwealth that exceeds or distracts from the mandates of the JCAP or any of the existing court orders, especially when rendering compliance assessments in the next reports. Furthermore, any departure from the JCAP mandates will trigger an immediate notification to the Parties and if warranted, in our discretion, a notification to the Court.

# II. JCC Progress Evaluations and Recommendations Regarding Non-Outcome Measures

#### a. Community Placement from Institutions

Following an evaluation of the non-outcome measures that correspond to the initial Benchmarks and to the ones in the Community Placement from Institutions section of the JCAP (Benchmarks Nos. 1-10), the Federal Monitor's Office is satisfied with the progress that the DSPDI has achieved since our last Report. For example, the Commonwealth has translated the Benchmark document into Spanish and disseminated it to pertinent personnel, created a Master List and sub-lists of participants, issued a policy that all institutionalized participants can be successfully transitioned to the community with adequate support and services, and formulated Individual Community Transition Plans ("ITPs") for the participants; we are currently reviewing these documents to assess if they are adequate and complete. Nevertheless, more work needs to be done with regard to a few items that the undersigned will subsequently illustrate.



For instance, although the DSPDI has prepared separate lists of all participants that reside in institutions and all participants that live in integrated community settings (see Benchmarks No. 4 and 13), these lists do not include participants that reside in highly congregate settings,<sup>2</sup> such as the homes operated by the Administration of Health Services and Against Addiction ("ASSMCA" for its Spanish acronym) and the Department of Family Affairs ("DFA").<sup>3</sup>

Although the JCC has requested that the DSPDI include data and information on participants that reside in such congregate settings in the aforementioned lists, the DSPDI has objected to our request. The above objection is deeply concerning to the undersigned as all participants in ASSMCA and DFA homes are included in this case, and all are afforded the protections set out in the Consent Decree and other court orders in this case. See, e.g., JCAP Section III.1.D (specifically referencing that the Commonwealth must provide services to "participants who currently reside in mental homes, ASSMCA homes, or other settings that may not be truly integrated").

The JCC notes with great concern that, unfortunately, most of the participants in these residences do not receive the same level of services as participants that reside in integrated DSPDI community homes. The JCC has identified at least three participants in non-DSPDI homes that are only receiving limited services from social workers and nurses. All residential settings with participants, including ASSMCA and DFA homes, are covered in the JCAP and should be fully analyzed to ensure, among other things, participants' safety, and well-being. Moreover, these highly congregate homes possess institutional elements and are typically overcrowded with a dozen or so individuals living under one roof, and often are not truly integrated in the community.

Provided that the DSPDI has issued a policy directive that all institutionalized participants can live in the community with adequate supports and services as set forth in Benchmark No. 5, participants living in congregate ASSMCA and DFA settings are similarly entitled to live in integrated community homes just like their institutionalized brethren. We noted our serious concern regarding the above congregate home settings in our previous Semi-annual Report. The JCC recommends that if said reality is not promptly addressed and corrected, an on-site inspection with the Court may be warranted.

Notwithstanding the above, the JCC commends the DSPDI for developing written ITPs for each participant residing in an institution (see Benchmark No. 6).<sup>4</sup> The above is a very important step towards reaching compliance with this very important JCAP mandate. Additionally, the Office of the JCC is working with the Commonwealth to obtain needed information to evaluate whether the ITPs were completed as part of an evidence-based Person-Centered Planning ("PCP") process (as mandated by the

<sup>&</sup>lt;sup>2</sup> In previous Semi-annual Reports, the JCC has interchangeably referred to the above congregate home settings as *institution-like settings* and overcrowded homes. It is important to note that the above terminology was never objected in any of the previous Reports by the Parties. Please see JCC September 2019 Report, Docket No. 2610, at pages 7-8 and 14; JCC March 2021 Report, Docket No. 3493-1, at page 14; and JCC September 2021 Report, Docket No. 3548, at page 16.

<sup>&</sup>lt;sup>3</sup> As of the preparation of the present Report, 91 out of 639 participants remain in institutions and highly congregated settings. These are distributed as follow: 73 in two institutions and 18 in about 12 congregate settings throughout the Island.

<sup>&</sup>lt;sup>4</sup> Participants residing in highly congregated settings from ASSMCA and DFA also have the *Therap* Phase I ITP prepared.



JCAP), given that, after a careful evaluation, the JCC has concluded that several ITPs were incomplete (some of the ITPs had sections that remained blank).<sup>5</sup> As such, we will conduct an additional evaluation of the current approach being used by DSPDI and its staff and we are optimistic that any deficiencies in the same can be resolved with the proper technical assistance. The result of our evaluation will be included in our next JCC Report.

In order to achieve compliance with the above Benchmarks, the JCC recommends that the DSPDI first ensure that all ITPs are completed in their entirety. The JCC recommends that the DSPDI establish a protocol for ITP preparation, including requirements and timeframes for contacting the participants' family members, as well as to locate any family members or custodians that the DSPDI has not been able to reach in order to include them in the preparation of the participants' ITPs. It will be necessary to define the particular criteria for certifying the completion of an ITP when contact with family members and/or custodians was not achieved. Said information will be monitored by the JCC Office.

Moreover, the Office of the JCC applauds the Commonwealth for taking our recommendation and pursuing a technical assistance grant from the National Center for the Advancement of Person-Centered Practices and Systems ("NCAPPS"). We understand that Puerto Rico was one of a select few jurisdictions across the United States to be awarded this grant. The JCC recommends that the DSPDI take advantage of the technical assistance available through NCAPPS to inform any changes and new strategies that need to be embedded within the ITP preparation process to assure the approach being used is reflective of evidence-based person-centered planning practices and complies with the JCAP mandate.

The JCC further notes that upon following up on the status of the technical assistance to be provided by the NCAPPS, we have learned that the DSPDI has submitted plans regarding the *Therap* Personal Focus Worksheets ("PFWs") and the protocol for Individualized Support Plans ("ISPs") for the NCAPPS review and comments. However, the above documents cannot be reviewed by the NCAPPS because a Technical Assistance Plan ("TA Plan") has not yet been established.

The DSPDI's team on the project decided that they would like to draft the TA Plan, however, this plan has not been shared with NCAPPS team. The documents submitted by the DSPDI to NCAPPS will only be reviewed once the TA Plan is in place, and once NCAPPS is able to review the scope of Technical Assistance that is being requested and have identified a Subject Matter Expert to do the review. The JCC recommends that DSPDI afford the NCAPPS team an opportunity to review and assess the Commonwealth's existing PCP process and provide support to the development of the TA Plan so as to expedite the process and in order to obtain the desired objective.

<sup>&</sup>lt;sup>5</sup> For example, the Office of the JCC found nine ITPs that were "completed" without having involved the participants' family members, which is an essential component of PCP. The JCC also found some ITPs where important information was missing such as: the institution placement date, the person who provided orientation to the participants' family, the specific level of support required for the participant (behavioral, physical, etc.), nutritional evaluations, the participant's level of functionality, and the Referral date to Admission, Transfer and Discharge Committee ("CITE" for its Spanish acronym) after having determined that the participant should be placed in a community home, among others.



Moreover, and in relation to the above concerns, the DSPDI is strongly encouraged to meet with the Commonwealth of Puerto Rico's Council on Developmental Disabilities and seek their assistance to:

- a) Create listening sessions with family members to better understand the challenges families are facing in securing adequate supports for participants to live, work and thrive in integrated communities;
- b) Establish a family peer supports network, connecting families of participants who have successfully transitioned from institutions to community living with families of participants in congregate or institutional settings who are considering a return to the community;
- c) Develop additional educational processes, materials and programming to improve family engagement in the implementation of participant ITPs;
- d) Advise the DSPDI on recommended programmatic enhancements and policy reforms that would improve access to higher quality home and community-based services for participants who are currently institutionalized and those living in other congregate settings; and
- e) The Office of the JCC and its team, particularly subject-matter expert Dr. Serena Lowe, is always available to assist the DSPDI whenever our assistance is sought in objectives concerning third parties and/or different Governmental Agencies.

