JCC SEMI-ANNUAL REPORT
UNITED STATES V. PUERTO RICO
CASE NO. 99-1435 (SCC)
MARCH 2023

Benchmarks and Supplement Narrative

Office of the Joint Compliance Coordinator

Joint Compliance Coordinator Office
United States v. Commonwealth of Puerto Rico, et al. Civil No: 99-1435 (SCC)

I, Alfredo Castellanos, Esq., in my independent capacity as Joint Compliance Coordinator ("JCC" and "Federal Monitor"), hereby certify that the present June 2023 Semi-annual Report has been prepared by the undersigned (with the input and contributions of the Party-Stipulated Experts, Subject-Matter Expert, and JCC team Experts (collectively referred to as "Experts")[1], discharging my duty to evaluate the progress of the Commonwealth of Puerto Rico ("Commonwealth") and its Department of Health's Division for Adults with Intellectual Disabilities (hereinafter referred throughout the Report as "DSPDI," "Division," and "Program") in complying with the consent decrees and orders in this case, primarily the Joint Compliance Action Plan ("JCAP", also referred to as the "Agreement" as reflected in the Benchmarks). When warranted, in our role as a guiding hand, we recommend remedial advice and action plans to assist the Commonwealth to reach sustainable compliance with the Agreement.[2] The following Experts and JCC team members contributed to the present Report:

JCC Team Experts:

- Dimaris García, Psy. D. (Psychologist and JCC Team Expert).
- Carmelo Rodríguez, Psy. D. (Psychologist and JCC Team Expert).
- Ms. Tirsa Sosa, MSW (Social Worker and Ex-Director of the Bayamón CTS/Daily Center).

JCC Team:

- Ms. Diana Alcaraz, Esq./CPA (Court-appointed Special Investigator and Legal Advisor to the Federal Monitor).
- Mr. Salvador M. Carrión, Esq. (Legal Advisor to the Federal Monitor).
- Mr. Javier González (Executive Director of the Office of the JCC/Federal Monitor).
- Ms. Jeannie Castillo (Administrative Assistant/Expert Liaison with Participants).

Party-Stipulated Experts: Emily Lauer and her team of experts at the University of Massachusetts/CDDER.

Subject-Matter Expert: Serena Lowe (AnereS Strategies, LLC).

Court-Appointed Expert: Dr. María Margarida Juliá [3]

Special contributions by: Justice (ret.) Federico Hernández Denton (Senior Advisor to the JCC).

Alfredo Castellanos, Esq.
JCC/Federal Monitor

[1] **All assessments in this Report were reached by unanimous consensus of the undersigned and the Experts.**

[2] All comments furnished by the Parties were considered. The final version of the report Stands as a joint effort between the observations and comments from the Parties and the assessments of the Office of the JCC.

[3] Dr. Margarida's contributions are noted in specific matters addressed in the Report.

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I. INTRODUCTION

This is the first Semi-Annual JCC Report for 2023, covering the time period between July 1 and December 31, 2022.[4]

As has always been the case, during the review period, the Office of the JCC maintained constant and ongoing monitoring of the Commonwealth's compliance with the JCAP. In the JCC's March 2022 Report (Docket No. 3576), we adopted a modified assessment structure which distinguishes between the outcome and the Non-Outcome JCAP Benchmarks. The Non-outcome Benchmarks are generally process-oriented items that can be readily assessed without multi-layered onsite and expert clinical reviews. The Outcome items, on the other hand, require in-depth expert clinical-based review and assessment to determine if the JCAP mandates are met and if participants' health and well-being are being ensured as required by the JCAP/Benchmarks. The Office of the JCC has created, using the Parties' bestowed guiding hand authority (See Docket No. 2285), specific work plans to help the Commonwealth reach sustainable compliance with certain outcome items.

The work plans, in conjunction with the exceptional and solidified collaborative working relationship that exist between the current Commonwealth administration and the Office of the JCC, have yielded favorable results for participants, as well as notable progress and accomplishment for the Commonwealth. As reflected in this report, the Commonwealth has achieved its highest level of compliance in the history of the Consent Decree, in regard to the non-outcome benchmarks.[5]

In this report, we provide a brief overview of the current achievements and ongoing activities of the work groups that have been created as part of the work plans. This Report will also focus on discussing our findings, observations, and recommendations on specific Outcome Benchmarks that pertain to: (1) the **opening of specialized community homes; (2) integrated employment and day activities; and (3) polypharmacy**. In order that our Report can be used as a convenient working instrument, we will divide our assessments in three independent sub-reports for each covered subject matter areas, which will include specific recommendations from the Office of the JCC and Experts. Our findings are based on direct observations from numerous on-site monitoring visits, meetings, interviews, and extensive review of documents furnished by the Commonwealth and/or obtained by the Office of the JCC, along with the specific evaluation and contributions by the Experts.

Although not an emphasis in the present Report, the JCC commends the Commonwealth for recently opening two temporary placement service pilot homes (also referred to as transitional homes),[6] and for

[4] Although the main focus will be on the above period, we will highlight positive events and achievements that have transpired during the preparation of the present report with the purpose of illustrating the readers of the same.

[5] The Office of the JCC, whether through monthly meetings or direct and independent reports, is continuously sending and sharing information with the DSPDI in relation to our findings regarding JCAP mandates with recommendations as to how to address said findings or deficiencies.

[6] These homes are to provide temporary accommodations, primarily for individuals who present to DSPDI with no or little notice, such as those individuals who local courts have ordered DSPDI to serve, for those who face unplanned

its commitment to opening crisis diversion apartments, which will serve as multi-functional respite facilities in the community to prevent participant contact with hospital, institutional, or other congregate settings during a crisis The JCC will more closely assess and then report on these new initiatives in the next report.

A. Standard of Assessment

Although the benchmark assessment table included herein does not include a compliance level assessment in certain Benchmarks (especially in outcome areas), we can report that the Commonwealth is working arduously on remedial measures regarding the same. In addition, the Office of the JCC is actively providing technical assistance in all relevant areas. For the benefit of the Parties, the Court and stakeholders, our Office furnished observations and recommendations for certain outcome Benchmarks. The Office of the JCC will focus on different outcome Benchmarks going forward and expects to complete a comprehensive assessment of all Benchmarks within a three-to-four-year cycle as recommended by the Parties' joint experts premised on empirical data and clinical considerations.

B. Status of the Implementation of the Six-Month Work Plan and Work Groups

As part of the Six-Month Work Plan that was established in the March 2022 Report, the Division of Services for Adults with Intellectual Disabilities (DSPDI, at times also referred to as DSPADI by the Commonwealth) as expected has been working in collaboration with the JCC and the Experts[7] in individual work groups with the objective of the Commonwealth receiving and implementing technical assistance in the areas of deinstitutionalization, independent living, high-risk conditions/population, polypharmacy, employment and job placement, incident reporting, and investigations. In relation to the above, the JCC provides the following work group updates:

i. Employment Work Group:

The Employment Work Group has been primarily focused on the introduction of Discovery and Customized Employment Strategies[8] into the Vocational Rehabilitation Counseling Services Area ("ASCERV") infrastructure via the Vocational Rehabilitation Counseling Area. All CTS rehabilitation staff completed a three-day in-person training in early June 2022. The training was then supplemented with a weekly virtual e-Learning Community of Practice, which should conclude by the filing of this Report.

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emergency circumstances, such as when a primary provider or family caregiver becomes unstable or fails, and for other emergency purposes.

[7] The term "Experts" refers collectively to the Party-Stipulated Experts, Subject-Matter Expert, and JCC team Experts.

[8] Discovery is the first step in the Customized Employment process. It is a strengths-based, individualized, qualitative assessment strategy that avoids the comparative strategies that often exclude job seekers with disabilities and other barriers from conventional workforce programs. The process opens up possibilities for further exploration by the job seeker rather than just trying to "fit" into a rigid job description. This modality is consistent with the integrated employment areas in the JCAP and Benchmarks and should promote significant progress towards compliance with these important mandates.

It is worth highlighting that the above training is the first of its kind to ever be offered to the DSPDI rehabilitation staff and marks a significant steppingstone in enhancing the system's capacity to effectively support and empower participants in pursuing and attaining competitive integrated employment. The JCC recommends additional commitment of resources to support ongoing training and professional development for vocational rehabilitation and other CTS staff and/or personnel.

ii. De-institutionalization and Independent Living Work Group

The De-Institutionalization and Independent Living Work Group has been focused primarily on providing technical assistance to the Commonwealth on strategies to more effectively work with families and guardians of participants who still live in institutions and who will benefit from more updated information and being exposed to service options available for community living, as well as to the progress that have been achieved in workforce training for specialized home providers.

The work group has also focused on reviewing and providing feedback on procedures and protocols related to de-institutionalization, inclusive of planning, transfer, and post-move monitoring. In addition to the above, the exploration of independent living models in and outside of the Island for potential implementation and/or expanded service options, has also been an area of priority for the work group.

iii. High-Risk and Polypharmacy Work Group

The main priority of this work group has been to define the highest risk conditions and health-related situations for participants and create useful and proven tiered risk levels (high, moderate, low) to establish the priorities of the work that needs to be done by the "Attention Committee to High-Risk Participants" (CAPAR, Spanish acronym).[9]

The above definitions have resulted in revisions to the CAPAR evaluation protocol, and in the corresponding communication to other DSPDI service areas about the participants that will be prioritized for review.

The work group has also focused on strategies to support CAPAR's individualized reviews of participants, prioritizing high-risk conditions/situations, and associated changes to medication regimens and related services, as well as in working through strategies to train the workforce in high-risk medical conditions.

In addition to the above, the workgroup has been discussing various strategies for working with prescribers to better ensure that they understand the need for, and then adopt, the recommended medication strategies that will promote better treatment outcomes. The workgroup has also worked to improve CAPAR's approach to working with managed care entities to better ensure that the managed care groups understand CAPAR reviews and recommendations. The group has also worked on efforts to

[9] The Federal Monitor will be participating in upcoming CAPAR and CEEC meetings.

better build capacity in prescribers to enable them to support and properly prescribe next generation medication for individuals with IDD. [10]

iv. Incident Reporting and Investigations

This work group has focused on the review of policies and protocols related to incidents and incident review, complaints and grievances, and associated investigations. This review also includes examining how protocols are implemented and how the same can be improved.

The group has also focused on identifying strengths and weaknesses of the current use of electronic reporting systems, and any modifications and/or updating needed for effective implementation. It is of high importance that the DSPDI implement effective measures so that incidents and investigations are more consistently and uniformly documented in electronic systems (whether through the existing Therap platform or other platforms) used by the DSPDI.

Additionally, the group has worked on a referral process connected with incident reviews, and has started a fall prevention initiative, including the pilot of a process to better identify and address causal factors in said extremely serious incidents to prevent reoccurrence. It may very well be time for the Commonwealth to entertain the possible need of using the latest available monitoring and service delivery technology that will assist the Department of Health and the DSPDI in identifying in real time the underlying causes that lead to all serious and dangerous incidents so that the same can be effectively prevented.

C. Pending and Ongoing Matters Identified by the Office of the JCC and the Experts

In our previous Semi-annual Report, the Office of the JCC provided a status update regarding several important Commonwealth pilot initiatives that may have a direct impact on the health, safety, and well-being of individuals with IDD in our jurisdiction. Given that said initiatives continue to be developed, we furnish the following update, as well as other several new matters that the JCC Office is currently monitoring:

i. Individuals with IDD in the local court system

The Federal Monitor has continued to hold meetings with the Administrator of the Office of Courts Administration ("OAT" for its Spanish Acronym), to address the challenges that individuals with IDD confront when they appear in the local courts, in both criminal and civil proceedings.[11] These meetings have been possible, in part, thanks to the valuable assistance and contributions of the JCC's Senior Advisor, Justice (ret.) Federico Hernández Denton, who has coordinated and actively participated in all of the above meetings.

[10] Matters related to over-medication and polypharmacy will be further discussed in Section A of this Report.
[11] Cases include individuals with IDD being incarcerated for behavior that is often merely a manifestation of their disabilities instead of as a result of criminal behavior or illegal activity; being placed in inadequate homes or institutions; and having to plead guilty to crimes or misdemeanors in order to benefit from diversion programs, among others.

The OAT has sought the advice and input of the Office of the JCC regarding several plans that they are considering implementing to address the above challenges, including the creation of a collaborative agreement with the Department of Health to have access to the Therap platform in order to enable the courts to access information of participants embroiled in judicial proceedings. The OAT also invited the Office of the JCC to participate in a conference organized by the Judicial Academy regarding mental health and related disability challenges confronting the local judiciary, which was held at the Supreme Court of Puerto Rico on June 15-16, 2023.

In addition to the above, members of the Judiciary participated in onsite visits to transitional homes with the JCC and representatives of the DSPDI to obtain a first-hand look at how the Program is improving by offering new services, and to see the benefits of serving individuals with IDD in the community, as opposed to in institutions, congregate facilities like ASSMCA homes, or even jail/prison.

ii. Status of the Use of the $10M Budgetary Reserve Amidst the Increase of Participants

Late last year and early this year, the JCC and the Parties participated in various meetings related to the $10M reserve funding established by the Court since fiscal year 2021-2022. (See Dockets Nos. 3499 and 3602).

The above-mentioned meetings and discussions have proven constructive as the Parties, with the support of the Office of the JCC, are making significant strides towards reaching a consensus on the productive use of the reserve funds in accordance with the directives of the Court at Docket No. 3499. The objective is to establish important and effective programs and to effect positive systematic changes that will benefit the IDD population in Puerto Rico and will assist the Commonwealth in achieving compliance and sustainable compliance with the JCAP/Benchmarks. Specifically, the Parties are working on initiatives, among others, to expand the transitional homes project, create crisis apartments, expand integrated day activities in meaningful community settings, and address ongoing polypharmacy issues. The Commonwealth has provided assurances that the $10M in budgetary reserve funding will be available next fiscal year, in addition to the regular annual DSPDI budgetary allotment.

The establishment of such programs and the implementation of reforms will be crucial in the coming years considering that the IDD population serviced by the DSPDI will be significantly increased when eligible individuals that are currently under the jurisdiction of the Department of Family Affairs (DFA), as well as those in the Department of Education, start receiving services from the Department of Health.

According to the information obtained as a result of the collaborative agreement between the above agencies, there are currently 640 individuals with IDD under the DFA's jurisdiction, out of which the vast majority (perhaps about 75 percent) of whom are likely eligible to receive services from the DSPDI. Additionally, in 2018, the Department of Education reported that it serves 5,480 students with IDD, out of which 438 could have been eligible for DSPDI services at the time. We expect that eligible individuals formerly served by DFA and/or DOE will be included in the DSPDI's census by the next Report.

The JCC and the DSPDI are working in collaboration with Court-Appointed Expert, Dr. María Margarida Juliá, who is actively engaged in assisting the Division in the transition process for the individuals from DFA to DSPDI. Beginning with the next report, the DSPDI should ensure that individuals from DFA with IDD are included in the Master List. If not yet admitted, the DSPDI should, at minimum, include these individuals in the DSPDI waitlist and in the Statistical Data Report presented for Benchmark 32.

Dr. Margarida Juliá, in conjunction with the JCC and our team members, is also assisting the DSPDI in the creation of emergency transition plans; such plans are currently non-existent. Dr. Margarida is also working with the Commonwealth to develop comprehensive and written individualized plans for participants in transition centers that will serve as an essential working instrument for the DSPDI personnel.

iii. Status Report of Town Hall Meetings as Ordered by the Court

The Office of the JCC has held three Town Hall meetings since our last Report. The first took place in San Juan in December 2022, followed by one in Aguadilla in February 2023, and another in Ponce in April 2023. (See Dockets 3618, 3644, and 3653).[12] The Secretary of Health, Hon. Carlos R. Mellado, and Counsel for the United States, Richard Farano, have participated actively in all these meetings. The Department of Health has been extremely cooperative and actively engaged with participants and stakeholders in all of the Town Halls.[13]

As the Town Hall minutes illustrate, these meetings have provided a valuable forum for the JCC and the Parties to receive important information from participants, family members, service providers, government officials, and other stakeholders, especially regarding participants' needs and aspirations, among other very important information. The JCC uses the Town Hall meetings to address recurring and/or previously raised issues in earlier Town Halls, as well as specific matters that pertain to the region in which the Meetings are held.[14]

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[12] The minutes of the Town Hall meetings are attached here as Exhibits 1-3

[13] **In stark contrast to the cooperation of the Department of Health/DSPDI, the JCC is extremely disappointed by the lack of cooperation shown by the Executive Director of the Forensic Psychiatric Hospital in Ponce (which is operated by ASSMCA), Ms. Luz Torres Díaz, who ignored three invitations that were sent by the Office of the JCC, to participate in the Ponce Town Hall meeting to address issues regarding participants in ASSMCA homes and institutions.**
The above actions were surprising to the undersigned considering that, in the past, Commonwealth government officials (including the Governor's Personal Representative, the Secretary of the Department of Education, and the Secretary of Family Affairs) have always cooperated with the JCC and maintained effective communication channels. We will soon address the lack of cooperation with the Administrator of ASSMCA, who will be receiving a copy of the present Report.

[14] The next Town Hall Meetings will cover the towns of Aibonito and Cayey after a joint visit to Kansas City so that the Commonwealth can see how the use of new technologies (among other models in rural settings) are permitting similar IDD programs to effectively address the needs of its participants notwithstanding the labor challenges that presently exist throughout the United States. The Governor's Personal Representative (GPR) and the Secretary of

The meetings have created a higher level of awareness in the community regarding the services that are available for the IDD population and have served as an opportunity for a new generation of parents to voice their concerns and pre-occupations and to get acquainted with the Program and the Secretary of Health, as well as with family associations, and the Office of the JCC.

As referenced, we have addressed specific matters pertaining to each region in which the meetings are held, including deficiencies in services, day activities, transportation, employment opportunities, and housing, among others. We also learn things during our visits in the region. For example, during a visit before the Aguadilla Town Hall, our Office became aware of a participant who was improperly housed in an ASSMCA facility for individuals with drug addiction even though this participant never had any form of drug dependency issues. We worked with the Commonwealth to ensure that he was expeditiously transferred to a proper community home. Around the time of the Town Hall, our Office also became aware of a participant with severe IDD who lacked a wheelchair for her daily and community-based necessities and activities, and we assisted her in obtaining one, among other services she needed.

Around the time of the San Juan Town Hall, we also received information regarding deficiencies in the Río Grande CTS, which are now being addressed by the DSPDI, including the possibility of finding a new location for the daily center. Around the time of the Ponce Town Hall, we received information regarding the need for additional vehicles for the Ponce CTS, which we passed along to DSPDI for action.

Before each Town Hall, the Office of the JCC conducts unannounced evening visits to community homes in the regions where the Town Halls are set to take place to assess conditions and practices and to ensure that they have proper emergency plans for hurricanes, earthquakes, and fires, including the proper inventory of emergency backpacks with water, food, clothes, and prescription medicines, in the event that an evacuation by the home needs to take place.

The results of these visits are then discussed with the DSPDI to ensure that the service providers, which are the first responders in case of emergencies, can meet individualized needs in an emergency. We have also identified homes with municipal permit challenges; we have shared outstanding issues with the Division so that DSPDI can assist these providers in addressing the challenges.

iv. Special Recommendations Regarding Interagency Collaboration

In order to enhance participants' access to community-based activities and foster social inclusion, independent living skills development, and employment and training opportunities, the undersigned recommends that the DSPDI strengthen its collaboration with other Commonwealth agencies, entities, public corporations, and municipalities. This will require active engagement with all Commonwealth governmental components, including but not limited to, agencies specializing in transportation, vocational rehabilitation, law enforcement, correction, sports and recreation, and workforce investment

Health's General Counsel have expressed their commitment to join the members of the DSPDI and the JCC in their visit to Kansas City.

to align policies, funding, and initiatives to guarantee that the entire IDD population in Puerto Rico receives the maximum level of services that they are capable of receiving from the government. In addition to the above, we expect that a collaborative agreement between the DSPDI and ASSMCA be formalized by the next JCC Report.

v. Collaboration with Hyundai of Puerto Rico for Recruitment of Participants into Integrated Competitive Employment

The Office of the JCC, the Experts, and the DSPDI are currently conducting collaborative efforts to establish an alliance with Hyundai of Puerto Rico, and all the big automotive distributors in Puerto Rico, to develop recruitment programs for individuals with IDD to join their work force.

This may prove to be the single biggest employment procurement accomplishment to positively impact the IDD population on the Island to date and may pave the way for other corporations to provide integrated competitive community employment opportunities to people with disabilities. This then could ultimately allow participants in this jurisdiction to realistically aspire to independent living.

As part of the above efforts, on June 22, 2023, the JCC participated in an event hosted by the car dealerships association, who has also approached our Office to provide a presentation similar to the one provided to the automobile distributors association, which will be provided in July 2023. The DSPDI has also scheduled a meeting with the human resources department of Ambar Motors. The JCC will continue to assist the DSPDI in these meetings with the automotive industry.

II. ASSESSMENT OF SPECIFIC JCAP MANDATES

A. Polypharmacy and CAPAR

General Observations

The Commonwealth is in the midst of taking meaningful steps to address outstanding issues related to polypharmacy.

The Commonwealth's Committee for the Assessment of Polypharmacy and High-Risk Participants (CAPAR) is undertaking reviews of the healthcare/mental health care of participants, including their current diagnoses and their prescribed medications. To facilitate this process and prioritize people at the highest risk for adverse health-related outcomes, the CAPAR has developed a process and related form to guide the reviews. The CAPAR team has been regularly working with JCC experts; we have conducted a joint collaborative review and worked together to refine their prioritization criteria.

The CAPAR team has distributed the prioritization criteria to the DSPDI Incident Review Committee, to service mediators (in progress), and to other professionals (e.g., EID team members) that may refer participants to CAPAR for this review who either meet the high-risk criteria or have had a significant change in condition.

Over 150 participants have been reviewed through the end of this period, with at least 25 participants having been reviewed twice. Most of the reviews of participants conducted through the current period have been of participants living in community-based group homes.

As part of the CAPAR reviews, the clinicians are reviewing and confirming the diagnoses listed in each participant's record. The CAPAR team reports finding some diagnoses that appear to be inaccurate (for example, schizophrenia) in an adult with profound ID), as well as diagnoses that are given to justify the use of psychotropics with sedating effects, likely to manage behaviors, without clinical justification.

The CAPAR team has directly observed participants and has reported that participants are showing signs of substantial sedation in multiple cases. These observations are consistent with observations made during the current and previous periods by the JCC team. The CAPAR team has observed multiple instances of extended-release medications being administered 3-4 times per day, and intraclass polypharmacy (e.g., use of two or more concurrent antipsychotics).

The CAPAR team is also finding the secondary effects of polypharmacy, such as chronic constipation and tardive dyskinesia, in participants. In addition to the high-risk criteria, the CAPAR neurologist (Dr. Porfirio Rodriguez) has been reviewing and seeing all participants with a seizure disorder (responsive to Benchmarks 67-72), including with home visits, with the intent of establishing monotherapy whenever appropriate.

For many of the participants that have been reviewed to date, the CAPAR team has recommended reductions in psychotropic medications. They presented multiple examples to JCC experts (e.g., participants #332, 1155, 11, 1087, 714, 388, 354, 507, 761, 909, 775). The CAPAR is finding the use of multiple psychotropic medications, which may not be supported by the person's diagnoses, or are supported by diagnoses that appear to be inaccurate (e.g., the wrong type of diabetes listed, psychosis-related diagnoses that do not appear to be justified).

Examples of medications recommended for reduction by the CAPAR include anxiolytics (anti-anxiety medications that frequently have sedating and other side effects), anticonvulsants (used to treat seizures and sometimes for other off-label uses, that frequently have side effects related to sedation, constipation, among other things), and first-generation antipsychotics.

While some of the medication regimens prescribed to manage seizures have been found to be appropriate, there are also patterns of improper use of medications, such as using multiple antiepileptic medications at subclinical diagnoses, which is not considered to be good clinical practice and may be ineffective in managing seizures. In other cases, participants who have not had a seizure in a long period (e.g., greater than five years) are on antiepileptic medications that may not be necessary and are being recommended for reduction or elimination.

The CAPAR issues recommendations for medication changes to prescribing physicians, which are generally community-based physicians. Some prescribers have been receptive to the changes. CAPAR experts (e.g., Dr. Santiago Noa, psychiatrist) have been offering education to community-based prescribers regarding the effects of barbiturates on behaviors and inter- and intra-class polypharmacy combinations that are not supported, as well as by the neurologist on proper use of medications for seizure management.

Changes recommended by CAPAR have mostly been successful, and they have been able to successfully taper off some participants from one or sometimes multiple psychotropic medications. Changes have been observed among multiple participants after medication changes, such that they are less sedated/more alert, less constipated, eating better, are having fewer adverse behaviors, etc.

The CAPAR has often reported encountering resistance to these recommended medication changes from some of the community-based prescribers, some of whom manage prescriptions for multiple participants. The CAPAR presented examples to the JCC experts.

For example, a prescriber cited a diagnosis of 'intermittent explosive disorder' for a participant and behaviors that the prescriber states are a risk to the participants or other people; however, there is frequently no known history of these behaviors in these participants and observations by CAPAR clinicians do not support these diagnoses.

In cases of persisting resistance by prescribers to change medication regimens that are substantially sedating and deemed contraindicated for the participants, changes in prescribers are being sought. In some cases, CAPAR clinicians are taking on these participants as patients, even if on a time-limited basis, to be able to properly readjust their medication regimens and reduce unwarranted polypharmacy before

transitioning these participants to other prescribers. In other cases, the CAPAR team is helping participants exercise their right to change insurance plans, prompting a change in prescribers under Medicaid managed care programs.

As part of more systemic approaches, the CAPAR team is working with Medicaid managed care programs to increase their understanding of the needs of people with I/DD, and to train providers on medication management. They are also working with insurers to explain why these reviews are occurring to try to get buy-in from these payers on recommendations for medication changes, and in turn from prescribers associated with these plans.

Although there has been significant progress in this area, CAPAR needs to continue conducting reviews until all participants have received them. Nonetheless, we are confident that the progress that we have recently witnessed will ultimately lead to systemic reforms and the eradication of harmful polypharmacy practices.

There is still important and complex work to be done to complete a full review of participants. We will be addressing this matter (and polypharmacy in general) in future reports.

B. Opening of Specialized Community Homes[15]

In August 2021, the DSPDI introduced the concept of Specialized Community Homes ("SCH") to address the specific healthcare and behavioral management needs of certain participants. This initiative resulted in the creation of two distinct types of specialized home models.

The unique design of these homes promises to offer dedicated living spaces where participants can receive specialized attention and aspires to ensure that their special needs and challenges are serviced in the community with the highest levels of support – beyond what typical community homes offer.[16]

One of the SCH models, known as the **specialized health care services** home model, is designed to cater to participants who are bedridden, have compromised immune systems, experience significant mobility limitations, and require assistance in all their activities.[17] This home model is required to have its own interdisciplinary team comprised of a social worker, a graduate nurse per shift and, a nurse practitioner per shift (Home EID). Per the home contract, the social worker shift consists of 40 hours per week and should be available in case of emergency during non-working hours including nights, weekends, and holidays. In addition to the Home EID, the home is required to have one regular support staff for a total staff of three during every shift, not including the social worker.

The **specialized behavioral management** home model is tailored to participants with dual diagnoses of developmental disability and mental health.[18] This home model is required to have its own interdisciplinary team comprised of a psychologist, a recreational therapist, and a social worker (Home EID). Per the home contract, the Home EID shifts are 40 hours per week and should be available in case of emergency during non-working hours including night, weekend, and holidays. In addition to the Home EID, the home is required to have two regular support staff per shift for a total staff of two during every shift, not including the psychologist, recreational therapist, or the social worker. The Commonwealth recognized that these high-risk participants need individualized and consistent support and planning to address their complex health care and mental health needs.[19]

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[15] In their response to the JCC's first draft of the present Report, USDOJ requested that the Office of the JCC include additional factual information on its findings. Thus, additional detail, examples and facts were included based on interviews conducted with parents and family members of participants, direct caregivers, and service providers, DSPDI Central Office and CTS personnel, on-site visits, observations, direct communications with participants and review of information and documents furnished by the DSPDI and/or obtained by the Office of the JCC.

[16] "Opening of New Providers of Residential Communities" (Period 2021-2023, as revised and summitted for Benchmark 14).

[17] Id., page 4.

[18] Id., page 4.

[19] DSPDI reports that 447/660 participants in the Program have a dual diagnosis and are considered as high-risk. We note though that as a result of its ongoing reviews, CAPAR (discussed in Section II, Part C of this Report) is finding that some participants do not have a mental health diagnosis that justifies the utilization of psychotropic medications, and instead, is finding that these medications are likely being used for behavioral management and/or sedation. Thus, the number with a dual diagnosis may be overestimated at this time. Reinforcing this conclusion, we note that the sublist of participants with a mental health diagnosis on the Commonwealth's list at Benchmark

As of December 31, 2022, the DSPDI has six SCH: three specialized behavioral management homes and three specialized health care services homes, see below. The Office of the JCC and its team of experts have visited all six specialized homes on more than one occasion in our monitoring capacity. DSPDI reports that an additional specialized health care home (House of Heaven) with six beds for female participants is soon scheduled to open in the Municipality of Bayamón.

Specialized Community Homes as of December 31, 2022:

i. **Specialized Behavioral Management Homes (three homes with a total of 19 male participants):**

1. ***Hogar Casa Elvira*** **-** This specialized home opened on February 17, 2016, in the Municipality of Toa Alta and is the home of six male participants**.** Per lists submitted by the DSPDI, five of the six participants attend the Bayamon CTS (See Benchmarks 32 and 33). However, after we interviewed the home personnel, we learned that none of the participants actually attend the CTS. Of the six participants residing in the home, three participants are working in the community (Participants #591, #902 and #1032 work at Tonka Car Wash in Toa Alta 20 hours a week for piece work pay, See Benchmark 17). Working participants are supported in their employment by home personnel and not the CTS "job promoters" or "job trainers". The Home EID receives support services in a consulting capacity from the EID of the Bayamón CTS.

2. ***Hogar Belén I*** **-** This specialized home opened on November 30, 2021, in the Municipality of Toa Alta and is the home of seven male participants**,** which the JCC considers to be overcrowded. Placement of six of the participants was due to the abrupt closure of the Erickmar community home in January 2022. The seventh participant was initially transferred from Erickmar to the Frank Santiago substitute home, and on March 7, 2022, transferred to *Belén I*. Per a list submitted by the DSPDI, none of the participants attend the Vega Baja CTS (See Benchmark 33, reason for not attending: "participates in activities of the specialized team belonging to the home"). Further, none of the participants work in the community. The Home EID receives support services in a consulting capacity from the EID of the Vega Baja CTS.

3. ***Hogar Belén II*** **-** This specialized home opened on July 11, 2022, in the Municipality of Corozal and is the home of six male participants. Per a list submitted by the DSPDI, four of the six participants attend the Bayamon CTS (See Benchmark 32). However, after we interviewed the home personnel, we learned that none of the participants

93, includes only 340 participants with a mental health diagnosis, which is less than those identified as at high risk with a dual diagnosis.

actually attend the CTS.[20] Further, none of the participants work in the community. The Home EID receives support services in a consulting capacity from the EID of the Bayamón CTS.

ii. Specialized Health Care Services Home (three homes with a total of 12 males and 6 females)

1. ***Brisas del Paraíso II –*** This specialized home opened on November 30, 2021, in the Municipality of Aguadilla and is the home of six male participants. Per a list submitted by the DSPDI, one of the six participants attend the Aguadilla CTS (See BM 32). However, after we interviewed the home personnel, we learned that none of the participants actually attend the CTS.[21] Further, none of the participants work in the community. The Home EID receives support services in a consulting capacity from the EID of the Aguadilla CTS.