Subject-matter Expert Dr. Lowe can help arrange for the meeting with the Council when DSPDI's leadership is ready to pursue a dialogue.

Furthermore, as is required in the JCAP, and as the JCC has previously recommended multiple times in the past (including in monthly meetings and reports), the DSPDI should arrange in-person tours of community residential units for family members of participants identified to transition out of institutional care.<sup>6</sup> Indeed, per the JCAP, the Commonwealth is even to arrange for visits to homes with an open bed for possible use by the participant. Failure to offer a home with an open bed coupled with the families' lack of knowledge regarding the current array of direct services that participants may receive in these community residential settings prevents families and guardians/custodians from taking advantage of the benefits of community living.

The JCC also stresses the continuing importance of notifying our Office of upcoming transfers so that we can adequately and effectively monitor the transitions and provide timely recommendations.<sup>7</sup> Although we are happy to see that they have recently renewed the above notifications, we expect them to continue doing so until compliance in the relevant areas has been met.

<sup>&</sup>lt;sup>6</sup> The above efforts should have commenced over ten years ago and due to the JCC's insistence the DSPDI finally began to do so. Although the JCC notes that there has been substantial progress, we will continue to monitor the DSPDI's efforts in this regard to see if compliance has been reached.

<sup>&</sup>lt;sup>7</sup> This is important as a recent transfer involving Participant INR #156 was carried out without the corresponding ITP and without notifying the JCC. Unfortunately, the participant was transferred to a home that at the time of the transfer was not qualified to provide the specialized services that the participant requires. We remain disappointed that the treatment plan that was recommended by Expert Dr. María Margarida Juliá regarding the participant has yet to be implemented.



# b. Provider Capacity Expansion in the Community

As for the non-outcome measures that correspond to the Provider Capacity Expansion in the Community section of the JCAP (Benchmarks Nos. 13-14), the JCC notes that the DSPDI is headed in a **positive direction** and should be able to continue to progress over the course of the next six months. The JCC is satisfied with the improvement that has been obtained in the above Benchmarks.

For instance, the DSPDI has created a sub-list of all participants living in the community, specifying the name and location of each person's residential provider and the total number of individuals living in each home (see Benchmark No. 13).<sup>8</sup> The JCC is highly satisfied with the DSPDI's progress as it relates to this Benchmark.

Moreover, the JCC is very satisfied that the DSPDI has developed a system-wide plan to increase the number of community residential providers to meet participants' individualized needs, as established in Benchmark No. 14. While there is room for improvement in the plan,<sup>9</sup> it represents a solid foundation and an important step in the right direction to reaching compliance, which can be achieved by the next JCC Report.

Other achievements that highlight the DSPDI's progress with regard to the above Benchmarks include the implementation of new/increased rates for service providers, the reimbursement of hospitalization expenses, and the opening of new and specialized service community homes.<sup>10</sup>

Despite the fact that the JCC is satisfied with the progress that the DSPDI has achieved with the abovementioned Benchmarks, in our role as a "guiding hand," we are providing a few recommendations which should assist the DSPDI in reaching a compliance assessment in future, and thereafter, sustain said compliance.

<sup>&</sup>lt;sup>8</sup> The Office of the JCC recommends that the DSPDI work with *Therap Services* in order to automatize such lists for continued compliance and to guarantee the timeliness and accuracy of the furnished information.

<sup>&</sup>lt;sup>9</sup> With regard to areas of improvement, said plan: does not address participants that reside in congregate settings like ASSMCA or DFA homes; lacks essential details regarding components and specialists; and needs to provide clarification as to how they will work with participants that reside in non-specialized homes, but meet the criteria to reside in specialized homes, among others. The plan also seems to envision arbitrarily moving participants out of their community homes if they exceed a certain age or if their condition worsens. No participant should be forced from their home just because of arbitrary plan criteria. Instead, the plan needs to ensure that services and supports are brought into the existing home to meet their individualized needs without displacing any participant. To address issues of concern (like this one) at the outset, the Commonwealth, before finalizing any new policy or guideline that is created per the JCAP or the Benchmarks, should allow the Office of the JCC and the United States to review and provide input on each new policy or guideline. The Commonwealth may need to assist the United States by providing a translation of any new policy or guideline.

<sup>&</sup>lt;sup>10</sup> During the period covered in this Report, the DSPDI has signed contracts for the opening of 12 new homes, six of which opened as of December 31, 2021. Four of these contracts are intended for specialized service homes for health and behavioral management. In addition, there are 11 prospective homes that are in the pre-qualification, remodel, or contract process, which would represent a total of 89 additional living units. The Commonwealth also reports that it will open 23 additional new home sites with a total of more than 100 beds. This is a very positive development.



For instance, in order for the new specialized service models to succeed, it is critical that the specialized service homes have knowledgeable, skilled staff to ensure the successful transfer and ongoing support of any participant in the community. The DSPDI should work closely with providers to ensure the staff has adequate qualifications, training, and specialized skills in all areas related to the services and supports they deliver to participants. The JCC Experts are willing to offer recommendations on technical assistance programs that could support the training and development of the above staff, who are ultimately the Program's frontline.<sup>11</sup>

#### Immediate Rate Reassessment Recommendation

Due to the record-setting inflationary issues that are currently being confronted in the United States, including the Commonwealth of Puerto Rico, the JCC recommends that the DSPDI diligently address the above reality by commissioning a comprehensive updated rate assessment study<sup>12</sup> to guarantee that all services remain uninterrupted, including those that pertain to the existing labor market challenges, minimum wage adjustments and basic utilities expenses (i.e. food, water, electricity, and transportation costs, among many others).

As the DSPDI is fully aware, the JCC has been raising its concern over the potential interruption of services if the above updated rate adjustment study is not conducted and implemented in an expeditious manner. The above interruption of services simply cannot be an option for the DSPDI pursuant to the express provisions of the JCAP.<sup>13</sup>

Therefore, the JCC is expecting an updated rate study before the JCC September Report, as represented on numerous monthly meetings since 2021 by the DSPDI leadership and consistent with Health Management Associates' own representations regarding the need to conduct a new study that tempers to the current realities that the economy of Puerto Rico is confronting which has direct bearing and impact on all program providers. Assessing the current national average inflation rate of 8.5% and how the local labor market has transformed itself due to the labor force seeking significantly higher minimum compensation is not a matter that requires insurmountable work.<sup>14</sup>

<sup>&</sup>lt;sup>11</sup> If the DSPDI pursues federal funding to match the Commonwealth's investments in these non-segregated community living options, it is highly advised that the DSPDI work with the Experts to assure that all providers receive needed training and technical assistance to comply with the federal regulations governing home and community-based settings.

<sup>&</sup>lt;sup>12</sup> It is imperative to mention that when the first-Rate Assessment Study was prepared (based on provider information from 2019), the above issues that we are currently confronting were not present.

<sup>&</sup>lt;sup>13</sup> See JCAP, Sec. II-C. "The Court reminds the Secretary of Health that, as agreed by the parties, the services to the participants shall remain uninterrupted unless otherwise ordered".

<sup>&</sup>lt;sup>14</sup> The JCC anticipates that the inflation rate in Puerto Rico is even higher because of the realities of an economy that relies almost in its entirety on the importation of all commodities, energy sources, food, etc.



The JCC feels compelled to mention that the significant progress obtained by the DSPDI as reflected in present Report can be derailed if proper measures are not immediately taken to address the above economic changes, including shortages in the supply chain, among others.

Moreover, the DSPDI should seek additional consulting support in follow-up to the above study to design a new value-based reimbursement model to incentivize the transition of the Commonwealth's existing service delivery models to more individualized, integrated supports, such as individualized budgets for some participants in community settings. As an initial step, the JCC recommends that the DSPDI entertain the possibility of reassessing the services, service definitions, and parameters of how services are currently funded.

## c. Integrated Employment and Day Activities

After analyzing the information furnished by the DSPDI to evaluate the non-outcome measures of this area of the JCAP, the JCC is not satisfied with the Commonwealth's overall progress in this area. Although the JCC recognizes that some progress has been achieved in certain items, the fact remains that with the amount of job opportunities that currently exist in the Island, the DPSDI efforts need additional support from Experts to achieve a proper level of employment that will allow participants to move in the direction of independent living. Nevertheless, the undersigned furnishes several recommendations, which will assist the DSPDI in possibly reaching compliance levels by the time of the next JCC Report.

For instance, the DSPDI has complied with the Benchmarks that require the preparation and maintenance of lists and sub-lists of participants who are working in the community (see Benchmark No. 17); those who are currently not working in the community, but have been professionally assessed or identified as able to work in the community (see Benchmark No. 20); those who are currently not working and have been professionally assessed as not able to work in the community (see Benchmark No. 24); and those that do not work or participate in formal day program activities in a CTS (see Benchmark No. 33).

However, the non-outcome measures that require the development of concrete individualized action plans and/or professional assessments for participants on each of the above-mentioned lists (Benchmarks Nos. 18, 21, 22, 25, 26, 30, 34, and 36) still need work in order to achieve compliance. Nevertheless, the JCC finds that the DSPDI has taken important and positive steps in this area and is on the right path towards reaching compliance in future.

For example, for the first time since the adoption of the JCAP, each Transitional Service Center ("CTS" by its Spanish acronym, also referred to as Daily Centers) has a complete work team from the Vocational Rehabilitation Counseling Services Area ("ASCERV"). Each team is led by a licensed Vocational



Rehabilitation counselor and includes a Job Promoter and Job Coaches. The JCC is extremely satisfied with the above accomplishment.<sup>15</sup>

The DSPDI *Therap* Services Platform reveals positive improvements in this area as well, allowing us access to the updated information of each participant related to employment history. Through the electronic platform, a robust profile of each participant has been developed regarding their potential for employment, which can be instrumental to identifying opportunities to help participants leverage interests, skills, experience, and talents toward exploring possible employment options in the community.

However, although the use of ASCERV instruments, analysis, recommendations, and follow-up, are evident in the *Therap* platform, there is little to no evidence currently available to the JCC that other professional disciplines are actively engaged. Furthermore, the observations or recommendations of ASCERV are not provided. This is an area of concern as ASCERV is to develop and reinforce the essential skills in the individual to be reevaluated for a job. The JCC recommends strengthening the use of the Interdisciplinary Referral as a method of identifying the needs of the participants from other disciplines, and then integrating or continuing the ASCERV services. Notwithstanding the above, the JCC recommends that the DSPDI schedule a meeting with Expert, Dr. Serena Lowe, to go over the information that the DSPDI has internally to be able to assess whether the above has been complied with and/or if any further recommendations are warranted.

The JCC also recommends that the DSPDI and ASCERV provide needed funds for any technical assistance that is necessary to conduct these assessments and to work with participants during the day to assure they have the training and support consistent with evidence-based practices so as to effectuate a more positive pathway to employment. It is deeply concerning that some participants who had been previously assessed as able to work have since been reassessed as not able to work. If that is the case, it means that the skills that said participants had previously obtained and developed have been lost due to the lack of further continuity.

It is imperative to note that all this is taking place during an unprecedented historic moment in which Puerto Rico is facing labor shortages in many businesses and industries that should open opportunities for participants to obtain employment. The Commonwealth should capitalize on the opportunities that currently exist using the assistance of Dr. Serena Lowe and other Experts as needed and capacitate those who were previously able to work so they can obtain employment in the current labor market. The time to act is now.

On February 25, 2022, Governor Pierluisi issued Executive Order No. OE-2022-016, establishing a public policy directed towards providing employment opportunities to individuals with intellectual disabilities

<sup>&</sup>lt;sup>15</sup> Notwithstanding the above, there are still numerous outstanding issues in the Daily Centers related to past damage caused by Hurricane María and seismic activities; these unresolved issues may negatively impact delivery of vocational services at the CTS sites. Our Office will be working with the DSPDI in the next monthly meeting to discuss how these issues can be resolved as soon as possible. It is unacceptable that the above issues have still not been resolved after years of the JCC raising them and given that the DSPDI has unused resources in its budget.



in government agencies and dependencies in order to achieve their integration and to strengthen their development. This is a very positive initiative from the Commonwealth's top official and it is entirely consistent with the JCAP. The Office of the JCC appreciates the Governor's leadership here. With the proper training that we expect participants to receive from ASCERV and DSPDI personnel, along with new employment opportunities, the number of participants that are working in integrated community settings should significantly increase in future.

Nonetheless, the bottom line is that there are still too few participants employed in integrated community settings. The Commonwealth has reported that only 14 participants are working and that none of the 14 are working full time. Moreover, five of the 14 individuals are not working in an integrated community setting, so the real number is only nine. The Commonwealth needs to take additional steps to address system deficiencies so that more participants will be working in the community.

The Office of the JCC offers its resources and technical assistance to help train government agencies so that they can offer genuine employment opportunities for the ID/DD population in the Island in a non-segregated community environment.

On multiple occasions, the JCC has informed DSPDI that multiple Daily Centers did not have adequate transportation for participants to go to jobs or vocational or other activities in the community. During several on-site inspections, we noted that almost all of the official vehicles that are used by the CTS's to transfer participants are in a dire state, lack proper maintenance, do not have working accessibility ramps, and are unsafe for any person to ride in. (See JCAP, Section III.3.H, at 10, referencing the need for the Commonwealth to ensure that transportation is adequate to meet individualized participant needs). In response, DSPDI accepted the JCC's recommendations and issued a recent directive to address this very important matter once and for all.

Specifically, on March 24, 2022, the Commonwealth agreed to replace old inadequate vehicles with safer replacement vehicles. The JCC commends the Commonwealth for taking this action. Not all of the replacement vehicles have yet arrived thus putting an unfair and unsustainable burden on community providers to fill the transportation void while awaiting designation and delivery of the replacement vehicles. The Commonwealth needs to make it a priority to gain permanent access to these replacement vehicles very soon, or else services to participants may be compromised.<sup>16</sup>

# d. Safety and Restraint Issues

The Office of the JCC recognizes and commends the DSPDI for its use of digitized documentation on the *Therap* platform and for the expansion of the modules from July to December 2021.

Since the non-outcome measures in this area require the use of *Therap*, the fact that we are seeing significant progress in the use and expansion of the above platform is a clear indication that the DSPDI is

<sup>&</sup>lt;sup>16</sup> Although it is outside of the period covered in the present Report, the JCC has recently received information that two vans have been delivered to each CTS and they are currently waiting to have accessibility ramps installed in each of them.



taking important steps towards compliance in this area. The JCC expects even further improvements for the September 2022 Report.

In addition to *Therap*, the DSPDI has taken other positive steps by creating the Incident Committee, the Polypharmacy Committee, and a new Committee for the Assessment of Polypharmacy and High-Risk Participants ("CAPAR" by its Spanish acronym).

These committees are expected to focus on the technical and/or clinical components addressed in these Benchmarks, such as addressing peer-to-peer interactions to prevent harm (see Benchmarks No. 42-43); minimize or eliminate risk of harm for vulnerable participants (see Benchmarks No. 44-45); minimize or eliminate risk triggers among aggressor participants (see Benchmarks No. 46-47); the prompt reporting and investigation of serious incidents (see Benchmark No. 48); and the analysis of incident patterns and trends to prevent serious incidents in the future(see Benchmark No. 49).