2. ***Huellas de Amor* -** This specialized home opened on May 31, 2022, in the Municipality of Cabo Rojo and is the home of six female participants. Per a list submitted by the DSPDI, five of the six participants do not attend CTS. (See BM 33, reason for not attending: "Community activities adapted to health condition and/or severity of ID"). Further, none of the participants work in the community. The Home EID receives support services in a consulting capacity from the EID of the Ponce CTS.

3. ***Quality Care Assistance* -** This specialized home opened on August 16, 2022, in the Municipality of Manatí and is the home of six male participants**.** None of the six participants attend a CTS (See BM 33, reason for not attending: "They receive recreational therapy and occupational therapy services in the home, adapted to their needs according to their medical diagnoses). Further, none of the participants work in the community. The Home EID receives support services in a consulting capacity from the EID of the Vega Baja CTS.

General Overview

Unfortunately, despite the complexity of the participants and the diverse range of services required to meet their needs, there is an absence of clinical criteria in the DSPDI for the placement and ongoing service of participants in the SCH.

Although we found that some SCH (such as *Huellas de Amor* in Cabo Rojo) are effectively documenting incidents and important information in Therap, maintaining effective communication with participant

[20] It should be noted that none of the participants were included in the sub-list submitted for Benchmark 33 regarding participants not attending a CTS. This needs to be rectified – both the reporting and the failure to attend CTS services.

[21] It should be noted that none of the participants were included in the sub-list submitted for Benchmark 33 regarding participants not attending a CTS. This needs to be rectified – both the reporting and the failure to attend CTS services.

family members, and have a properly trained staff to provide the intended specialized services, other SCH show some deficiencies in these and other areas.

Given this, the JCC recommends that the Commonwealth develop a clear description and operational guidelines for both models of specialized care to ensure that they properly render the intended services to participants. The guidelines should provide clear inclusion and exclusion criteria for participant placement/ongoing services and should outline the specific responsibilities of providers in terms of staffing, training, and all related specialized services. This will improve the delivery of needed services to the individuals living in the SCH.

Specific Observations and Recommendations

1. Participant placement process in Specialized Community Homes

There are deficiencies in the SCH placement process that need to be addressed, and modifications that need to be implemented. DSPDI needs to ensure that the placement of participants in SCHs meets the high-risk criteria established by the DSPDI.[22]

The current transition and placement process often lacks needed specific details and proper documentation. Case discussions fail to integrate evaluations by the Specialized Clinic in Evaluation and Consulting ("CEEC", for its Spanish acronym) with the input of the interdisciplinary team of the specialized home, the home provider, and the participant's family members (which are valuable, and at times, essential resources). Similarly, the CAPAR's involvement in treatments and diagnoses also lacked coordination with family members and providers.[23]

Whenever appropriate, the transition process should promote family involvement. As recommended by Court and Party-Expert, Dr. Margarida Juliá, in other similar complex behavioral management and dual diagnoses cases, regular family visits and relationships with participants are important and should be

[22] For example, upon the closing of *Erickmar* group home, all seven participants were ultimately placed in *Hogar Belen I*, a specialized behavioral management home. Although all seven participants are listed in the high-risk list for mental health (see Benchmark 59) not all require persistent and specialized support. For example, Participant #648; per interviews with the Home EID participant has responded to the psychiatric and psychological management plans and his high-risk behaviors have dramatically reduced. That is, the participant remains stable, alert, and responsive without exhibiting high-risk behaviors. Further, not all participants placed in the specialized health care homes are "bedridden, have compromised immune systems, experience significant mobility limitations". For example, Participant #791; participant was placed on *Huellas de Amor* on May 31, 2022, due to uncontrolled epilepsy episodes, participant was then transferred out of *Huellas de Amor* on December 14, 2022. On the other hand, Participant #24 who is bedridden, immune compromised and has had a recent high number of hospitalizations could benefit from placement in a specializes health care service home.

[23] In its response to the draft report shared with the Parties, the DSPDI reported that "since recently, the CAPAR meetings include the participation of the participant's caregivers, family members and/or providers, in each case discussion. This has enriched the case discussions and has proved to be a valuable tool in CAPAR's assessment, as well as a way for the caregivers to be more involved in its family members' care."

encouraged when appropriate to maintain emotional connections, improve mental health, and higher motivation for independent living.

2. Treatment planning and services

Once it is determined that a participant would benefit from placement in a SCH, the Commonwealth needs to develop an adequate treatment and service plan for each person, using person-centered planning principles at all times, to ensure that the specialized services are tailored to the participant's particular needs. The Office of the JCC has several concerns related to these plans that need to be addressed promptly by the DSPDI.

As established by the Court, Person-Centered Plans ("PCPs"), which are now also referred to as Individualized Support Plans ("ISPs"), are to address the participants' needs and preferences. These plans serve as the foundation for treatment and service going forward.[24] See Docket No. 3510.

Unfortunately, our review of Personal Focus Worksheets ("PFWs") and ISPs revealed insufficient involvement of participants, family members, and providers which may ultimately affect the assessment and determination of the participants' personal goals, desires, preferences and skills and the effectiveness of the services and supports rendered to the participant.[25]

For example, the ISPs often do not include the foundations, goals, and measurable objectives that should form the basis of the services that need to be provided to participants in the SCH. Moreover, we found that the outings and integration activities do not always align with the ISP or the associated case notes, as required by the plan's provisions. [26]

[24] Per narrative presented by the DSPDI at Benchmark 40, the EID performs recurrent participant assessments to ensure that the health and safety of participants and aimed at risk prevention to promote the optimal level of functioning of the participants. The contents of these evaluations are materialized in three electronic file areas, the ITP (Individual Transition Plan which records specific recommendations related to identified needs and precipitating factors in areas of physical and mental health, areas of support and independence, nutrition, behavioral aspects, psychiatric indicators, relational, social and environmental factors), the PFW (annual assessment by the EID on interests and needs of the participant), followed by the ISP in which all the disciplines make transdisciplinary recommendations in conjunction with the interests of the participant, formulating an integrated plan of services that will govern the work of the interdisciplinary team. Participants' case discussions agenda and minutes of said case discussions are recorded in the Individual Plan Agenda (IPA).

[25] For example, Participant #1093. This participant was placed in *Hogar Belén II* on July 11, 2022. Case discussion on the participant's diagnosis took place on October 28, 2022, almost four months after placement. Participant's PFW was also developed close to this date, on November 3, 2022, and there is no evidence of the integration of the participant and the provider in the same. Inconsistencies regarding the supports needed by the participant were identified. As of December 31, 2022, no ISP had been developed for the participant.

[26] Per narrative presented by the DSPDI at BM 40, the EID performs recurrent participant assessments to ensure that the health and safety of participants and aimed at risk prevention to promote the optimal level of functioning of the participants. The contents of these evaluations are materialized in three electronic file areas, the ITP (Individual Transition Plan which records specific recommendations related to identified needs and precipitating factors in areas of physical and mental health, areas of support and independence, nutrition, behavioral aspects, psychiatric

Too often participants do not have Individualized Care Plans (ICP) that correspond to their needs such as with regard to: aspiration risk, epilepsy, constipation, hypothyroidism, fall risk, hypertension, among others.[27] [28] Such failures could ultimately lead to preventable deaths. In the past, DSPDI has immediately addressed other areas of concern; we expect the same level of coordination to address these matters. Further, upon review of individual ICPs it was found that some recommendations are not being followed. For example, participant #153 has an ICP for hypothyroidism approved and updated by the nursing area as of October 24, 2022, which recommend that the participant's weigh be recorded on a weekly basis in the electronic record. No weekly recording was found from the date of approval of the ICP to December 31, 2022. The next weigh recording evidenced was on February 25, 2023.

For participants with behavior problems, especially those residing in specialized behavioral management homes, the Commonwealth must provide all participants with separate comprehensive health and mental health assessments. For those with non-health, non-mental illness-related behaviors, the Commonwealth must provide each participant with a functional behavioral assessment (to identify the underlying causes of their behavior) and a behavior support plan (that is then properly implemented 24/7 by trained staff).[29]

Based on the interviews conducted by members of the JCC of the three specialized behavioral homes, home personnel, including Home EID, supervisors, and caregivers, with few exceptions, lack a clear understanding of participants' risk and behavior, as well as their role in the treatment plans, and in their implementation. The current services provided by home personnel are primarily based on day-to-day events and observations, rather than following a well-defined and established plan.

To address unresolved issues, the Commonwealth must (with a sense of urgency) improve guidance and training to home personnel to ensure they have a comprehensive understanding of the above matters

indicators, relational, social and environmental factors), the PFW (annual assessment by the EID on interests and needs of the participant), followed by the PCP/ISP in which all the disciplines make transdisciplinary recommendations in conjunction with the interests of the participant, formulating an integrated plan of services that will govern the work of the interdisciplinary team. Participants' case discussions agenda and minutes of said case discussions are recorded in the Individual Plan Agenda (IPA).

[27]Currently individualized care plans to participants includes: Constipation/Intestinal Obstruction, Hypertension/High Blood Pressure, Risk of Falls/Head Trauma, Hypothyroidism, Epilepsy and Risk of Aspiration. These plans are prepared by the CTS or Central Office Nurse and implementation is monitored by the CTS Nurse Supervisor or Nurse Coordinator from the Central Office. During the period of evaluation, the DSPDI was in process of revising the "Manual de Servicios de Enfermería," 2018 version. The revision should be finalized to reflect current procedures.

[28] There were various participants listed in the high-risk list per Benchmark 59 that do not have an ICP. For example, Participant #74 is identified as high risk for constipation and does not have the corresponding ICP; Participant #388 is identified as high risk for constipation and does not have the corresponding ICP; Participant #332 is identified as high risk for dysphagia and epilepsy and does not have the corresponding ICPs.

[29] During our review, it was found that most of the participants in the specialized behavioral management homes do not have behavioral support plans. Services are provided based on day-to-day needs.

and to ensure a consistent level of services across all SCH. The above endeavor can be diligently accomplished by the DSPDI.

3. Personnel Components of the Specialized Community Homes

To ensure that the participants in the SCH are receiving the specialized services that they require, the DSPDI must ensure that the SCH personnel are properly trained to provide such services and that they have the corresponding team of professionals available to support them. The DSPDI requires that the interdisciplinary team for each specialized behavioral management home consist of professionals from various fields, including psychology, recreational therapy, and one social worker (this is considered the "Home EID"). For the specialized health care homes, the Home EID consist of one social worker, a graduate nurse, and a nurse practitioner. All of the above professionals should be ready to render important specialized support services to SCH and its personnel.

Monitoring findings

In some of the SCHs, the following deficiencies were observed:

a) Key personnel of the Home EID of the specialized behavioral management homes do not have any prior experience with the IDD population or have been adequately trained to provide services to individuals with IDD. Given that these SCH provide services to complex and high-risk cases, the DSPDI should set forth in its guidelines some minimum, professional requirements (experience and/or training) for the professionals comprising the Home EID;
b) Personnel of the Home EID of the specialized behavioral management homes are shared between homes not providing the 40 hours per week shifts required per contract. (For example, professionals in Social Work and Psychology offer services to both *Hogar Belen I* and II). Moreover, distribution of services per home and participants are based on day-to-day needs and not planned;
c) The Home EIDs of the of the specialized behavioral service homes lack a designated Recreational Therapist, as such discipline is defined by the DSPDI protocols and being a mandatory requirement in the home service contract;[30]
d) During the evaluation period, one of the two psychologists of the Bayamon CTS, one of CTS' with the highest census was also responsible for providing consulting and support services to the three specialized behavioral management homes. As mentioned above, there is a lack of guidance and protocols regarding the consulting services to be provided by the CTS EID to the Home EID. These guidelines are essential in order to determine the adequacy of the services provided in said homes;
e) There is no clear definition or guidance as to the services to be provided from the Home EID, CTS EID, the CEEC and other services provided by the DSPDI. In the interviews that were conducted

[30] During the period of evaluation, the homes had support staff to whom the designation of "Recreational Leader" was assigned.

for this report, we found uncertainty regarding the responsibility of developing and implementing plans and the level of support expected from the "consultant" of the CTS; and

f) There is a notable disparity in the accessibility of the CTS' interdisciplinary services between participants in regular community homes receiving services from the CTS EID and those in the SCH. For example, the three employed participants residing in Casa Elvira do not receive necessary support services from the Bayamon CTS' vocational rehabilitation staff. Said participants are accompanied and assisted in their work tasks by Casa Elvira caregivers.

Although not required by the JCAP, it is worth acknowledging that three of the homes had a cook available per shift that seemed knowledgeable on the nutritional requirements of the participants. This allows the support personnel to continue to provide services to participants while the meals are cooked, per the needs of the participants.

Recommendations

In order to guarantee that the required specialized services are provided, the full-time Home EID should assist the support staff in essential areas, such as:

a) Emotions and behaviors;
b) Managing participants' frustration;
c) Decision-making;
d) Managing participants' sexual needs in appropriate ways;
e) Strategies for coping with and adapting to change, managing loneliness, managing mood swings, and self-care among others;
f) Social skills training through modelling and regular feedback;[31] and
g) Among others.

SCH providers should consider sharing their experiences, available resources, and the challenges they are confronting in an effort to provide uniform and elevated services across all SCHs. Providers in the same regions should also share their emergency plans, including meeting points and challenges they could confront during an emergency. This is based on our unannounced visits before Town Hall Meetings, as well as recommendations requested by providers.

4. <u>Incident Review of Specialized Community Homes:</u>

[31] It is also necessary to have a regular routine of group and individualized activities outlined and supervised by staff in collaboration with regular support personnel that includes some source of social interaction, outdoor activities, exercise, and contact with other individuals when possible.

Regarding the above, many of the incidents that were reported or identified are high-level and some unsurprisingly, ultimately led to hospitalizations under Law 408, which is the most drastic and restrictive legal measure for individuals with IDD.[32]

The DSPDI reported that two participants suffered fractures as a result of inadequate interventions from the staff of *Hogar Belén II* (Participants #1123 and #1127).

The JCC recommends that the DSPDI develop an Education Guide for service providers, the Home EID, and the support staff of behavioral homes to ensure that staff are adequately and continuously trained. Said training should be competency-based and should provide for pre-tests and post-tests to validate learning in continuation of competent services, which should be the standard for continuous capacitation. For example, training topics could include:

a) Adequate clinical and incident-related documentation in Therap;
b) Continued education on the Mental Health Disorders that predominate in the population (Benchmark 59), and their manifestations; cognitive impairments;
c) Crisis Intervention and positive behavioral supports;
d) Protective Techniques;
e) Suicide Prevention;
f) Intervention models;
g) Legal consequences for staff who engage in negligence or abuse;
h) Assessment and screening of participants;
i) American with Disabilities Act (ADA);
j) Right of individuals with disabilities to request and obtain employment free of discrimination due to illness;
k) Right of individual with disabilities to receive technical or professional assistance to reach their potential; and
l) Among others.

As previously stated, the DSPDI should consider using available monitoring technology that may assist them in identifying, in real time, the underlying causes that lead to serious and dangerous incidents so that the same can be effectively prevented and/or immediately serviced.

5. Therap Documentation by Specialized Community Homes:

There is a lack uniformity in the SCH information supplied to Therap, which is of great concern to the undersigned. For example:

a) *Hogar Bélen I* - Only recorded vital signs in October;

[32] Specifically, there were 11 incidents involving four participants in *Hogar Belen II* that led to hospitalization under Law 408. Participant #990 with one incident, participant #1093 with two incidents, participant #1123 with six incidents of aggressiveness towards support staff and participant #1127 with one incident.

b) *Hogar Bélen II* – Did not document participants' bowel movements;
c) *Brisas del Paraiso II* – Did not document participants' weight;
d) *Huellas de Amor*- Only documented vital signs; and
e) *Hogar Casa Elvira* – Did not provide proper documentation for November and provided minimal documentation in December 2022.