The "Participant Health, Safety and Well-being Protocol," issued in March 2021, is also an important improvement that should serve to strengthen compliance in safety and restraints. This protocol refers to the staff in charge of dealing with incidents and the process to be followed. However, there is still additional information that is needed in order to make a thorough evaluation of the content of this protocol and its effective implementation. The JCC and relevant Experts look forward to working with the DSPDI on getting all needed information to complete its review in this very important area.

The protocol establishes that participants who are on the High Behavioral Risk list will have Quality Area Personnel ensure that each participant receives a psychiatric evaluation at least once a year. The JCC will be discharging its monitoring duties to assess whether the services that the DSPDI will be rendering under said protocol are in accordance with JCAP mandates.

The JCC commends the DSPDI for creating the Incident Committee, which meets on a monthly basis, collects data, classifies incidents, and furnishes meeting minutes. However, important information is sometimes missing from the minutes. We consider this information to be necessary in order to conduct the proper assessment of the work that is being carried out by the committee, as it pertains to safety and restraint issues.

Going forward, the following information is needed to evaluate outcomes in this area: the result of the committee's systemwide analysis and implementation of systematic measures to ensure the well-being of the participants; evidence of measures implemented to prevent high level incidents and their investigation within 45 days; participation from the Quality area in the incident committee; evidence of integration with the Training Program; and analysis of all incident reports, types of incidents and continuous follow up of the same participants, among others. This is a pressing area, given the large volume of incidents, serious incidents, and injuries the Commonwealth has reported in recent months.



## e. Healthcare and Mental Health Care

In regard to the non-outcome measures related to the Health Care and Mental Health Care section of the JCAP, the JCC recognizes the DSPDI's significant effort in improving the accurate documentation of medication and other records in *Therap*, and is satisfied with the overall progress achieved by the DSPDI. Although the JCC has several observations on how the DSPDI can improve in particular areas in order to ultimately reach compliance, the undersigned is certain that with the proper effort, good progress towards compliance can be achieved within the next six months.

For instance, the DSPDI has created a list of the participants that includes their primary care physicians and neurologists (when applicable) as required by Benchmark No. 53. The Commonwealth needs to ensure that all participants are included and that there is no one missing. The Commonwealth also needs to include all information regarding the physicians. These deficiencies can certainly be remedied promptly with minimal effort in order to achieve compliance in relation to this particular Benchmark.

We have begun to see a critical volume of referrals made by CTS nurses to community primary care physicians of participants, alerting them of significant changes in the participants' health status (see Benchmark No. 54). Although we have not yet determined whether these alerts were timely or complete, there is more evidence than we have ever seen to conclude that finally the DSPDI is taking meaningful steps to comply with existing requirements. **The JCC is very satisfied with this progress.** 

With regard to the implementation of an effective system to gather and provide participants' individual information to community clinical personnel (see Benchmark No. 56), the JCC commends the DSPDI, per a previous JCC written recommendation, for creating "Health Passports" for all participants. These participants provide community clinicians with the participants' pertinent health information. The passports need to be printed for the benefit of the community clinicians that do not have access to *Therap.* The JCC is extremely satisfied that the passports are now available and are being used day to day. The JCC expects that Health Passports will remain a permanent part of DSPDI operations going forward and that they will be used by future administrations.

The DSPDI has also shown some improvement in terms of prescription patterns and medication profiles, as recommended in Dr. Roberto Blanco's Polypharmacy Report. Nonetheless, there is still significant work to be done in this important area, as it pertains to the desired results of eradicating overmedication, polypharmacy, and improper psychotropic medications that are being used without a proper diagnosis.

It appears that participants that have experienced multiple seizures have more consistent access to a neurologist. It also appears that the system has compiled updated information regarding their medications (and justification for prescribing them), which was not the case for the period covered in our previous Report. These are positive developments.



In regard to some of the non-outcome measures that pertain to the Mortality Review Committee ("MRC"), the DSPDI is close to reaching compliance in many areas. For example, the MRC is producing the corresponding mortality reports within the JCAP-established timeframe of 30 days (except in cases where an autopsy is required, where the MRC has to wait to issue a final report until the Forensic Sciences Institute furnishes the autopsy report). However, there is still room for improvement in regard to the required root-cause analysis to identify any preventable causes of illness and death and recommendations to address outstanding issues (see Benchmarks Nos. 89 and 90).

There are still outstanding issues with regard to the implementation of needed remedial measures and in identifying preventable causes of illness and death in sufficient detail. Unfortunately, too often, clearly preventable causes are not sufficiently specified in the MRC reports. The JCC expects the MRC Chairwoman, Dr. Brugal, to address this going forward. Nonetheless, the fact that MRC reports and meeting minutes are being issued in a timely manner is a positive step forward towards identifying systemic problems and reaching meaningful progress towards compliance. Overall, the JCC commends the work that is being done by the MRC.

Lastly, although there are still areas for improvement regarding the non-outcome measures regarding the CEEC, the JCC deems that there has been progress in comparison with our previous Report. For example, the DSPDI has provided skilled training on critical topics to CEEC members, and it appears that they are committed to providing more consultations and evaluations than in previous periods since the Court adopted the JCAP. The JCC looks forward to further improvement of the CEEC going forward.

The DSPDI has reported that it has created and activated Mobile Crisis Units, which are available at each CTS, to attend to participant emergencies and provide support in crisis situations. This has required changes in the CEEC's clinical staff. The CEEC is also now involved in the Polypharmacy Committee, which is a positive step in helping to eradicate overmedication, improper use of psychotropic medication, and polypharmacy practices.

In addition to the above, the JCC commends the efforts of Dr. Juan Molina, from the DSPDI Dental Clinic, for his continuous commitment to the ID/DD population and the excellent work he has done in catching up to the almost 600 dental appointments that were lost due to the pandemic while still being able to prioritize dental urgencies that arise. Dr. Molina's contributions to the ID/DD population serve as an inspiration and an example to all that with empathy towards participants and the ID/DD population in general, the sky is the limit as to what the DSPDI can accomplish.

Notwithstanding the above, it is very important to emphasize that the DSPDI still needs to address infrastructure deficiencies in the Dental Clinic, such as the need for air conditioners in hallways and a power generator, among others. Furthermore, the Commonwealth needs to supply necessary



equipment to the Aguadilla Dental Clinic.<sup>17</sup> The JCC expects that the above matters and deficiencies will be promptly remedied.

## f. System-wide Reforms

The JCC recommends that the DSPDI focus its efforts over the next six months to pursuing Medicaid funding to support ongoing provision of Home and Community-Based Services (HCBS) for the target population.

Specifically, the DSPDI and the Department of Health should explore submitting a State Plan Amendment ("SPA") to the Centers for Medicare and Medicaid Services ("CMS") proposing to exercise the rehabilitation benefit option under the Commonwealth's state Medicaid plan to pay for a variety of services (including case management services, day habilitation, home-based habilitation, career exploration, supported employment, clinical and rehabilitative services). The above would open up access to additional Federal Medical Assistance Percentage ("FMAP").

We understand that there are concerns about the financial implications of opening the State Plan to funding services through the rehabilitation benefit given the Commonwealth's existing Medicaid funding cap. However, there is a chance that Congress will pass a package in 2022 to increase the existing cap for the Commonwealth as well as to offer additional increased FMAP to states and territories for expanding and enhancing the provision of HCBS.

As the DSPDI is fully aware, Experts are now available to assist the DSPDI in some areas, but the undersigned strongly recommends that the Secretary of Health should contact Puerto Rico's Resident Commissioner to address the above objective. The Department of Health should proactively reach out to and meet regularly with the Experts and the National Association of State Directors for Developmental Disabilities Services (NASDDDS) to benefit from their technical assistance and support in pursuing the above-mentioned strategies.

The DSPDI and the Department of Health are also encouraged to seek assistance from CMS in applying for support through Money Follows the Person, which pays 100% of all services for 365 days to support the successful transition of an individual from an institutional to qualified community setting (i.e., someone's own home, family home, or residential setting of four or fewer people with disabilities). These Medicaid funding levers could accelerate important systemic reforms related to the Commonwealth's evolution in providing high-quality HCBS to individuals with I/DD.

The above efforts will also provide the Commonwealth with more options and services that can be of enormous benefit when working with family members on a plan to address quality issues that impact participants, thus moving towards reaching compliance with Benchmark No. 103.

<sup>&</sup>lt;sup>17</sup> All information pertaining to the DSPDI Dental Clinic has been obtained through the JCC's monitoring efforts. The same was not provided by the DSPDI.



# III. JCC Progress Evaluations and Recommendations Regarding Outcome Benchmarks

As previously mentioned, and elaborating on the proven working mechanisms from other jurisdictions that we are trying to implement in collaboration with the DSPDI, for the first six-month working plan the JCC, the Experts and the Parties have identified four main areas in which they agree that the DSPDI should concentrate their efforts during the above period of time in order to increase their levels of compliance in outcome benchmarks.

The following outcome areas were selected because they are of fundamental importance in supporting and advancing the health, welfare, and optimal support to participants. Additionally, they represent areas where particular complex challenges can be addressed in collaboration between the DSPDI, JCC team experts and the Experts, through targeted technical assistance. Moreover, due to their fundamental nature, progress in these areas can also translate to positive impacts across a broader array of downstream aspects of services and other highly relevant outcome measures, thus producing successful achievements in meeting the mandates of the JCAP.

In essence, given the results that they have produced in other jurisdictions, the JCC is convinced that the level of success can be accomplished in Puerto Rico and consequently, much higher compliance levels and ultimately sustainable compliance. Notwithstanding the above, the following are some areas which relate to those that will be addressed in the work plan which we deem important to provide certain observations.

#### a. Medication Prescribing Patterns and Polypharmacy

One of the most important areas that will be addressed in the proposed six-month working plan pertains to medication prescription patterns, polypharmacy and the improper use of psychotropic medications. This is an issue that has been present but unaddressed in the Consent Decree for decades and **the JCC is very pleased by the fact that the DSPDI is adopting efficient strategies with the purpose of eradicating said issue once and for all**.

As established in multiple Reports by the JCC, as well as by party-stipulated expert Dr. Roberto Blanco,<sup>18</sup> polypharmacy can contribute to significant morbidity and mortality in the ID/DD population (es evidenced in recent mortality reports) through addictive side effects such as constipation, weight gain and the development of metabolic syndrome or through drug-drug interactions that often go unnoticed. These effects can also contribute to numerous other serious health risks and preventable deaths such as those caused by aspiration pneumonia, which is an area that we will address in-depth as part of the sixmonth working plan.

<sup>&</sup>lt;sup>18</sup> Dr. Blanco's Polypharmacy Report has been the first and only report of its kind that has been commissioned in the history of the Consent Decree. Said Report was commissioned by the undersigned in the year 2020 and the same has served as the starting point for the DSPDI to finally begin to address the above issue.



The JCC is extremely concerned in regard to this very important area given that the DSPDI raised objections in furnishing essential information that was requested by the Federal Monitor's Office. In addition to the DSPDI's objection to provide a list of diagnoses associated with each psychotropic medication prescribed to participants, no evidence was provided by the DSPDI that the dosage of psychotropic medication is appropriate and needed for each participant. However, upon discussing the matter with the DSPDI, it was clarified that their objection was premised on the fact that they furnished all the information that was available to them and not that they objected to furnishing the same.

Moreover, there is not sufficient evidence to assess whether participants receiving psychotropic medication have a clinically justifiable diagnosis or diagnoses of mental illness. Multiple participants who are currently prescribed psychotropic medication(s) do not have a diagnosis of mental illness listed in *Therap* or other data provided by the DSPDI.

This lack of information not only hinders monitoring efforts; it presents limitations of important information to staff at the DSPDI, for example CTS staff and clinicians, in providing care for participants. It also hinders efforts by the DSPDI's own committees, for example the polypharmacy committee, in being able to evaluate whether participants with high degrees of polypharmacy, especially where multiple prescribers are involved, are on optimal medication regimens.

The JCC acknowledges that improving medication profiles for participants is a complex task, but also underscores its critical importance to the health and well-being of participants. The JCC strongly recommends that the DSPDI work more closely with the JCC and Experts to achieve further progress in regard to polypharmacy and the optimal use of medications, which remains an area of urgent and important attention.

Notwithstanding the above, and as previously mentioned in the present Report, the DSPDI has achieved a very important leap forward in regard to this area by establishing CAPAR. Moreover, the DSPDI furnished a draft regarding the preliminary guidelines of the above committee, which, as stated by the DSPDI in said document, may be subject to modification, correction or supplementation upon further review and approval by the DSPDI, pursuant to recommendations proposed by any of the parties, the Office of the JCC or the Experts.

Nevertheless, the JCC will include and promote review, discussion, recommendations, and implementation of said guidelines in the six-month work plan that will be adopted (see Exhibits A and B). Due to the urgent nature of the matter at hand and the decades of use of psychotropics and polypharmacy which have deprived participants of the opportunity of developing themselves in a meaningful and effective way towards independent living, we strongly recommend that said guidelines be adopted and implemented within 45 days of the approval of the present Report.



#### b. Incident Management and Investigations

Even though the JCC acknowledges that the DSPDI has initiated establishing guidelines to address incident management and investigations, the JCC is certain of the urgent need that the DSPDI improve the identification, documentation and implementation of immediate corrective action plans when addressing incidents pertaining to participants.

As the DSPDI can easily understand, failure to implement the corresponding corrective action plans will hinder the prevention of future incidents and will ultimately impede system-wide reforms.

The JCC also notes that significant work is needed in regards to the proper investigation of incidents, including assigning qualified personnel to carry out said investigations, improve documentation of allegations in *Therap* and the establishment of a consistent process that will allow DSPDI personnel to properly investigate and respond to **any and all** allegations of abuse and/or neglect.

The Office of the JCC is aware that the DSPDI has established protocols and provides attention to participant incidents, <u>but the follow up and the implementation of prevention action plans have not</u> <u>been furnished to the JCC</u>, therefore impeding the office of the JCC from monitoring corrective action plans that are prepared by the DSPDI.

From the incident narratives that we have reviewed, the undersigned, our team of experts and Experts find that it is deeply concerning that far more physical restraints are being used on participants than are being reported under the categories of "restraint" in *Thera*p.

The JCC recommends that the above inconsistent reporting be remedied immediately. This continued observation underscores and magnifies the need for behavioral training for providers and caregivers to ensure they fully comprehend what a restraint as mandated by the Consent Decree. After 21 years after the inception of the case, it behooves the undersigned that DSPDI personnel and providers still recur to this disturbing practice of using restraints on participants.

Moreover, immediate guidance and capacitation is warranted to allow the corresponding personnel to properly classify incidents, as similar ones appear to be rated in *Therap* as "high" level incidents in some reports, but "low" or "medium" in others with no elaboration and/or explanation about the distinction of said type of incidents.

The Office of the JCC and all experts are ready to immediately assist the DSPDI in resolving all matters concerning incident management and investigation as part of the six-month work plan, as well as provide further instruction on capacitation for incident reporters, among others.

Even though the present Semi-Annual Report is only the second report that has been issued under the new administration, improper incident report practices must be addressed and resolved as a top priority in the next six-month working plan.