Moreover, behavioral plans were not included in the Plans Module of the Therap platform. In some instances, behavioral plans were attached in the psychologist case note, although we must note that they were not consistent.

The DSPDI should keep monitoring the adequacy of the information entered in Therap and training the home personnel on the use of the platform as there continues to be lack of documenting in order to avoid "trash in, trash out" documenting practices. Participants in specialized behavior homes should have individualized and accessible behavioral plans on the Therap platform for the benefit of the provider and direct service employees.

It is imperative for the DPSDI to understand that he above recommendations are being furnished to assist the DSPDI in resolving identified deficiencies in the services provided by SCH and achieve the intended positive outcome in participants with specialized behavioral and health care needs. The JCC and all Experts agree that if implemented as intended, these home models have the potential to guide the Division towards positive outcomes in matters related to the overall health, safety, and well-being of participants in order to comply with the mandates of the JCAP. To achieve this, the DSPDI at a minimum needs to: provide clear and clinical placement parameters; provide necessary basic and specialized training to the home personnel; develop and ensure the implementation of guidelines on the responsibilities of specialized providers, the identification of the services to be provided, and the interventions and consultation that should be provided by the Home EID and the CTS and/or Central Office EID; develop quality assurance procedures for the verification and monitoring of the qualifications and services that need to be provided to participants by the Home EID, preparation and implementation of plans and such, among others. The Office of the JCC and Experts are willing to assist the DSPDI in all matters that pertain to specialized services in SCH.

C. Integrated Employment and Day Activities

General Overview

The JCC notes the progress the DSPDI has made in continuing to build the capacity and expertise of front-line rehabilitation staffing by introducing training around evidence-based practices[33] (discovery, employer engagement, customized employment strategies) to support participants in pursuing competitive integrated employment opportunities.

We encourage the DSPDI to continue to address gaps and barriers in current policies and standard operating procedures that are impeding participants from pursuing employment and preventing staff within community homes and the CTS system from adequately supporting job and independent living skills development of the participants.

Commitment of resources by the DSPDI is required for continued training and professional development of the multidisciplinary teams to support and prioritize participants' individual employment goals. The above funding is critical to the successful implementation of existing evidence-based models like customized employment.[34]

The JCC and the Office's subject-matter expert also recommend that the DSPDI place a greater emphasis on addressing gaps in available community-based day activities (due to accessibility and transportation challenges[35]) and to facilitate and integrate family support. This will consequently allow participants to access the support services that they need at home and in the community to successfully attain desired employment opportunities and outcomes.

Specific Observations and Recommendations

Throughout our review of integrated employment and community practices, the Office of the JCC has identified the following as the primary challenges the DSPDI must overcome to reach full community inclusion and competitive integrated employment for participants:

[33] Evidence-based employment models refer to approaches or strategies in the field of employment and workforce development that are founded on rigorous research and empirical evidence. These models are designed and implemented based on proven effectiveness and positive outcomes demonstrated through systematic evaluation and analysis.

[34] Customized employment is defined as competitive integrated employment, for an individual with a significant disability, that is: based on the individual with disabilities' unique strengths, needs, and interests; designed to meet the specific abilities of the individual and the business needs of the employer; and carried out through flexible strategies, such as job exploration, and working with an employer to facilitate placement.

[35] The JCC has been recently informed that the DSPDI has acquired 11 new vehicles with assistive equipment to help transport participants to their jobs among other activities.

i. Updating Departmental Policies and Protocols to Support Employment and Community Integration

Through our in-depth document review, interviews, and on-site visits with participants and providers, the JCC team identified several practices and policy implementation challenges internal to the DSPDI that are impeding its direct support staff from adequately assisting participants in considering, procuring, and attaining competitive integrated employment and optimal community integration.

While the Commonwealth's Manual of Standards and Procedures Services in Rehabilitation Counseling (the "Manual") states that, "*The applicability of this Manual includes all Rehabilitation Counseling service professionals and Central Level Interdisciplinary Team and Transitional Center Personnel,"* we continue to identify a disconnect among members of the interdisciplinary team, as well as a general lack of prioritization of employment and community integration in the daily life for participants.

In at least two cases during the monitoring period, psychologists made a determination without consulting the vocational rehabilitation counselors that participants should be removed from employment due to recent behavioral challenges. Additionally, psychologists and other specialists involved in the interdisciplinary team have received little to no training on the importance of competitive integrated employment to recovery/treatment, or the principles behind customized employment strategies. Consequently, and in detriment of participants, the DSPDI does not engage in or prioritize the employment modules of the ISP.

It is essential that the DSPDI proactively support necessary revisions to key policies and updates to internal procedures as needed to elevate and ensure sufficient prioritization of employment and community engagement goals. In Exhibit #4, the JCC will provide recommendations that, when adopted and implemented by the DSPDI, will assist the Division in significantly improving the services that they give in the area of evidence-based integrated employment and day activities.

ii. <u>Continue Capacity Building Efforts to Expand Adoption and Implementation of Effective Practices that Lead to Competitive, Integrated Employment</u>

The DSPDI is committed to capacity building and the undersigned commends the Division for the same. The Office of the JCC expects that capacity building among DSPDI personnel, contract staff, providers, and families will continue to be a top priority since the Commonwealth recognizes that systemic reforms will accelerate compliance levels and positive outcomes. The following recommendations arise from work group sessions and from reviews and analytical activities that were completed during this reporting period:

- <u>Continue to Build the Capacity of the Vocational Rehabilitation Counseling Services Area (ASCRV) and CTS Staff in Supporting Employment and Community Integration Goals of Participants:</u> The DSPDI should commit additional resources in a longer-term training and technical assistance initiative to help continue to support and coach ASCRV and CTS staff in the implementation of

Customized Employment (including Discovery and Exploration, Employer Engagement, Job Negotiation, and ongoing Job Coaching). The DSPDI should also review challenges within the CTS programs in Aibonito, Cayey and Aguadilla that result in lack of employment outcomes.

- Conduct Training of Entire Interdisciplinary Team on Customized Employment Model: Now that the ASCRV staff has completed an in-depth training on customized employment best practices, it is imperative that the DSPDI continue to train all other professionals serving on participants' interdisciplinary teams (psychology, social work, occupational therapy and recreational therapy) on the philosophy behind evidence-based customized employment, as well as techniques in the discovery process that can be easily applied and interwoven within their work to benefit participants and inform person-centered thinking and practice.

  Clinical staff should also be encouraged and trained to proactively engage ASCRV staff in the development and discussion of ISPs and clinical interventions to assure better coordination on strategy and actions.

- Provide Orientation, Training and Ongoing Coaching Supports for Families to Spur Stronger Community Integration: The Office of the JCC further commends the exploratory work that the DSPDI has conducted to better understand what families need to do to become more supportive of participants transitioning into the community while achieving independence and community inclusion.

  In particular, the undersigned commends the work that is underway to connect families with other family peers with the objective of sharing resources and experiences to give families tools, strategies, and models for helping participants engage in and enjoy the benefits of community living and employment.

  It is important that the DSPDI continues to work towards an agreement with Puerto Rico's Council for Developmental Disabilities (known as CEDD in Spanish) to obtain the assistance and expertise of family advocates and peers in developing training and technical support for parents and families who need further outreach/education/service options and support for their loved ones in daytime community activities.

  The JCC also recommends that the DSPDI offer both general and specialized training to families, CTS provider staff, and suppliers/vendors on the Customized Employment Model, and specifically on ways to encourage and even use Discovery and Exploration to further encourage relationship building and priority setting with participants.

- Increase Focus on Socializing Participants and Families on Benefits Planning and Work Incentives: As more participants begin to explore and secure employment, and express an interest in earning higher wages, working more hours, or securing multiple jobs, it is critical that they and their families have access to accurate information, tools, and strategies for protecting participants' Social Security and other public benefits that help sustain their ability to live, work and thrive in

the greater community. As such, the JCC encourages DSPDI to expand existing benefits planning orientations to be conducted at least quarterly, with family members invited to attend. The orientation should provide a basic overview and include a referral of participants and families to a federally-funded Work Incentives Planning and Assistance (WIPA) site.

- Continue to Expand Employment Opportunities through Robust Employer Engagement Activities: Although the previously mentioned initiative with Hyundai of Puerto Rico is an extremely positive step forward, the DSPDI must continue to expand employment options in other sectors and types of employers throughout the Commonwealth, deploying customized employment strategies to identify ways participants can address gaps and challenges employers are experiencing.

  The undersigned has been historically concerned about the overreliance of a small group of employers (supermarkets, car washes) that may not be a good fit for many participants based on their skills, experiences, desires, and preferences.

- Provide Technical Assistance to Community Home Providers: In addition to families and CTS providers, community home providers and direct support professionals can play a vital role in encouraging participants to seek out and explore employment.

  The JCC observed several instances where direct support staff in community homes pamper participants instead of actively engaging them in skill development tasks related to daily life (like shopping, cooking, cleaning, picking out clothes, gardening). This adversely impacts their growth and development and limits their independence.

  Substantive training of front-line staff and provider leadership is imperative to assuring that the community home model produces desired outcomes prompting socioeconomic advancement, independent living, and full community inclusion of participants.

- Develop a Continuing Education Program for Participants served by ACRV: Participants need access to ongoing, adaptive, accessible training in several areas (soft skills and independent living skills development; task completion; communications with colleagues and supervisors; financial/benefits planning and work incentives; stress management; small business planning and entrepreneurship; business law; and workplace harassment) to make employment a feasible option for them.

  In addition to completing intensive on-the-job training, it is important that participants are adequately prepared during the pre-employment stage and have ongoing training support to reinforce key areas post-employment.

  Moreover, in addition to making tailored curriculum and training programs available for participants in each of these areas, it is recommended that the DSPDI work with the CTS system to establish an Employment Support Program (support group) for participants who are currently employed, are developing their own business, or are in self-employment.

The above comprehensive recommendations are being furnished to resolve internal policy deficiencies and overcome identified process barriers, while our Office simultaneously assists the DSPDI to significantly improve the capacity of its service delivery system and to promote the inclusion of families to support participants in achieving competitive integrated employment.

III. CONCLUSION

Based on the JCC's visits, meetings, interviews, and review of pertinent documents, the DSPDI continues to make meaningful strides towards reaching compliance in important areas of the JCAP.

As mentioned in our two previous Reports, the collaborative environment that has prevailed between the Commonwealth, the United States, and the Office of the JCC has been critical to the progress that the DSPDI has achieved thus far and which would not have been possible without the leadership of the Secretary of the Department of Health, Hon. Carlos R. Mellado; Auxiliary Secretary, Dr. Marilú Cintrón Casado; the DSPDI Interim Director, Mr. Danniel Soto; the DSPDI Compliance Officer, Sheila Torres, Esq., and counsel for the Commonwealth, Mr. Gabriel Peñagarícano, Esq. and Mr. Rafael Barreto, Esq.

The JCC would like to, once again, recognize the valuable contributions and participation of Secretary Mellado, and attorney for the United States Richard Farano, in the Town Hall Meetings that have been held so far, which have proven valuable to the Special Master, the Office of the JCC, the Parties, family members, service providers, and most importantly, to participants.

In addition to the above, the JCC also recognizes, once again, the valuable and continuous contributions and support received by the family organizations such as APIADI, as well as the new group of family members that have become active in Town Hall Meetings and through direct communications with the Office of the JCC. We look forward to continuing to work with all family associations and family members individually in identifying solutions so that the DSPDI can better serve the IDD population in Puerto Rico.

Although there are still areas that need to improve and services that need to be rendered, the JCC is confident that through the technical assistance that is being furnished, the DSPDI will be able to effectively improve in deficient areas in the near future. The expectation is that DSPDI then will be able to render the best possible services to participants which will have a significant impact on improving their health, safety, and wellbeing, as well as assisting the Division in achieving compliance and sustainable with the JCAP.

The deficiencies that are noted in the present report currently include gaps in current policies that impede participants from pursuing employment; gaps in community-based day activities (due to accessibility and transportation challenges, which as represented by the DSPDI will be improved); resistance to recommended medication changes from the community-based prescribers to avoid harmful polypharmacy; and lack of adequate services for both models of specialized homes so that they can meet individual participant needs, as intended.

The JCC is hopeful that transformative change in the scope and quality of the support services that participants receive from the Commonwealth of Puerto Rico as they aspire towards integrated independent living can be achieved in the near future. The Office of the JCC is committed to seeing this come to fruition both through our monitoring activities and through the technical assistance we provide as a guiding hand.

IV. BENCHMARK COMPLIANCE ASSESSMENT TABLE

- **No Compliance –** None or a negligible portion of the items of the Benchmark has been met.
- **Partial Compliance –** Some items of the Benchmark have been met.
- **Substantial Compliance –** Almost all of the Benchmark items have been met.
- **In Compliance –** Compliance with all items of the Benchmark have been met.
- **Working Towards Compliance - Still Under Review** - A compliance assessment cannot yet be provided due to ongoing and/or future technical assistance.

BM No.	Benchmark	Assessment	Finding and Recommendation
1	Translate this benchmark document, as well as any updated versions, into Spanish	In Compliance	The DSPDI has translated the benchmark document into Spanish. The Office of the JCC believes that the translation is accurate and complete.
2	Disseminate both the English and Spanish versions of these Benchmarks to all pertinent personnel	In Compliance [1]	*Finding* • The DSPDI has made strides in the trainings and orientations of home personnel and requires home providers deliver a copy of the Benchmarks to the community home personnel and that acknowledgement of receipt be included in the personnel files. However, from the JCC's reviews, interviews and visits, there continues to be instances where community home, private home and other support personnel providing direct services to participants lacked understanding and knowledge of the JCAP and the Benchmarks. *Recommendation* • As stated in the prior report, the DSPDI should ensure that all individuals providing frontline services to participants understand the JCAP requirements and how to undertake necessary actions to identify and comply with such requirements and to ensure essential services and needs are being met and integrated to their daily work.
3	Create a "Master List" of all participants -- all persons with DD in the Commonwealth's IDP (or successor) -- and update quarterly; provide this list and all other lists below to JCC and US initially and as they are updated	In Compliance	The DSPDI provided a Master List that included 660 participants. *Recommendation* • As stated in the prior report, the DSPDI should also continue its efforts to ensure that the IDD diagnoses in the list are consistent with what is reported in Therap, eliminate the recording of multiple IDD diagnoses, and clarify the diagnoses of participants currently classified as having "no intellectual

[1] **In its response to the draft report shared with the Parties, the DSPDI presented compelling arguments which unanimously persuaded the Office of the JCC and Experts to change the current compliance assessment to "In Compliance". The JCC will continue to be vigilant and monitor that the Benchmarks are disseminated to caregivers as they are "pertinent personnel" that should receive the Benchmark document. Failure to adhere to this Benchmark's mandates will entail a potential regressive assessment in the next Report.**

BM No.	Benchmark	Assessment	Finding and Recommendation
			disabilities" by designating diagnosed IDD (Participants #292, #505, #903, #1072, #1154 and #1172). • Beginning with the next report, the DSPDI should ensure that individuals from the Department of Family Affairs ("DFA") with IDD are included in the Master List. If not yet admitted, the DSPDI should, at minimum, include these individuals in the DSPDI waitlist and in the Statistical Data Report presented for Benchmark 32.
III.1 Community Placement from Institutions			
4	From the Master List, create a sub-list of all participants who live in an institution (e.g., Instituto Psicopedagógico, Modesto Gotay, Centro Shalom)	In Compliance	During the period covered by this report, 10 participants were transferred out of institutions (three from IPPR and seven from Shalom). As of December 31, 2022, of the 660 participants receiving services from the DSPDI, 56 participants (about 8.48%) are still living in institutions. Although outside the scope of this report, on May 17, 2023, the DSPDI Director created a Deinstitutionalization Committee comprised of interdisciplinary professionals to work with the Office of the JCC and experts to advance deinstitutionalization of participants and evaluate and develop the protocols, standards, policies, and procedures necessary in order to achieve this. The numbers above do not include the nine participants living temporarily in a psychiatric hospital or other congregate setting (DFA and ASSMCA private homes). However, it is important to note that on November 23, 2022, the Mortality and Morbidity Committee issued a recommendation that all participants living in these types of settings be transferred to DSPDI homes as a priority.
5	Issue a policy directive that all institutionalized participants can live in the community with adequate supports/services OR for each institutionalized participant, conduct and document an individual evaluation on his/her appropriateness for community placement regardless of community capacity (JCAP III.1.A) (all cites below are to JCAP)	Substantial Compliance [2]	*Finding* • The Commonwealth provided a draft of Administrative Order that is being translated to English for discussion. Once the parties have discussed the policy and agreed upon final language, the Commonwealth should be in compliance with this Benchmark. *Recommendation*

[2] In its response to the draft report shared with the Parties, the DSPDI requests that "the Office of the JCC re-consider its assessment of this Benchmark and assess the same as "In Compliance". Although we deem that there is some merit to the DSPDI's argument, the same was not enough to unanimously convince the Office of the JCC and the Experts that an adjustment in our original assessment was warranted. However, we will continue to work with the DSPDI and will establish a team to provide the necessary support to assist the DSPDI in reaching the desired assessment level within the next reports.

BM No.	Benchmark	Assessment	Finding and Recommendation
			• The parties should discuss the policy and agreed upon final language.
6	Develop a written individualized community transition plan for each participant in an institution using person-centered planning techniques (III.1.A, E)	Substantial Compliance – Still Under Review	*Finding* • Although all participants living in institutions (Shalom and IPPR) have ITPs, as reported in the prior report, some of the ITPs reviewed are over a year old and some of the interdisciplinary teams' recommendations on community placement were recorded in the Therap case notes, but not incorporated into the ITPs. *Recommendation* • The DSPDI should continue its efforts to ensure that the ITPs identify the participants' current needs and desires
7	For each participant, identify and document in the transition plan the individual and systemic obstacles to community placement from the institution (III.1.B)	Substantial Compliance – Still Under Review	*Finding* • Per the ITPs reviewed the main obstacles continue to be family opposition and lack of available community homes. *Recommendation* • The Experts jointly with the DSPDI continue to evaluate and discuss various approaches to working with families and addressing their needs and concerns in the De-institutionalization and Independent Living Work Group. See prior report.
8	For each participant, identify and document in the transition plan any family members/guardian opposed to community placement from the institution (if any) and the reason(s) for opposition (III.1.C)	Substantial Compliance – Still Under Review	*Finding* • See prior report. *Recommendation* • The Experts jointly with the DSPDI continue to evaluate and discuss various approaches to working with families and addressing their needs and concerns in the De-institutionalization and Independent Living Work Group. See prior report.
9	Meet with all family members/guardians opposed to community placement, provide them with education on expanded community capacity, and offer viable community residences to effect the placement of the participants from the institutions (III.1.C)	Working Towards Compliance - Still Under Review	*Finding* • During the period covered by this Report the DSPDI met and/or contacted with 19 family members who continue to be opposed to community placement. • Of the 19, 16 indicated that they may consider community placement if certain conditions are met such as: location of community home, home is administered by the institution's

BM No.	Benchmark	Assessment	Finding and Recommendation
			directive, and/or participant is assigned a one-on-one caregiver. • The DSPDI contacted opposed families to invite them to integration activities in community homes of which seven accepted. As of December 31, 2022, the DSPDI was in the process of coordinating the before mentioned activities. *Recommendation* • As stated in the prior report, various approaches to working with families and addressing their needs are currently being evaluated and discussed in the De-institutionalization and Independent Living Work Group as parents continue to oppose community placement. In addition, on May 17, 2023, the DSPDI Director created a Deinstitutionalization Committee comprised of interdisciplinary professionals to work with the Office of the JCC and experts to advance deinstitutionalization of participants and evaluate and develop the protocols, standards, policies, and procedures necessary in order to achieve this.
10	Take the opposed families/guardians on tours of prospective, successful community residences (III.1.C)	Working Towards Compliance - Still Under Review	*Finding* • Similar to BM 9. *Recommendation* • As stated in prior report, various approaches to working with families and addressing their needs are currently being evaluated and discussed in the De-institutionalization and Independent Living Work Group.
11	For each appropriate participant, overcome all necessary obstacles (other than entrenched guardian opposition) to effect community placement from the institution in a manner consistent with Olmstead and the CBSP (III.1.B)	Working Towards Compliance - Still Under Review	*Outcome Measure* • Various approaches are currently being evaluated and discussed in the De-institutionalization and Independent Living Work Group. In addition, on May 17, 2023, the DSPDI Director created a Deinstitutionalization Committee comprised of interdisciplinary professionals to work with the Office of the JCC and experts to advance deinstitutionalization of participants and evaluate and develop the protocols, standards, policies, and procedures necessary in order to achieve this. • Compliance with this benchmark is to be determined after a more comprehensive review.

BM No.	Benchmark	Assessment	Finding and Recommendation
12	Monitor all participants placed in the community to ensure they receive all the necessary protections, supports, services to meet their individualized needs in community settings (III.1.E)	Working Towards Compliance - Still Under Review	*Outcome Measure* *Recommendation* • See Section II, part A of this Report.
III.2 Provider Capacity Expansion in the Community			
13	From Master List, create sub-list of all participants living in the community, specifying name and location of each person's residential provider and total number of individuals living in each home	In Compliance	During the period covered by this report, the DSPDI the DSPDI had 55 group community homes (330 participants for a 50%), 19 substitute homes (40 participants for a 10.8%), and 220 participants living in biological homes (33.3%). *Recommendation* • Beginning with the next report, the DSPDI should ensure that individuals from the DFA with IDD are included in all lists. If not yet admitted, the DSPDI should, at minimum, include these individuals in the DSPDI waitlist and in the Statistical Data Report presented for BM 32.
14	Develop a systemwide plan to increase the number of community residential providers to meet participants' individualized needs (III.2)	Working Towards Compliance - Still Under Review	*Finding:* • See prior report. *Recommendation* • See prior report.

15	Implement the plan to reduce the number of individuals in each community group and substitute home to meet individualized needs, to increase the level of individual attention devoted to participants day-to-day, to create a more peaceful and therapeutic living environment, and to improve outcomes for participants day-today (III.2); each participant shall have a private or semi-private bedroom	Working Towards Compliance - Still Under Review	*Outcome Measure*
			• During the period covered by this report, the DSPDI opened seven new community homes with a total of 39 additional home units:
			  • one specializes behavioral management home - Belén II in Corozal with six beds,
			  • one specialized health care home - Quality Assistance Care in Manatí with six beds,
			  • four group homes - Mekadesh III in Moca with six beds, Respaldo de Amor in Aguadilla with six beds, Hogar Tus Pasos in Aguada with six beds and Kairos II in Vega Baja with six beds (due to allegations of abuse and neglect, during the month of May 2023, the group home Kairos II was closed, and the contract will not be renewed for the next fiscal year), and
			  • one substitute home (Hogar Sustituto Edwin Rodríguez in Dorado with 3 beds).

BM No.	Benchmark	Assessment	Finding and Recommendation
			• However, the group home Modesto Gotay located in the Carolina (six beds) closed in October 2022. Thus, the net gain during the six-month period was 33 home units. • As of December 31, 2022, of the 55 homes, 7 continue to be overcrowded by having a census of 7 to 8 participants. *Recommendation* • See prior report.
16	Ensure that community homes: provide participants with adequate protections, supports, services; meet their individualized needs; ensure their health, safety, welfare; provide increased individual attention; provide a more peaceful and therapeutic living environment; improve outcomes (III.2)	Working Towards Compliance - Still Under Review	*Outcome Measure* *Recommendation* • See Section II, Part A of this Report.
III.3 Integrated Employment and Day Activities			
17	From the Master List, create a sub-list of those who are currently working in the community, specifying the name and location of the employer, the number of hours per week the participant is working, and the participant's hourly wage or compensation rate	Substantial Compliance[3]	*Finding* • List included a total of 22 participants, of which 19 are currently employed working anywhere from 8 to 35 hours per week (three had resigned as of December 31, 2022). ○ Fourteen participants are working at least 20 hours per week in the community earning between $5 to $12. ▪ Nine are working in competitive employment (at least 20 hours per week) earning at least $8.50 per hour, which is Puerto Rico's current minimum wage through June 2023 with a scheduled increase of $1 in July 2023. ▪ The DSPDI provided the following justification for the five participants (Participants #425, #591, #903, #1032 and

[3] In its response to the draft report shared with the Parties, the DSPDI requests that "the Office of the JCC re-consider its assessment of this Benchmark and assess the same as "In Compliance". Although we deem that there is some merit to the DSPDI's argument, the same was not enough to unanimously convince the Office of the JCC and the Experts that an adjustment in our original assessment was warranted. However, we will continue to work with the DSPDI and will establish a team to provide the necessary support to assist the DSPDI in reaching the desired assessment level within the next reports.

BM No.	Benchmark	Assessment	Finding and Recommendation
			#1163) that are earning less than the minimum wage: piece work pay, municipal jobs that are exempt from paying minimum wage and employment with family-owned business. ○ Two participants experienced an increase in weekly work hours (Participants #411 and #268), and ○ One participant (Participant #1134) that was earning $8 per hour is now getting paid $10. • From the current list, three participants (Participants #577, #693, and #952) resigned from their previous employment, 15 were carried over from the last Report, and four recently became employed for the first time (Participants #1032; #1118; #1007; and # 674). Additionally, three participants marked as employed in the last report were not employed during this period (Participants #196; #76; and #1113).. *Recommendations:* • List should only include participants currently working. Information regarding participants that were employed at some point during the reporting period may be detailed in a separate list. • Present total earnings acquired in the last three months.
18	For those working in the community, develop individualized action steps to ensure no one working in the community is underemployed (III.3.A)	No Compliance[4]	*Finding* • Despite many participants saying they would like to work more hours, no steps are listed to resolve identified barriers. • No corrective action plans on how to rectify the situation were included in Therap, only justifications as to why people are making below minimum wage. *Recommendations* • Justify the non-increase in hours of employment of the remaining participants who have maintained between 15 and 20 hours of work per week. • Prioritize individuals' requests for expanded employment opportunities and hours. Explore participants' current

[4] In its response to the draft report shared with the Parties, the DSPDI requests that "the Office of the JCC re-consider its assessment of this Benchmark and assess the same as "In Compliance". Although we deem that there is some merit to the DSPDI's argument, the same was not enough to unanimously convince the Office of the JCC and the Experts that an adjustment in our original assessment was warranted. However, we will continue to work with the DSPDI and will establish a team to provide the necessary support to assist the DSPDI in reaching the desired assessment level within the next reports.

BM No.	Benchmark	Assessment	Finding and Recommendation
			employment and other alternative employment options that can meet and achieve expanded employment goals. • Focus on transitioning individuals in subminimum wage jobs to competitive wages. Identify in the ISP the strengths and needs, to encourage them to reach competitive jobs. • Proactively explore with all participants if they want to work more hours. Implement Discovery Activities and Record Findings in ISPs. • Identify other work scenarios and employers across industries/sectors. • See Section II, Part B of this Report.
19	Implement the action steps to ensure that no one working in the community is underemployed (III.3.A, B) This is in addition to original Benchmarks: (with the understanding that the Commonwealth cannot guarantee optimal employment, but nonetheless will continue its efforts to avoid underemployment) (III.3.A,B)	Working Towards Compliance - Still Under Review	*Outcome Measure* • Compliance with this benchmark is to be determined after a more comprehensive review. See Section II, Part B of this Report.
20	From the Master List, create a sub-list of those who are currently not working in the community, but have been professionally assessed or identified in the past as able to work in the community; designate on this sub-list the date/author(s) of the most recent assessment	Working Towards Compliance - Still Under Review	*Finding* • The DSPDI furnished a table that combined Benchmarks 20, 21, 24 and 25 and lists 662 participants which is inconsistent to the Master List at BM3. The difference is due to the death of a participant (Participant #87: passed away on January 1, 2023, and was not included in the sub- list), a participant that was readmitted (Participant #997: re-admitted on December 1, 2022, and not included in the sub-list) and participants being included in the sub-list that were admitted after December 31, 2022 (Participants #1191, #1192 and #1193). • List indicates that of the 660 participants served by the DSPDI, 641 are not employed (97%). Of those not employed 78 (12%) have been assessed in the past as able to work. • Lack of frequency in assessments so the sublist may not reflect an accurate grouping, with 67 outstanding assessments to be conducted. *Recommendations* • Focus on completing outstanding assessments (67 still to be conducted). • Work on completing additional assessments after introduction of Discovery activities.

BM No.	Benchmark	Assessment	Finding and Recommendation
21	Professionally assess or re-assess for community employment all participants who are currently not working in the community but have been professionally assessed or identified in the past as able to work in the community (III.3.C)	Working Towards Compliance - Still Under Review	*Finding* • Same at BM 20 *Recommendations* • Focus on completing new assessments for all participants AFTER completing Discovery & Exploration activities in the community. See Section II, Part B of this Report.
22	Develop individualized, concrete action steps with timeframes to maximize their community employment (III.3.C)	Working Towards Compliance - Still Under Review	*Finding* • Lack of individualized actions and timelines in ISPs. Language extremely generic around employment goals. *Recommendations* • Continue to work on improving person-centered service planning process to include more specific action items and timelines. • Use findings from Discovery process to inform action steps. • See Section II, Part B of this Report.
23	Implement the action steps to ensure that: everyone who is able to work is working in the community; and everyone working in the community is not underemployed (III.3.D) This is in addition to original Benchmarks (with the understanding that the Commonwealth cannot guarantee optimal employment, but nonetheless will continue its efforts to avoid underemployment) (III.3.D)	Working Towards Compliance - Still Under Review	*Outcome Measure* • Compliance with this Benchmark is to be determined after a more comprehensive review. • Various initiatives are currently being evaluated and discussed in the Employment and Day Services Work Group. The work group has been primary focused on the introduction of Discovery and Customized Employment Strategies into the ASCERV infrastructure via the Vocational Rehabilitation Counseling Area. See Section II, Part B of this Report.
24	From the Master List, create a sub-list of all other participants who are currently not working in the community; designate on this sub-list the date/author(s) of the most recent professional employment assessment, if any; designate those who have been professionally assessed as not able to work in the community	Working Towards Compliance - Still Under Review	*Finding* • Similar to Benchmarks 20-21. • The DSPDI furnished a table that combined Benchmarks 20, 21, 24 and 25. The list indicates that of the 660 participants served by the DSPDI, 641 are not employed (97%) of which 548 (83%) have been classified as not able to work in the community. *Recommendation* • Prioritize the completion of in-depth Discovery & Exploration activities in the community with sub-list of participants to inform a new or updated assessment with a presumption of employability and information collected during the