# c. Provider Transformation and Workforce Development

The JCC is concerned by the fact that key personnel are not properly trained and do not have the proper skill set to effectively manage participants with specialized needs. The JCC strongly recommends the DPSDI to work with the JCC and all Experts to rapidly improve the amount of relevant, high quality training material that should be consistently available to providers and their staff and employees working directly with participants. The above will help ensure that services and proper support is offered to participants by knowledgeable and adequately capacitated professionals.

In addition to the above, the JCC has identified other areas that also require further training and capacitation for most, if not all, staff members. For instance, there is no evidence that trainings and capacitation are being provided to address findings and recommendations for remedial actions regarding individual and systemic issues related to deaths that are issued by the Mortality Committee in mortality reports. Without the above information, the JCC cannot monitor whether the above recommendations for remedial actions are being implemented as system-wide reforms, whenever appropriate as mandated by the JCAP.

There are also no trainings to address patterns and trends that adversely impact the safety, well-being, health and mental health of participants, so as to minimize or eliminate their occurrence in future, such as frequent incidents, falls and injuries, among others.<sup>19</sup>

Furthermore, there is no evidence of specialized training for the specialized community homes. The DSPDI is required to train new staff for providers, but there is not consistent training available or provided by the DSPDI to ensure a still workforce.

The JCC recommends that the DSPDI engage in further collaboration with different organizations or entities that can assist them in providing training and capacitation. For example, the National Alliance for Direct Support Professionals (DSPs) provided the technical assistance to CMS in the development of their 2010 core competency guidelines for DSPs and has an evidence-based competency program that could be tailored for the DSP workforce in Puerto Rico.

Dr. Serena Lowe can facilitate an initial conversation for the DSPDI to inquire about the types of Technical Assistance and training that NADSP offers. The training that is currently being provided to the staff is minimal and does not include all the pertinent staff (it is mostly available to CTS staff only). There needs to be consistent quality training available for all staff before they are allowed to work with participants. Moreover, specialized homes should have heightened training for the specialized personnel to ensure that they can provide the required services for the participants.

<sup>&</sup>lt;sup>19</sup> A fall prevention training was offered but not to home caregivers.



# IV. <u>Conclusion</u>

The DSPDI has continued to show significant progress in regard to the communication, transparency, collaboration, and furnishing of information to the Office of the JCC, as initially mentioned in the JCC's previous Report. These positive efforts have significantly improved the DSPDI's progress in relation to the non-outcome measures of the Benchmarks and have created an effective collaborative environment in which a six-month work plan can be established in order to facilitate compliance with the outcome measures.

The JCC commends the Commonwealth for fostering a non-litigious, collegial working relationship with the Office of the JCC and the United States. This has allowed resolution of several issues in a collaborative manner without the need to move the Court for emergency remedies. Most recently, this environment enabled us to address and resolve the transportation issue, referenced above.

The JCC further commends the Department of Health for its excellent work in guaranteeing that all participants (that were able to) received their COVID-19 vaccines and initial booster shots. The JCC looks forward to the same level of diligence with regard to the second booster inoculation for participants that qualify now that the Federal Food and Drug Administration (FDA) and the Centers for Disease Control (CDC) have approved second booster shots for immunocompromised individuals and for persons over 50 years of age. This is of extreme importance, especially considering the newly emerged Omicron BA.2 variant of coronavirus that we are currently seeing in multiple jurisdictions.

The DSPDI is commended for its nascent efforts to begin tackling the polypharmacy, over-medication, and improper use of psychotropic medications issues among participants, which has been a very serious and longstanding problem. The JCC is optimistic that meaningful reforms will be developed and implemented, which will allow participants to be healthier and maybe aspire to independent living.

The JCC would also like to thank the various family organizations, especially the Association for the Inclusion of Adults with Intellectual Disabilities ("APIADI", for its Spanish acronym). The JCC acknowledges the valuable contributions made by APIADI over the years and the unwavering commitment of its president, Ms. María Juliana Vilá, and of Mr. Frank Nieves from the Moca chapter of APIADI.

The JCC is hopeful that if the upcoming six-month work plan is embraced, it will promote increased compliance with existing orders, and, most importantly, will significantly advance the health, well-being, and quality of life of the participants in integrated community settings.



# Exhibit A: Initial Expert Recommendations for Six-Month Work Plan

#### I. Non-Outcome Measures

- In regards to the few non-outcome measures that have yet to reach compliance, the JCC recommends that the DSPDI Compliance Officer, Mr. David Rodríguez Burns, schedule a meeting with the JCC Team in order to discuss and resolve said items with the objective of achieving compliance by the JCC September Report.

#### II. Outcome Measures (identified priority areas)

#### a. High-Risk Populations and Polypharmacy

Expert recommendations regarding the DSPDI's Committee for the Assessment of Polypharmacy and High-Risk Participants guidelines:

- 1. When a participant is prescribed a new psychotropic medication, the DSPDI should document any additional therapeutic interventions provided prior or as an alternative to the psychotropic medication that are known to DSPDI and the person's care team at the time.
- 2. A comprehensive medical and psychiatric assessment must be conducted for each participant.
- 3. For mental health diagnoses in particular, the Committee or the CEEC should provide support through skilled assessment.
- 4. Make sure that the application of mental or behavioral health diagnosis (and associated medications) for underlying physical health issues and other distinct issues process is not just based on a paper record review, and fully reliant on the diagnosis from the community prescriber, particularly where the CTS, CEEC or Committee observes reasons to question the accuracy of the diagnosis.
- 5. The recommendations of the Committee should be put into written form for the prescribers. The committee should also consider other supplemental communication (e.g. phone call) to ensure the information is received and considered.
- 6. Conduct clinician-to-clinician discussion of the participant's medications and needs. We are concerned that relying on the asynchronous communication that's described in the protocol will not be as constructive as an interactive exchange between professionals. The latter can do more to help elicit concerns that the prescriber may have, such as the safety of deprescribing while the person is a community setting with unskilled staff/family members, etc. that they may not be as willing to put in writing. It also provides the opportunity to



work through some of the challenges/concerns raised more collaboratively and constructively.

- 7. Review the bowel management of participants on medications known to induce constipation, such as those on one or more medications with a high relative anticholinergic potency, to ensure that people (staff, substitute providers, family members) are aware of the increased likelihood of constipation from these medications and that there is a plan for bowel management.
- 8. In the event that a prescriber is willing to engage in de-prescribing, it should be made clear what supports DSPDI will provide to ensure this is done safely. It would be helpful for prescribes to be aware of any supports that are available because their availability may influence their willingness to change medications.
- 9. The CAPAR should be ready to support community prescribers on the steps of deprescribing (how to do this safely, is tapering needed, what to monitor). If evidence-based guidelines exist for deprescribing the specific medication, these should ideally be consulted. The CAPAR's own process should consider the risks and benefits of stopping the medication for the person.
- 10. During deprescribing, the CAPAR should work with the community prescribers to identify what signs/symptoms should be monitored and ensure that those supporting the participant are educated on what to watch, when to seek help, etc. if the deprescribing is to be done in the person's community setting.
- 11. The CAPAR should support the identification of data that should be monitored during medication changes.

#### Critical Incident management and investigations:

- 1. The DSPDI should make sure to provide proper capacity building and training to their staff in relation to the corresponding protocols and the steps for implementation.
- 2. Include a medical professional such as a psychiatrist and a pharmacist in the Incident Committee to consult cases of clinical nature.
- 3. Ensure the active participation of qualified personnel in the analysis of incidents.
- 4. Provide a universal term or definition of what corrective actions and immediate response means and entails.



- 5. Provide training and capacitation for providers and service mediators on acceptable corrective actions.
- 6. Provide incident pattern analysis and preventive plans.