BM No.	Benchmark	Assessment	Finding and Recommendation
			assessment that speaks to the strengths, skills, interests, training needs and potential employment opportunities in the community.
25	Professionally assess or re-assess for community employment all participants who are currently not working in the community but have been professionally assessed or identified in the past as able to work in the community (III.3.C)	Working Towards Compliance - Still Under Review	*Finding* • Continue to work on reassessments for this subpopulation. Need to accelerate Discovery, Exploration and Job Development activities now that staff have completed robust customized employment training. *Recommendations* • All participants on sub-list need to undergo extensive Discovery and Exploration activities. These activities should then inform a new or updated assessment with a presumption of employability and information collected during the assessment that speaks to the strengths, skills, interests, training needs and potential employment opportunities in the community. • Track/monitor impact of recent training of rehabilitation staff in customized employment strategies on quality of discovery & exploration. • Job Exploration in the community should be offered for all participants in this subcategory. Participants in this subcategory should be offered opportunities for integrated work-based learning experiences with businesses/organizations in the community, internships, and customized apprenticeships. and be prioritized for job development activities (including internships, apprenticeships, small business training, job shadowing, informational interviewing). • See Section II, Part B of this Report.
26	For those with professional assessments that they can work in the community, develop individualized, concrete action steps with timeframes for these other participants to maximize their community employment (III.3.A)	Working Towards Compliance - Still Under Review	*Finding* • The is a lack of detail included in the ISPs and subsequent employment modules in Therap about concrete action steps planned or completed for supporting participants who can work in the community to conduct job exploration, access training in vocational skills development, and take advantage of integrated work-based learning experiences. Part of this may be due to a lack of training/experience among some of the trainers and job developers/promoters. *Recommendation*

BM No.	Benchmark	Assessment	Finding and Recommendation
			• Continue to work on improving person-centered service planning process to include more specific action items and timelines. • Use findings from Discovery process to inform action steps. • All plans for these participants in this subcategory should include the completion of at least one integrated work-based learning experience in the community within the next 6-12 months.
27	Implement the action steps to ensure that: everyone who is able to work is working in the community; and everyone working in the community is not underemployed (with the understanding that the Commonwealth cannot guarantee employment, but nonetheless will continue its efforts to find paid employment and avoid underemployment) (III.3.D)	Working Towards Compliance - Still Under Review	*Outcome Measure* • Compliance with this benchmark is to be determined after a more comprehensive review. • Various initiatives are currently being evaluated and discussed in the Employment and Day Services Work Group. The work group has been primary focused on the introduction of Discovery and Customized Employment Strategies into the ASCERV infrastructure via the Vocational Rehabilitation Counseling Area. • See Section II, Part B of this Report.
28	Develop and implement a program to promote self-employment for appropriate participants, specifying the number of times per trimester each participant is to be engaged in community self-employment activities; examples of self-employment may include, but not be limited to, work at fairs and urban markets selling arts and crafts participants create	Working Towards Compliance - Still Under Review	*Outcome Measure* • Compliance with this benchmark is to be determined after a more comprehensive review.
29	Systemwide, ensure that at least 25 percent of all participants of working age are employed in the community, on a full-time or part-time basis based on individualized needs, at minimum wage or above, at a location where the employee interacts with individuals without disabilities and has access to the same opportunities for benefits and advancement provided to workers without disabilities. (With the understanding	Working Towards Compliance - Still Under Review	The total employed participants represent 2.9% of DSPDI's current census, which is 0.03% less than the last report due to the increase of DSPDI's census from 649 to 660 total participants. *Outcome Measure* • As stated in the prior Reports, per the US Department of Labor, the working age range is 18 to 65 years. Per DSPDI's ASCERV, the working age range for DSPDI participants is 20 to 40 years with Mild, Moderate or no IDD diagnosis. The latter criterion reinforces the fact that DSPDI's ASCERV automatically deems participants with a severe or profound IDD diagnosis as unemployable and excludes them from the

BM No.	Benchmark	Assessment	Finding and Recommendation
	that the Commonwealth cannot guarantee employment, but nonetheless will continue its efforts to find paid employment and avoid underemployment)		employability screening process. While some of these participants may not be able to work for valid reasons, they should not be categorically excluded. Retirement and/or the decision "not to work" should be person centered. See Section II, Part B of this Report. • Compliance with this benchmark is to be determined after a more comprehensive review.
30	For those participants with professional assessments that they are not able to work in the community, develop individualized plans to maximize meaningful, functional community activities that foster their growth and independence (III.3.E)	Working towards compliance - still under review	*Finding* • Similar to Benchmark 26. • The DSPDI provided the criteria used to determine whether a participant is unable to work in competitive integrated employment. The criteria include low levels of functioning, residual functional capacity (based off CIF), severe or profound level of IDD level, advanced aging and complications, comorbidities, behavioral issues, and lack of appropriate natural supports. • The DSPDI reported that during the period for this report 415 ISP were completed which include individualized plans for community integration and inclusion, home activities and CTS activities. Upon review conducted by the Office of the JCC it was found that some of the completed ISP lacked, for example, the participation of key components of the EID and participation from family and support resources (Participant #599). *Recommendations* • Consider immediate updates to current DSPDI policies that require only a minimum of 2 community outings/month. Raise minimal requirements to at least 3-5 outings per week with a goal of daily community exposure, depending upon participant preferences as outlined in their person-centered ISPs. • Create financial incentives for providers to increase outings in the community (group and individual), and revisit transportation reimbursement to support adequate mobility for all participants. Require 85% of all outings to include one or more of the following components: rehabilitation, independent skill development, or employment exposure.
31	Implement the plans (III.3.E)	Working Towards Compliance -	*Outcome Measure* • Compliance with this benchmark is to be determined after a more comprehensive review.

BM No.	Benchmark	Assessment	Finding and Recommendation
		Still Under Review	
32	For those participants who are not working in the community but attend a day program at a CTS, ensure that these participants attend the day program at least four days per week; ensure that staffing, transportation, and other resources are adequate to meet individualized needs; ensure that buses have ramps and other needed accessibility supports	Working Towards Compliance - Still Under Review	The JCC commends the DSPDI on the Statistical Data Report furnished for the first time by the DSPDI detailing the following: number of participants admitted during the year (for the period covered by the report, 20 participants were admitted), number of deaths (for the period covered by the report (six participants were admitted), female (243 participants) v. male (417 participants), number of participants per diagnosis (Mild: 99, Moderate: 215, Grave: 298, Profound: 42, No IDD: 6), number of participants per age group and other useful and pertinent statistical information. The before mentioned report was furnished for Benchmark 32. For future reports, the DSPDI should consider including statistical data on the number of participants per diagnosis per CTS. *Outcome Measure* • Monthly CTS programming frequency was only available for participants assigned to CTS Vega Baja, which ranged anywhere from 4 to 20 times per month. • Compliance with this benchmark is to be determined after a more comprehensive review.
33	From the Master List, create a sub-list of those who do not work or participate in formal day program activities at a CTS and assess why they do not and remain at home (III.3.F)	Working towards compliance - under review	*Finding* • List does not seem to be complete or accurate as there are various duplicate entries, deceased participant (Participant #597 deceased on July 23, 2022) and only seven of the 37 participants residing in specialized community homes are included in the list. • Reasons cited for participants not attending CTS activities included: medical conditions/justifications (e.g., cancer, immobile/bedridden, severe IDD); family resistance; participant employment; receiving in-home services instead; participants residing in specialized health/behavioral home; death; geographic distance; lack of accessible transportation (for example vans without ramps); EID recommendations; ASSMCA/DFA private homes and personal refusal. • Need to ensure that participants that are attending a CTS infrequently are not included in this list. Also found inconsistency in completion of weekly/monthly visits by service mediators to participants currently at home unemployed and not participating in CTS programming. To establish scope of transportation and accessibility challenges, need to understand how many people on the list have wheelchairs and require ramps and mobile transportation.

BM No.	Benchmark	Assessment	Finding and Recommendation
			Recommendations • Need to establish a plan for addressing transportation & accessibility barriers for participants who wish to participate in CTS activities/ programming. • Should also assess those individual participants who are participating in activities at the CTS to determine if they are interested in attending/participating more regularly. • For those not currently attending CTS activities, identify ways to support participants and their families in seeking out and participating in rehabilitation, skills development, or job development strategies at home or in their local communities. • Service mediators should be visiting participants not participating in any CTS activities in their home more frequently to ensure community integration activities.
34	Develop individualized plans for these participants to maximize meaningful, functional community activities that foster their growth and independence (III.3.F); ensure that participants engage in such community activities at least two times per month	Working towards compliance - under review	*Finding* • Similar to Benchmark 30. *Recommendations* • Service mediators should be visiting participants not participating in any CTS activities in their home more frequently to ensure community integration activities. • Consider immediate updates to current DSPDI policies that require only a minimum of 2 community outings/month. Raise minimal requirements to at least 3-5 outings per week with a goal of daily community exposure, depending upon participant preferences as outlined in their person-centered ISPs. • Create financial incentives for providers to increase outings in the community (group and individual), and revisit transportation reimbursement to support adequate mobility for all participants. • Require 85% of all outings to include one or more of the following components: rehabilitation, independent skill development, or employment exposure. • Make sure ISPs are based on and continuously informed by introduction of ongoing Discovery & Exploration activities. See Section II, Part B of this Report.
35	Implement the plans (III.3.F)	Working Towards Compliance -	*Outcome Measure* • Compliance with this benchmark is to be determined after a more comprehensive review as the DSPDI continues to apply PCP principles and ongoing Discovery & Exploration activities.

BM No.	Benchmark	Assessment	Finding and Recommendation
		Still Under Review	
36	Develop a systemwide plan for all participants to maximize non- work activities in the community that are meaningful, functional, and foster growth and independence to meet individualized needs (III.3.G)	Working Towards Compliance - Still Under Review	*Finding* • Similar to Benchmark 30 & 34. *Recommendations* • Recommendations similar to Benchmarks 30 & 34. • Consider immediate updates to current DSPDI policies that require only a minimum of 2 community outings/month. Raise minimal requirements to at least 3-5 outings per week with a goal of daily community exposure, depending upon participant preferences as outlined in their person-centered ISPs. • Create financial incentives for providers to increase outings in the community (group and individual), and revisit transportation reimbursement to support adequate mobility for all participants. • Require 85% of all outings to include one or more of the following components: rehabilitation, independent skill development, or employment exposure. • More detailed recommendations on PAÍS Support Program for Social Inclusion have been previously shared with DSPDI leadership and is included in appendix.
37	Implement the plan (III.3.G)	Working Towards Compliance - Still Under Review	*Outcome Measure* • Compliance with this benchmark is to be determined after a more comprehensive review as the DSPDI continues to apply PCP principles and ongoing Discovery & Exploration activities.
38	Ensure that staffing, transportation, other resources are adequate and reliable to meet individualized needs for integrated day activities in the community (III.3.H); ensure that buses have ramps and other needed accessibility supports	Working Towards Compliance - Still Under Review	*Outcome Measure* • Compliance with this benchmark is to be determined after a more comprehensive review as the DSPDI continues to apply PCP principles and ongoing Discovery & Exploration activities.
39	Ensure there are sufficient job coaches and job trainers to meet individualized needs in the community (III.3.I)	Working Towards Compliance - Still Under Review	*Outcome Measure* • There are existing Job Coach and Job Trainer vacancies in the Bayamon and Vega Baja CTSs (which have the highest percentage of participants), which will hinder employment progress in these CTS areas unless filled. There are also

BM No.	Benchmark	Assessment	Finding and Recommendation
			vacancies in the Aguadilla CTS, which has zero employed participants. • Compliance with this benchmark is to be determined after a more comprehensive review as the DSPDI continues to apply PCP principles and ongoing Discovery & Exploration activities.
III.4 Safety and Restraint Issues			
40	Using data from Therap combined with onsite assessments, conduct a safety and welfare analysis of all individual participants and their residences (III.4.A)	Working Towards Compliance - Still Under Review	*Finding* • DSPDI provided a brief narrative on the safety and welfare analysis stating annual assessments are conducted by the interdisciplinary teams which are included in three areas of the Therap electronic file: the ITP which identifies participants needs in areas of physical and mental health, areas of support and independence, nutrition, behavioral aspects, psychiatric indicators, relational, social and environmental factors, the PFW which identifies participant interests and needs and the ISP which includes all transdisciplinary recommendation considering the interests of the participant and developing an integrated plan of services that will govern the work of the interdisciplinary team. • The quality of much of the information in Therap continues to be substantially deficient and some information is simply incomplete; this negatively affects the accuracy of the safety and welfare analyses the DSPDI has been undertaking, as well as delays the progress of systemic improvements, including risk mitigation and preventable deaths. It is not yet evident that accurately informed safety and welfare analyses are being conducted for all participants. • As reported by the DSPDI 15 community homes are not reporting or inconsistently reporting in Therap. No information was provided for 16 homes. • While provider access to Therap to report incidents and other critical information has improved over time, gaps persist. See prior Report. *Recommendation* • The DSPDI should continue to work on corrective action plans to address non-compliance with Therap documenting and to rectify other outstanding issues related to the use of Therap. • Essential information and documentation is included in separate modules of Therap resulting in the fragmentation of data for assessments. The DSPDI should consider creating a norm or protocol so that all pertinent clinical information is continuously updated in the participant's ITPs and ISP.

BM No.	Benchmark	Assessment	Finding and Recommendation
41	Implement measures to ensure participant safety and welfare based on this analysis (III.4.A)	Working Towards Compliance - Still Under Review	*Outcome Measure* • Compliance with this benchmark is to be determined after a more comprehensive review as the DSPDI continues to work on the quality of information in Therap.
42	Using data from Therap combined with first-hand accounts, analyze peer-to-peer interactions that create risk of harm (III.4.A.1)	Working Towards Compliance - Still Under Review	*Finding* • During this six-month period, the DSPDI provided a list of 164 distinct peer-to-peer incidents of which 98% were classified as high. • There continue to be challenges with how data about peer-to-peer incidents are entered into Therap that make it challenging to analyze patterns with these incidents. • The DSPDI is developing guidance for the entry of incidents to diminish errors in documentation and facilitate the analysis of incidents. *Recommendation* • Various initiatives are currently being evaluated and discussed in the Incidents and Investigations Work Group. See prior report.
43	Implement effective measures to address peer-to-peer risk factors to prevent harm (III.4.A.1)	Working Towards Compliance - Still Under Review	*Outcome Measure* • Compliance with this benchmark is to be determined after a more comprehensive review. As stated in the prior report, much more work to be done to reach compliance with this Benchmark.
44	Using data from Therap combined with first-hand accounts, identify vulnerable participants at risk of harm (III.4.A.2)	Working Towards Compliance - Still Under Review	*Finding* • The DSPDI provided a list of 50 participants characterized as "vulnerable". • The Commonwealth identifies vulnerable participants based on the criteria of vulnerability to aggression by the EID and incidents reported in Therap, where individuals have been the victim of an aggression or suffered an injury from their peers. The list is incomplete, as it omits, for example, Participant # 921 which was subject of an assault. • The DSPDI is developing guidance for the entry of incidents to diminish errors in documentation and facilitate the analysis of incidents. *Recommendation* • Various initiatives are currently being evaluated and discussed in the Incidents and Investigations Work Group. See prior report.

BM No.	Benchmark	Assessment	Finding and Recommendation
45	Implement effective measures to minimize/ eliminate their risk factors (III.4.A.2)	Working Towards Compliance - Still Under Review	*Outcome Measure* • Compliance with this Benchmark is to be determined after a more comprehensive review. See prior report.
46	Using data from Therap combined with first-hand accounts, identify aggressor participants (III.4.A.3)	Working Towards Compliance - Still Under Review	*Finding* • The DSPDI provided a list of 90 participants characterized as "aggressor". • The information provided is an improvement from prior periods and identifies more participants than in previous periods. • The DSPDI is developing guidance for the entry of incidents to diminish errors in documentation and facilitate the analysis of incidents. *Recommendation* • Various initiatives are currently being evaluated and discussed in the Incidents and Investigations Work Group. See prior report.
47	Implement effective measures to minimize/eliminate aggressor risk triggers (III.4.A.3)	Working Towards Compliance - Still Under Review	*Outcome Measure* • Compliance with this Benchmark is to be determined after a more comprehensive review. See prior report.
48	Informed by data from Therap, develop a systemwide plan to ensure that serious incidents, per JCAP criteria, are reported promptly and investigated within 45 days, all to prevent serious incidents in the future (III.4.B)	Working Towards Compliance - Still Under Review	*Finding* • There continue to be challenges with how data is entered into Therap and providers that do not consistently reporting in Therap (including DFA and ASSMCA private homes). However, the DSPDI has been working on defining serious incidents and developing norms for Therap classifications. • The top 14 high-level incident event types and respective counts include: Assault (213); Behavioral Issue (183); Injury (180); Change of Condition (176); Hospital (87); Altercation (81); Communicable Disease (64); Fall without injury (37); Accident no apparent injury (27); Seizure (15); Property Damage (12); Threatening Behavior (6); Medication Error (3); and AWOL/Missing Person (2). • The DSPDI reports that roughly 99% (771:775) of all high-level incidents were given follow-up within forty-five calendar days, and 88.5% (686:775) within 15 days. • The DSPDI provided the following information about "complaints," which are currently recorded outside of the

BM No.	Benchmark	Assessment	Finding and Recommendation
			Therap system: from January through June 2022: there were five complaints and two additional grievances reported. The Commonwealth reported that the time to resolve complaints took anywhere from seven day to thirty-five days. Of the seven complaints and grievances, the DSPDI reported that two were found not to be substantiated and two were still ongoing as of December 31, 2022. *Recommendation* • The DSPDI and the JCC Experts will continue to work collaboratively in a workgroup on Incidents and Investigations that will address many of the challenges in this area as part of a system-wide approach including the evaluation of the and implementation of the Incidents Norms and Proceedings Protocol effective January 2023.
49	Informed by data from Therap, develop a systemwide plan to analyze incident patterns and trends to prevent incidents in the future (III.4.B)	Working Towards Compliance – Still Under Review	*Finding* • The DSPDI provided a short plan at Benchmark 41 detailing the objectives and goals of the Incident Committee which meets on a monthly basis to discuss recent incidents and analyze trends. The DSPDI also provided an incident pattern and trend report with helpful data and information, including where incidents occur, the most frequent types of incidents, and perhaps most importantly, which participants are having the most incidents. • There is some evidence of DSPDI analysis of recent incidents, and some individualized patterns are discussed at the Incident Committee. • Progress continues to be achieved in this benchmark through the work of the Incident Committee and its efforts to identify patterns and trends. However, there continue to be challenges with how data is entered into Therap and providers not consistently reporting in Therap that make it challenging to analyze patterns and trends to prevent incidents in the future. *Recommendation* • The DSPDI and the JCC Experts will continue to work collaboratively in a workgroup on Incidents and Investigations to address many of the challenges in this area as part of a system-wide approach including the evaluation of the and implementation of the Incidents Norms and Proceedings Protocol effective January 2023.

BM No.	Benchmark	Assessment	Finding and Recommendation
50	Implement these systemwide plans and implement remedial measures to address any individual and/or systemic issues that arise from the investigations and incident analysis to ensure participant safety and welfare and minimize/eliminate abuse and neglect (III.4.B)	Working Towards Compliance - Still Under Review	*Outcome Measure* • Compliance with this benchmark is to be determined after a more comprehensive review. Although valuable statistical information is being compiled trough Therap by the Incident Committee to identify patters, more works needs to be done on the investigation and analysis of the underlaying reasons from incidents in order to generate remedial measures.
51	Implement effective measures to minimize/eliminate use of all restraints on participants (III.4.C)	Working Towards Compliance - Still Under Review	*Outcome Measure* • Compliance with this Benchmark is to be determined after a more comprehensive review. See prior report.
52	Prohibit use of standing PRN or "stat" orders for chemical restraints on participants (III.4.C)	Working Towards Compliance - Still Under Review	*Outcome Measure* • Compliance with this Benchmark is to be determined after a more comprehensive review. See prior report.
III.5 Health Care and Mental Health Care			
53	From the Master List, create a list of all participants and their current community clinicians, highlighting the primary care physicians and neurologists, if applicable (III.5.B)	Substantial Compliance	*Finding* • One or more clinicians were listed for 642 participants. Although this is a good list with helpful contact information, a total of 660 participants were listed in the Master List at Benchmark 3, so at least 22 participants are missing from the list. *Recommendation* • Continue to work on updating Therap to include community clinicians. Particularly in the case of participants residing in biological homes.
54	Through Therap and/or other means, implement an effective communication system to promptly alert all community clinicians and other pertinent personnel to significant changes in the health status of individual participants across the system (III.5.A)	Working Towards Compliance - Still Under Review	*Finding* • There appear to be some gaps in communication with community clinicians in certain cases, such as communication back with a PCP when there are significant changes in health status (ex. someone is hospitalized). There also continues to be under-recognition of people with significant changes in health status during the period (see Benchmark 55) *Recommendation*

BM No.	Benchmark	Assessment	Finding and Recommendation
			• Finalize the revision of the Nursing Service Protocol to current organizational chart, policies, and procedures.
55	Whenever there is a significant change in participant health status, ensure that appropriate treatment and other measures are provided promptly to meet the individualized needs of the participant.	Working Towards Compliance - Still Under Review	*Outcome Measure* • Compliance with this benchmark is to be determined after a more comprehensive review. See prior report.
56	Implement an effective system to gather and provide to pertinent community clinical personnel all individual participant information for use in monthly or more frequent appointments (III.5.B); participant information may be located in the home, CTS, CEEC, Central Office, and/or elsewhere.	Working Towards Substantial Compliance	*Finding* • See prior report. *Recommendation* • See prior report.
57	Maintain effective communication with community clinicians to determine if they provide informed and comprehensive individualized evaluations and treatment that meet individualized participant needs (III.5.B); However, the original benchmark reads as follows: Monitor community clinicians to ensure they provide informed and comprehensive individualized evaluations and treatment that meet individualized participant needs (III.5.B)	Working Towards Compliance - Still Under Review	*Outcome Measure* • Compliance with this benchmark is to be determined after a more comprehensive review. See prior report.
58	Ensure participants receive necessary health care in a timely manner to meet their individualized needs in the community (III.5.G)	Working Towards Compliance - Still Under Review	*Outcome Measure* • Compliance with this benchmark is to be determined after a more comprehensive review. See prior report.
59	From the Master List, create sub-lists of priority at-risk participants in the community, per JCAP criteria, that require heightened, enhanced	Working Towards Compliance -	*Finding* • The lists continue to improve but remains incomplete. There were also instances where there are discrepancies between

BM No.	Benchmark	Assessment	Finding and Recommendation
	attention and focus (III.5.H); priority at- risk condition criteria are set forth in JCAP III.5.H	Still Under Review	the diagnoses listed in Mental Health sub-list in comparison to other sub-lists of participants. • See Section II, Part C of this Report for effort being made by CAPAR regarding the prioritization of high-risk participants. *Recommendation* • See Section II, Part C of this Report.
60	Through Therap and other means, implement a systemwide plan to work with community clinicians to promptly and proactively develop and implement tailored and intensive protections, supports, services for priority at-risk participants to meet their individualized needs (III.5.I): **NOTE**, original benchmark did not mention THERAP.	Working Towards Compliance - Still Under Review	*Outcome Measure* • Compliance with this benchmark is to be determined after a more comprehensive review. See Section II, Part C of this Report.
61	Monitor to ensure that priority at-risk conditions are minimized or eliminated; document and track seizures, bowel obstructions, aspiration and aspiration pneumonia, decubitus ulcers, other conditions per JCAP criteria (III.5.I)	Working Towards Compliance - Still Under Review	*Outcome Measure* • Compliance with this benchmark is to be determined after a more comprehensive review. See Section II, Part C of this Report.
62	Establish a program of traveling nurses (from the CEEC and/or the CTS sites) to regularly conduct onsite visits with participants in their homes and/or day programs to assess, treat, and monitor their services and supports to ensure that the individualized needs of each priority at-risk participant are met day-to-day; these nurses are to provide ongoing technical assistance to community providers whenever needed, especially when there is a decline in health status; in biological homes, this service will be provided with the authorization of the parents, family members or custodians	Working Towards Compliance - Still Under Review	*Outcome Measure* • Compliance with this benchmark is to be determined after a more comprehensive review. See prior report.

BM No.	Benchmark	Assessment	Finding and Recommendation
63	Using data from Therap and other sources, regularly compile and analyze incident, outcome, intervention, treatment information for each priority at-risk person (III.5.J)	Working towards Compliance – Still Under Review	*Finding* • The JCC finds that the analysis required by this benchmark is not being done comprehensively, thus there is missing information regarding identification of many at-risk participants. *Recommendation* • See prior report.
64	Regularly share this information with community clinicians (III.5.J)	Partial Compliance	*Finding* • Further work is needed to address the quality and completeness of the information, particularly in the health passports and referral forms, to gain compliance in this area. *Recommendation* • See prior report. See Section II, Part C of this Report.
65	Maintain effective communication with community clinicians to determine how they utilize this information to implement measures to meet individualized participant needs (III.5.J)	Working Towards Compliance - Still Under Review	*Outcome Measure* • Compliance with this benchmark is to be determined after a more comprehensive review. See Section II, Part C of this Report.
Neurological			
66	From the Master List, create a sub-list of all participants with a seizure disorder/epilepsy, specifying any anticonvulsant medications they receive with dosage(s) (III.5.K)	Substantial Compliance	*Finding* • The DSPDI provided a list provided of 258 participants with a seizure disorder/epilepsy, which is similar to the number of participants reported in prior periods. While reviewing this information in Therap, the JCC team identified 30 differences with participants listed with active epilepsy (G40) diagnoses in their electronic record; additionally, not all participants on the DSPDI's sub-list for seizure disorder/epilepsy had a diagnosis of seizure disorder/epilepsy on their active diagnosis list in Therap. This means that the DSPDI did not identify participants with active epilepsy, and this has implications for monitoring the management of the condition and contact with appropriate clinicians. *Recommendation* • The above must be clarified and rectified promptly. • See Section II, Part C of this Report for progress made by CAPAR.

BM No.	Benchmark	Assessment	Finding and Recommendation
67	Ensure that neurologists provide participants with a seizure disorder with comprehensive neurology evaluations as needed, at least annually (III.5.K)	Substantial Compliance	*Finding* • See Section II, Part C of this Report for progress made by CAPAR. • There continues to be progress in this benchmark, with more participants with epilepsy receiving medical services from neurologists and more participants receiving visits. Out of the 258 participants listed as having epilepsy, 28 participants did not see their neurologist in the last year and did not have an appointment to see them in the near future. • Nevertheless, there is still progress to be made in this benchmark. For example, two participant was identified as having 10+ seizures annually (Participants #53 and #879) but had not seen a neurologist in over a year (December 2021 and September 2021 respectively), despite the ongoing and recent seizure activity. *Recommendation* • See Section II, Part C of this Report for progress made by CAPAR.
68	Using data from Therap and other sources, compile a sub-list of those participants who have had more than 10+ seizures in the past year, as well as a sub-list of those who have had no seizures for the past two years (III.5.K.1)	Substantial Compliance	*Finding* • The list submitted listed 10 participants having 10+ seizures in the past year, 2 of which have not visited a neurologist since the last quarter of 2021. See BM 67. *Recommendation* • See Section II, Part C of this Report for progress made by CAPAR.
69	Ensure that neurologists provide effective care for those having 10+ seizures per year (III.5.K.1)	Working Towards Compliance - Still Under Review	*Outcome Measure* • Compliance with this benchmark is to be determined after a more comprehensive review. See Section II, Part C of this Report.
70	Ensure that neurologists provide effective care for those who have not had a seizure in the past two years (III.5.K.1)	Working Towards Compliance - Still Under Review	*Outcome Measure* • Compliance with this Benchmark is to be determined after a more comprehensive review. See Section II, Part C of this Report.
71	Ensure that neurologists weigh the benefits of medication use and adequately document the Finding for anticonvulsant medication (III.5.K.2)	Working towards Compliance –	*Outcome Measure* • Compliance with this Benchmark is to be determined after a more comprehensive review. See Section II, Part C of this Report.

BM No.	Benchmark	Assessment	Finding and Recommendation
		Still Under Review	
72	Ensure the use of intra-class polypharmacy is minimized and fully justified (III.5.K.2)	Working Towards Compliance - Still Under Review	*Outcome Measure* • Compliance with this Benchmark is to be determined after a more comprehensive review. See Section II, Part C of this Report.
73	Formalize a relationship with the Epilepsy Foundation of Puerto Rico and use the relationship to improve neurological care and outcomes for participants (II.5.K.3)	In Compliance	*Finding* • The DSPDI is currently working on a five-year collaborative agreement with the Epilepsy Foundation of Puerto Rico. Said relationship has resulted in trainings to personnel and caregivers and access to neurologist. *Recommendation* • Finalize agreement with Epilepsy Foundation.
Aspiration Risk			
74	From the Master List, create a sub-list of those participants at risk of aspiration and/or aspiration pneumonia	Working Towards Compliance - Still Under Review	*Finding* • During the period covered in the present Report, 160 participants were included in a DSPDI sub list of participants at risk of aspiration which, although similar to the number of participants reported in prior periods, there were 31 participants eliminated from the prior period list of which three remain in the high-risk list for aspiration (See Benchmark 59, Participants #248, #854 and #1093). • There continues to be progress with this benchmark as it pertains to trainings to personnel and home caregivers. *Recommendation* • The DSPDI should continue its efforts to identify participants at risk of aspiration and participants having risk factors for aspiration like GERD or aspiration pneumonia.
75	Implement individualized plans to eliminate unsafe mealtime practices, per JCAP criteria, to minimize risk of aspiration/pneumonia (III.5.L)	Working Towards Compliance - Still Under Review	*Outcome Measure* • There are participants at risk of aspiration without a plan to address, manage and identify risk of aspiration. • Compliance with this benchmark is to be determined after a more comprehensive review.
76	Implement individualized plans to keep non-ambulatory individuals in proper alignment to minimize risk of aspiration/pneumonia (III.5.L)	Working Towards Compliance - Still Under Review	*Outcome Measure* • Compliance with this benchmark is to be determined after a more comprehensive review.

BM No.	Benchmark	Assessment	Finding and Recommendation
CEEC			
77	Ensure CEEC regularly evaluates all participants (III.5.C); compile list of ongoing evaluations	Working Towards Compliance - Still Under Review	*Finding* • See Section II, Part C of this Report for update of work being done by CAPAR. *Recommendation* • Finalize the revision of the CEEC Protocol and Manual to current organizational chart, policies, and procedures.
78	Ensure CEEC regularly reviews the adequacy and appropriateness of individualized community health care and mental health care (III.5.C); compile list of ongoing reviews	Working Towards Compliance - Still Under Review	*Finding* *Recommendation* • Finalize the revision of the CEEC Protocol and Manual to current organizational chart, policies, and procedures. • As stated in prior report, further improvements in the use of in-person CTS staff reviews with participants, training of clinicians to identify and address these flags, and better documentation across interdisciplinary staff going forward should all support progress in this benchmark by providing more accurate, timely information with which to identify report and communicate red flags. • See Section II, Part C of this Report.
79	Ensure CEEC promptly raises red flags and actively advocates on behalf of individuals when community services do not meet their individualized needs (III.5.C); compile list of ongoing instances of contacting community clinicians to raise red flags/advocate for participants, summarizing result of contact	Working Towards Compliance - Still Under Review	*Finding* *Recommendation* • Finalize the revision of the CEEC Protocol and Manual to current organizational chart, policies, and procedures. See Section II, Part C of this Report.
80	Ensure CEEC informs community clinicians of recent adverse health or mental health outcomes that may implicate treatment (III.5.E); compile list of ongoing instances where CEEC informed community clinicians, summarizing result of contact	Working Towards Compliance - Still Under Review	*Finding* • See Section II, Part C of this Report. *Recommendation* • Finalize the revision of the CEEC Protocol and Manual to current organizational chart, policies, and procedures. See Section II, Part C of this Report.