## b. Independent Living

#### c. De-Institutionalization of Participants

- 1. Develop and provide trainings to effectively manage participants with specialized needs.
- 2. Develop and provide trainings to address findings and recommendations form the various DSPDI Committees. For example trainings to address frequent incidents, injuries and falls.
- 3. Collaborate with different professional organization entities that can assist in providing training and capacitation.
- 4. Establish a robust alternate education plan for personnel that may need immediate training. For example, webinar trainings that area immediately available.

#### d. Employment and Job Placement for Participants

- The Experts will review the existing VR processes, policies and templates for assessing the employment readiness of Participants, and offer ongoing technical assistance and advice for improving the process and embedding evidence-based practices and protocols that assure participants are provided optimal chances and opportunities to explore potential career interests and pursue paid employment opportunities in the community.
- 2. The Experts will offer guidance, advice, and technical assistance on the design, implementation and evaluation of training, technical assistance and ongoing mentoring/professional development of staff and providers to support participants in pursuing, achieving and maintaining competitive integrated employment. The workplan will focus on:
  - i. The provision of training, direct/indirect technical assistance, introduction, and implementation of evidence-based practices in a culturally-competent approach, peer-to-peer mentoring across all levels of stakeholders (providers, front-line professionals, families, employers, and self-advocates engaged in each of the pilots), and facilitation of systems-change strategies for sustaining and scaling the work overtime;



- ii. The initiation of several pilot programs in the Commonwealth (i.e., 1-2 per region) to test and validate a new approach to service provision that result in services being provided directly in typical community settings as a means for fostering supported employment and community inclusion; and
- iii. The alignment of TA and DSPDI investments in provider transformation and capacity building with the *Criteria for Performance Excellence in Employment First Provider Transformation,* created by the U.S. Department of Labor's Office of Disability Employment Policy, and implemented in over thirty states across the U.S. The pilots could further the above-mentioned goals of building strong staff capacity by including a key component of supporting front-line personnel acquire training, mentoring and technical assistance in the successful application of customized employment, supported employment, and integrated community engagement practices. These pilots could also focus on a dual goal of helping existing facility-based congregate models to transition to models of integrated, individualized service provision.

# III. Additional JCC and Expert recommendations<sup>20</sup>

In addition to the <u>refresh rate assessment study</u> mentioned in the Report, the JCC and Experts further recommend the following:

- 1. Consider prioritizing enhanced reimbursement for the following home and communitybased services: Community Participation Supports, Environmental Accessibility Modifications, Family Model Residential Supports, Individual Transportation Services, Intermittent Employment and Community Integration Wrap-Around Supports, Medical Services in the Community (Nutrition Services, Occupational Therapy Services, Physical Therapy Services, Speech, Language, & Hearing Services), Personal Assistance, Personal Emergency Response Systems, Respite, Semi Independent Living, Specialized Medical Equipment & Supplies & Assistive Technology, Support Coordination, Supported Employment-Individual (Exploration, Discovery, Job Development, Job Coaching) Supported Employment-Small Group, Supported Living, Transitional Case Management. The majority of these services can be offered under the Rehabilitation Benefit of the state's Medicaid state plan (see Systems Reform section for more details).
- 2. Begin to explore other models that were observed by the JCC and government officials on trips to several parts of the United States in 2021. Namely, the DSPDI is encouraged to

<sup>&</sup>lt;sup>20</sup> The JCC recognizes that some of the following recommendations may take more than a six month period to develop and implement.



invest some of the funds it currently has available to support a pilot project of communitybased, individualized supported living.

- 3. The above pilot would test the developing of innovative alternative housing models in the Commonwealth (i.e. 1-2 per region) based on supported living guidance issued by the Technical Assistance Collaborative in support of states attempting to comply with *Olmstead* settlement agreements.
- 4. The JCC suggests that the DSPDI contract with one or more of the organizations that have demonstrated excellence in these models to work with local partners in designing and conducting the above pilot. Moreover, said pilot should include a strong capacity building component for front-line personnel supporting individuals with I/DD to live in the most integrated settings.



# Exhibit B: Executive Summary of the JCC's March 2022 Semi-Annual Report

# I. Introduction

The Federal Monitor's Office submits its seventh Semi-annual Report ("Report") to the Court, the United States, the Commonwealth of Puerto Rico and its Division of Services for Adults with Intellectual Disabilities ("DSPDI") evaluating the Commonwealth's progress or lack thereof, as it relates to the Joint Compliance Action Plan ("JCAP") and the party-stipulated Benchmarks. The present Report covers the period between **July 1, 2021, to December 31, 2021**.

From the outset, the JCC wants to acknowledge that the Commonwealth of Puerto Rico has **significantly progressed** in many Benchmark areas when compared to the JCC's September 2021 Report.

The JCC commends the DSPDI's Compliance Officer, Mr. David Rodríguez Burns, Esq., and the Department of Health's Auxiliary Secretary of Family Health, Integrated Services and Health Promotion, Dr. Marilú Cintrón Casado. Their work and commitment to progress and in improving the lives of participants has had a positive impact on the DSPDI during the period covering the last six months. The JCC also acknowledges the positive contributions of the Governor of Puerto Rico, Hon. Pedro Pierluisi and the Hon. Secretary of Health, Dr. Carlos R. Mellado in their effort of improving the living conditions and work opportunities of the intellectual and developmental disabilities ("ID/DD) population in Puerto Rico. The undersigned expects to recognize the same level of commitment in our next September Semi-annual Report.

Consistent with the directives of the Court, after receiving comments from the Parties, joint partyexperts and subject matter experts, the Office of the JCC and its team of experts recommended that various modifications take place in contrast to the last JCC Report.<sup>21</sup> As part of the new modification, the JCC proposed the creation of a joint six-month work plan to allow all Experts to conduct in-depth reviews and to provide technical assistance to the DSPDI in a number of specific areas that needed immediate attention such as: High Risk Populations and Polypharmacy; Independent Living; De-Institutionalization; and Employment/Job Placement.

Once the above plan is jointly established by all Experts and the DSPDI (within 45 days) and thereafter implemented by the Division, the fruits of the same will be assessed in the JCC 's September Report using individual evaluation criteria per Benchmark, as it was done in previous reports, unless the JCC identifies any deviation or departure from the JCAP mandates that warrants an immediate notification to the Court.

<sup>&</sup>lt;sup>21</sup> One of the main reasons for the above modification is because after approximately 23 years of following the same evaluation and assessment methods to ascertain the DSPDI's progress, the JCC felt compelled to recommend the creation of a new sixmonth work plan that has proven to generate better results in other jurisdictions in the United States.



# II. JCC Progress Evaluations and Recommendations Regarding Non-Outcome Measures<sup>22</sup>

# **Community Placement from Institutions**

The JCC is particularly satisfied that the DSPDI has achieved significant progress in the above area and that it is currently on track towards reaching compliance by the next JCC Report if a few recommendations are adopted and implemented.

The JCC highly commends the DSPDI for preparing written Individualized Transition Plans ("ITPs") for each participant still residing in an institution (since Olmstead<sup>23</sup> became the law of the land), which until recently was a JCAP mandate that was elusive.

As previously mentioned, the JCC will discharge its monitoring duties in relation to this and all areas of the JCAP with the hopes that any deficiencies found in the non-outcome measures can be resolved with the proper technical assistance by the next JCC Report.

## Provider Capacity Expansion in the Community

The JCC is satisfied with the improvement that the DSPDI has obtained in this area and believes they should be able to continue to progress over the course of the next six months. Said progress will be reflected when the Office of the JCC assesses compliance levels in the next September Report.

Moreover, the JCC is very satisfied that the DSPDI has developed a system-wide plan to increase the number of community residential providers to meet participants' individualized living units needs within non-congregate community settings. Although there is ample room for improvement in said plan, the above progress represents a constructive foundation and an important step in the right direction to reaching compliance. The results of the DSPDI's progress in expanding congregate community settings within the next months should lead to significant improvements when the JCC assesses the level of compliance that the DSPDI has reached in the relevant Benchmarks.

As explained further in the Report, the JCC recommends that the DSPDI commissions an updated Rate Assessment Study that is tempered to the impact of the record-setting inflation levels and the contracted labor market that we are confronting, which will ultimately guarantee the continuity of all services to participants as mandated by the JCAP.

#### Integrated Employment and Day Activities

In overall terms, the JCC is not satisfied with the progress that the DSPDI has achieved in this area. Even though we acknowledge that for the first time since the adoption of the JCAP, each Transitional Service

<sup>&</sup>lt;sup>22</sup> For further observations and recommendations on each of the following areas, please see the complete Report.

<sup>&</sup>lt;sup>23</sup> Olmstead v. L. C., 527 U.S. 581 (1999).



Center (CTS) has a complete work team from the Vocational Rehabilitation Counseling Services Area ("ASCERV"), among other positive initiatives, the fact remains that with the amount of job opportunities that currently exist in the Island, the DPSDI efforts need additional support from Experts to achieve a proper level of employment that will allow participants to move in the direction of independent living.

The fact that the Commonwealth has confronted a pandemic during the last two years should not serve as an excuse for abandoning support services and modified employment capacitation in regards to the participants' skills and their adaptation the new labor market, as has been mentioned by the JCC in multiple monthly meetings.

As in all areas of the JCAP, the JCC and all Experts are committed to assisting the DSPDI in improving what has historically been a highly deficient area of accomplishment.

# Safety and Restraint Issues and Healthcare and Mental Health Care

Since the non-outcome measures in this area require the use of *Therap*, we are seeing significant progress in the use and expansion of the above platform as a clear indication that the DSPDI is laying the foundation to place them in the position of moving towards improved compliance levels which may be reflected in the next JCC September Report.

Even though there is significant work to be done in these areas, it is worth noting that in addition to the above foundation, the DSPDI has taken other positive steps as they pertain to safety and restraint issues by creating for the first time the Incident Committee, the Polypharmacy Committee, and a new "Attention Committee to High-Risk Participants" (CAPAR). For the above initiatives, the JCC commends the current administration's accomplishments.

The DSPDI has also shown improvement in terms of prescription patterns and medication profiles, as recommended in Dr. Roberto Blanco's Polypharmacy Report. Nonetheless, there is still significant work to be done in this important area, as it pertains to the desired results of eradicating overmedication, polypharmacy, and improper psychotropic medications that are being used without a proper diagnosis.

# **Mortality Review Committee**

The JCC is extremely pleased that the Mortality Review Committee ("MRC") is producing the corresponding mortality reports within the JCAP-mandated timeframe of 30 days. However, as elaborated in the Report, there is still room for improvement in regard to the required root-cause analysis to identify any preventable causes of illness and death and recommendations to address outstanding issues which the JCC intends to monitor and work in conjunction with the MRC before the next Report is issued.



# System-Wide Reforms

As previously mentioned, the JCC is pleased with the progress that the DSPDI has achieved in regards to the *Therap* platform as well as other items that are included in the system-wide reforms area of the Benchmarks and the JCAP. Nevertheless, the JCC provided several specific recommendations in the Report with the objective of assisting the Commonwealth in obtaining federal funding that will serve to improve the quality of life and well-being of the participants which will ultimately lead to compliance.

# III. JCC Progress Evaluations and Recommendations Regarding Outcome Benchmarks

As previously mentioned, the Parties and the Experts have identified four main areas that the DSPDI will be working on during the six months in order to increase progress and, initially, levels of compliance in the above outcome Benchmarks. This method of addressing challenges in clinical areas has proven successful in other local and state jurisdictions and the JCC is highly optimistic that we can accomplish the same levels of success in the Commonwealth.

Therefore, during the next six months, the DSPDI, with the assistance of the JCC and all Experts, will work primarily on the following areas (without abandoning the work that needs to be done in other clinical areas that will be continually monitored by the JCC ):

- High Risk Populations & Polypharmacy;
- Independent Living;
- De-Institutionalization; and
- Employment/Job Placement.

Notwithstanding the above, the following are some areas which relate to those that will be included in the work plan that will be adopted by the Parties and Experts within 45 days which will generate observations and recommendations by the Experts and the JCC to ultimately reach compliance. The JCC will include a particular assessment report regarding the initial six-month plan in our next JCC Report.

# i. Medication Prescribing Patterns and Polypharmacy

This is an issue that has been present but unaddressed in the Consent Decree for decades and the JCC is very pleased by the fact that the DSPDI is adopting efficient strategies with the purpose of eradicating said improper medical practices.

The JCC acknowledges that improving medication profiles for participants is a complex task, but also underscores its critical importance to the health and well-being of participants. The undersigned strongly recommends that the DSPDI work closely with the Office of the JCC and all Experts to achieve expeditious progress in regard to polypharmacy and the optimal use of medications, which remains an urgent area that warrants immediate attention.



## ii. Incident Management and Investigations

Even though the JCC acknowledges that the DSPDI has initiated establishing guidelines to address incident management and investigations, the JCC is certain that the Division urgently needs to improve the identification, documentation and implementation of an immediate corrective action plan when addressing participant incidents.

Moreover, immediate guidance and capacitation is warranted to allow the corresponding personnel to properly classify incidents, as similar ones appear to be rated in *Therap* as "high" level incidents in some reports, but "low" or "medium" in others with no elaboration and/or explanation about the distinction of said type of incidents which impairs the Division from efficiently and at times immediately developing proper corrective action plans to address the safety and well-being of each participant subject to an incident.

## iii. Provider Transformation and Workforce Development

The JCC is very concerned by the fact that key personnel are not properly trained and do not have the proper skill set to effectively manage participants with specialized needs. Especially those that are transferring into community homes form institutions. The JCC strongly recommends the DPSDI to work with the JCC and all Experts to immediately improve the capacitation that is warranted for the providers, staff and employees who are the frontline of the Division. The above will help ensure that services and proper services are being offered to participants by knowledgeable and adequately capacitated professionals.

Moreover, the JCC will be closely monitoring the above capacitation process to assist the Commonwealth in substantially improving the above-mentioned deficiencies.

#### IV. <u>Conclusion</u>

The DSPDI has continued to show significant progress in regard to the communication, transparency, collaboration, and furnishing of information to the Office of the JCC. These positive efforts have significantly improved the DSPDI's progress in relation to the non-outcome measures of the Benchmarks and have created an effective collaborative environment in which a joint six-month work plan will be established within 45 days in order to assist the Commonwealth in confronting the challenges that clinical outcome measures entail. The JCC will be closely monitoring both the creation and implementation of the above work plan and will be particularly observant that the same is conducted within the parameters of the JCAP.

The DSPDI is commended for its nascent efforts to begin tackling the polypharmacy, over-medication, and improper use of psychotropic medications issues among participants, which has been a very serious and longstanding problem that has affected the lives and well-being of many participants. The JCC is optimistic that meaningful reforms will be developed and implemented, with the assistance of all



Experts, which will finally allow a significant number of participants to enjoy the benefits of healthier and productive lives that may ultimately lead them towards independent living.

Moreover, the JCC is highly optimistic that the new approach of addressing challenging clinical areas will reach levels of improvement that have been in great measure stationary since the inception of the case. The JCC firmly believes that the DSPDI, the Department of Health and the Commonwealth of Puerto Rico cannot expect different results that have impeded their advancement in reaching compliance levels while using the same methodology that has bore little progress. The time has come to implement alternative means to assist the DSPDI in furnishing participants with a level of healthcare that citizens with intellectual disabilities deserve to receive from their respective governments.