BM No.	Benchmark	Assessment	Finding and Recommendation
81	Develop and implement effective systemwide plan for CEEC to promptly communicate concerns to community clinicians that improve outcomes (III.5.E); compile list of improved outcomes after CEEC intervention	Working Towards Compliance - Still Under Review	*Outcome Measure* • Compliance with this benchmark is to be determined after a more comprehensive review. Finalize the revision of the CEEC Protocol and Manual to current organizational chart, policies, and procedures. See Section II, Part C of this Report.
82	Implement a systemwide protocol to alert licensing, ombudsman agencies of community clinician improprieties (III.5.F); compile list of alerts	Working Towards Compliance - Still Under Review[5]	*Finding* • The DSPDI included statement indicating that there were no alerts issued during the period covered by this Report. Thus, no list of alerts to licensing, ombudsman agencies were furnished. *Recommendation* • Currently, there is not enough information to validate that the absence of alerts fully reflects an actual absence of the need for any alerts. The Office of the JCC and Experts are willing to assist the DSPDI in all matters related to this benchmark as it pertains to events that should result in an alert.
83	Ensure CEEC serves as a mobile crisis team, providing prompt, effective, flexible, individualized, mobile, expert support, services, and advice at community sites during emergencies, crises, transitions 24/7 to meet individualized needs (III.5.C); compile list of mobile crisis team visits/interventions, summarizing result	Working Towards Compliance - Still Under Review	*Finding* • As stated in the prior report, it is unclear how the CEEC consistently directly supports and/or provides oversight to the responding CTS teams during crisis response. While basing the crisis response at the CTS may provide more localized response and knowledge of the participant, there is still an important opportunity for the CEEC to support in crises where the CTS staff may need additional support, and/or the response of the CTS teams may be inadequate, ineffective, or requiring more expertise. *Recommendation* • The Office of the JCC and Experts are willing to assist the DSPDI in all matters related to this Benchmark.
84	Ensure CEEC mobile crisis team is comprised of multi- disciplinary group of DD professionals (III.5.D)	Working Towards Compliance -	*Finding*

[5] In its response to the draft report shared with the Parties, the DSPDI requests that "the Office of the JCC re-consider its assessment of this Benchmark and assess the same as "In Compliance". Although we deem that there is some merit to the DSPDI's argument, the same was not enough to unanimously convince the Office of the JCC and the Experts that an adjustment in our original assessment was warranted. However, we will continue to work with the DSPDI and will establish a team to provide the necessary support to assist the DSPDI in reaching the desired assessment level within the next reports.

BM No.	Benchmark	Assessment	Finding and Recommendation
		Still Under Review	• As stated in the prior report, the document does not specify if any of the CTS have any vacant positions directly related to their Mobile Crisis Team • According to the furnished information, the CEEC at the Central Office has the following positions that are vacant: 2 general nurses and a psychiatrist. *Recommendation* • The DSPDI should provide a list of professionals on each of the seven CTS mobile crisis teams, along with their disciplines.
85	Ensure CEEC mobile crisis services maximize individuals' ability to live successfully in the community (III.5.D); compile list of instances where mobile crisis team intervention resulted in diversion from an institutional setting or prevented an adverse outcome	Working Towards Compliance - Still Under Review	*Outcome Measure* • Compliance with this benchmark is to be determined after a more comprehensive review.
Mortality Review			
86	Create and maintain a mortality review committee comprised of well-respected health care and quality review personnel, headed by an independent chairperson (III.5.N)	In Compliance	
87	Ensure MRC meets regularly and conducts an in-depth review of each death, per JCAP criteria, identifying individual and systemic issues related to each death (III.5.N.2, 4); compile list of MRC meetings and death reviews	In Compliance	
88	Ensure MRC has access to all pertinent people, information related to the course of care leading up to the death (III.5.N.3)	In Compliance	
89	Ensure MRC performs a root-cause analysis to identify any preventable causes of illness and death (III.5.N.5)	In Compliance	

BM No.	Benchmark	Assessment	Finding and Recommendation
90	Ensure MRC issues a final report on each death promptly, per JCAP criteria, with root-cause analysis and recommendations to address outstanding issues (III.5.N.5)	Substantial - Compliance	*Finding* • During the period covered in the present report, eight deaths were reported. Seven of which were issued within 30 days of each death, and one within 41 days (Participant #1151). *Recommendation* • The MRC should continue to work with the DSPDI so that all pertinent information is available, and reports are issued promptly per the JCAP. • The MRC should continue its efforts to provide discussion on root caused and include recommendations to address preventable causes going forward for similarly situated participants.
91	Monitor to ensure prompt and effective implementation of all MRC recommendations and continue to monitor until full implementation (III.5.N.7); compile tracking table of recommendations and implementation status	Working Towards Compliance – Still Under Review	*Finding* • See prior report. *Recommendation* • The DSPDI should present "actionable plans" for clear and measurable strategies specifying who will oversee the implementation of the remedial action plan. See prior report.
92	Monitor to ensure MRC process is effective to avoid preventable illnesses, deaths for similarly situated individuals (III.5.N)	No Compliance	*Outcome Measure* • There is not sufficient documentation of the actual activities taken, and correspondingly, there is no information about whether those efforts were effective. • Compliance with this benchmark is to be determined after a more comprehensive review.
Mental Health			
93	From the Master List, create a sub-list of all participants with mental illness, specifying their mental illness diagnosis/es (III.5.G)	Working Towards Compliance – Still Under Review	*Finding* • The sublist for participants with mental health diagnosis reports 340 participants with a mental health diagnosis, which is less than those identified as high risk for mental health in BM 59. In the process of its review, CAPAR is finding that some participants having a mental health diagnosis that is not justified have been assigned a diagnosis to justify the utilization of psychotropic medications, likely for behavioral management and/or sedation. Thus, this figure may be overestimated at this time. *Recommendation* • See Section II, Part C of this Report.

BM No.	Benchmark	Assessment	Finding and Recommendation
94	Ensure participants receive necessary mental health care in a timely manner to meet their individualized needs in the community (III.5.G)	Working Towards Compliance - Still Under Review	*Outcome Measure* • Compliance with this benchmark is to be determined after a more comprehensive review. • All participant having a mental health diagnosis should have a comprehensive behavioral plan or afunctional behavioral plan assessment to understand the causes of their behavior, target behavioral supports and manage behavior. • See Section II, Part C of this Report.
95	Ensure that all mental illness diagnoses are consistent with DSM criteria and justified in the record (III.5.M)	Partial Compliance	*Finding:* • See Section II, Part C of this Report for update on CAPAR progress. *Recommendation* • See Section II, Part C of this Report for update on CAPAR progress.
96	Ensure that no participant receives psychotropic medication in the absence of a clinically justifiable diagnosis of mental illness (III.5.M)	Working Towards Compliance - Still Under Review	*Outcome Measure* • Compliance with this benchmark is to be determined after a more comprehensive review. See Section II, Part C of this Report.
97	Ensure that type, dosage of psychotropic medication are appropriate and needed for each participant, per JCAP criteria (III.5.M)	Working Towards Compliance - Still Under Review	*Outcome Measure* • Compliance with this benchmark is to be determined after a more comprehensive review. See Section II, Part C of this Report.
98	Minimize use of typical/first generation psychotropic medication (III.5.M)	Working Towards Compliance - Still Under Review	*Outcome Measure* • Compliance with this benchmark is to be determined after a more comprehensive review. See Section II, Part C of this Report.
99	Minimize use of intra-class psychotropic medication polypharmacy (III.5.M	Working Towards Compliance - Still Under Review	*Outcome Measure* • Compliance with this benchmark is to be determined after a more comprehensive review. See Section II, Part C of this Report.

BM No.	Benchmark	Assessment	Finding and Recommendation
III.6 System wide Reforms			
100	Implement a comprehensive quality assurance program to track, analyze, and ensure participant safety, welfare, health care, mental health care issues and outcomes (III.6.A)	Working Towards Compliance - Still Under Review	*Outcome Measure* • Various initiatives are currently being evaluated and discussed in the Incidents and Investigations Work Group. See prior report.
101	Implement prompt and effective measures to address patterns and trends that adversely impact participant safety, welfare, health, and mental health (III.6.A)	Working Towards Compliance - Still Under Review	*Outcome Measure* • Various initiatives are currently being evaluated and discussed in the Incidents and Investigations Work Group. See prior report.
102	Ensure that each participant receives adequate and appropriate monitoring and oversight by a service mediator to meet individualized needs; per existing Court orders, ensure that each service mediator serves no more than 24 participants at any time	Working Towards Compliance - Still Under Review	*Outcome Measure* • Per the Mediator Distribution List, there are a total of 74 community homes and 370 participants assigned across 17 Service Mediators. Caseloads per Service Mediator range anywhere from 6 to 31 participants. • Compliance with this benchmark is to be determined after a more comprehensive review.
103	Work with family members of participants on a plan to address quality issues that impact participants	Working Towards Compliance - Still Under Review[6]	*Finding* • During 2022 the DSPDI reinstated the CTS' monthly meetings with family members and providers and quarterly meetings with APIADI. • There continues to be progress in this area as the DSPDI continues to have an open channel of communication with parents by holding monthly meetings in the CTS and quarterly meetings with the Parents Association. However, the Office of the JCC has seen no evidence of an actual plan as required by this benchmark to address quality issues raised and/or discuss during the before mentioned meetings that impact participants. *Recommendation*

[6] In its response to the draft report shared with the Parties, the DSPDI requests that "the Office of the JCC re-consider its assessment of this Benchmark and assess the same as "In Compliance". Although we deem that there is some merit to the DSPDI's argument, the same was not enough to unanimously convince the Office of the JCC and the Experts that an adjustment in our original assessment was warranted. However, we will continue to work with the DSPDI and will establish a team to provide the necessary support to assist the DSPDI in reaching the desired assessment level within the next reports.

BM No.	Benchmark	Assessment	Finding and Recommendation
			• The DSPDI should develop a plan and consider developing a tracking mechanism to address any matters raised in the meeting with parents and action plans with concrete timelines of implementation.
104	Create and maintain toll-free crisis hotline, staffed 24/7 by qualified professionals that can effectively help to resolve issues (III.6.B)	Working Towards Compliance - Still Under Review[7]	*Outcome Measure* • A Crisis Line Call Log was presented detailing the date, time, participant, home, name of the person calling, reason for consult, recommendation followed and the name of the professional answering the line, seven calls were registered for the current period. The crisis line is operated by the CEEC. According to the DSPDI, the number of calls is minimum provided that the cell phone number of the personnel (EID staff, service coordinators, central level staff, etc.) is widely available and individuals in crisis call directly to receive support and services. • Upon interviews held by the Office of the JCC to providers, guardians, and direct care takers, the JCC continues to find it is not commonly known that the DSPDI has a crisis line answered by professionals 24/7 to gain assistance for participants experiencing a crisis, including a health care emergency, a mental health or behavioral emergency, or other emergent situation and/or significant unmet needs-requiring timely- attention. • As stated in the prior report, the JCC recommends that any Hotline phone call along with the completed phone call registry and danger assessment forms be documented in Therap under the participant's record. • The DSPDI should finalize the revision of the CEEC Protocol and Manual (draft version dated August 2015), which includes a norm for the use, the operation and management of the Crisis Line, to current organizational chart, policies, and procedures. Pursuant to the before mentioned Manual, situations emergencies that may be reported through the HOTLINE are: health-related emergencies or situations, behavioral or mental health emergencies (crisis, suicide attempt, suicidal ideation, aggression, avoidance, etc.), situations of abuse or neglect, or other emergency or

[7] In its response to the draft report shared with the Parties, the DSPDI requests that "the Office of the JCC re-consider its assessment of this Benchmark and assess the same as "In Compliance". Although we deem that there is some merit to the DSPDI's argument, the same was not enough to unanimously convince the Office of the JCC and the Experts that an adjustment in our original assessment was warranted. However, we will continue to work with the DSPDI and will establish a team to provide the necessary support to assist the DSPDI in reaching the desired assessment level within the next reports.

BM No.	Benchmark	Assessment	Finding and Recommendation
			significant situation that affects the physical, emotional and psychological safety of the participant and that require immediate attention and/or action. • Compliance with this benchmark is to be determined after a more comprehensive review.
105	Create and maintain a systemwide email system to facilitate prompt communication to all pertinent individuals, per JCAP criteria to resolve outstanding issues (III.6.C)	Working Towards Compliance - Still Under Review	*Outcome Measure* • All DSPDI personnel has a personal email with the Health Department Outlook platform. • As stated in the prior report, it is highly recommended that these referrals be documented in the appropriate Therap module to ensure the completeness of each participant's record. • Compliance with this benchmark is to be determined after a more comprehensive review. See prior report.
106	Develop a family support program consistent with the criteria in the CBSP (V) that includes service mediators for participants living at home, as well as a subsidy and respite program; participation in the program will be voluntary with prior authorization in private homes	Working Towards Compliance - Still Under Review	*Outcome Measure* • Not all areas/regions (per CTS) have available respite "units". • Only two participants living in biological homes were provided respite services during this period. However, per other documentation furnished by the DSPDI two other participants were temporarily placed in respite while permanent placement was determined or made available (Participants #82 and #1170). • No updated respite program protocol nor document indicating DSPDI's current respite capacity were furnished. The DSPDI should work to finalize the Respite Protocol to current organizational chart, policies, and procedures. • Compliance with this benchmark is to be determined after a more comprehensive review.

EXHIBIT #1. San Juan Town Hall Meeting Minutes

Date: December 7, 2022
Location: Popular Center, 208 Muñoz Rivera Ave., San Juan, Puerto Rico
Time: 11:00 a.m.

Appearances:

Mr. Alfredo Castellanos, Esq. – JCC/Federal Monitor (Office of the JCC)
Mr. Richard Farano, Esq. – Legal Counsel for the United States Department of Justice
Mr. Rafael Barreto Solá, Esq. – Legal Counsel for the Commonwealth of Puerto Rico
Hon. Carlos Mellado – Secretary of Health of the Commonwealth of Puerto Rico
Dr. Marilú Cintrón Casado – Auxiliary Secretary of Health of the Commonwealth of Puerto Rico
Mr. Danniel Soto – Interim Director of the DSPDI
Dr. Emily Lauer – University of Massachusetts Center for Developmental Disabilities Evaluation and Research (CDDER)

Guest Speakers:

Mr. Rafael Madera
Mr. Ismael Nieves
Mr. Miguel López
Ms. María Vilá
Ms. Carmen Vázquez
Ms. Mary Irizarry
Mr. Erick Ríos
Ms. Ginaydie Ramos (recorded message)
Mr. Héctor Rodríguez
Ms. Laida Plá
Mr. Frank de la Torre and Ms. María López

Ms. Paz Catalina Salas
Ms. Yolanda Rosado
Mr. Kenneth Román
Mr. Alberto Ortiz

Proceedings

1. **Recorded Message from Hon. Silvia Carreño-Coll, United States District Court Judge**
2. **Opening Statement from Mr. Alfredo Castellanos, Esq. and rules of proceedings**
3. **Message from Hon. Carlos Mellado, Secretary of Health**

- The Secretary expressed that since he became Secretary of Health, his commitment has been to improve the services of the intellectual disability program and to have a program that they can feel satisfied with, but most of all, a program that all people who need support from the Department of Health can feel satisfied with.
- The Secretary also stated that he maintains excellent communication and collaboration with the JCC, and that he wants to listen to all matters that the guest speakers wish to bring to his attention with the hope to be able to resolve and find solutions to the same, and perhaps to be able to accept the things that may not be doing adequately.

4. Opening statement from Mr. Richard Farano, Esq. (USDOJ)

- Mr. Farano expressed that he is pleased to say that all six of the Commonwealth's DD institutions and several private institutions have closed, and that there is now a community network of substitute homes and small group homes along with some additional services for people living independently or those living in a family home.
- "*Hundreds of people with DD now live, work, and play in the community together with us, no longer locked up in scary institutions where they were once isolated and afraid, with no hope, no ability to leave and no prospect of an independent life. So hopefully we've replaced the darkness with some light, and despair with happiness.*"
- It's been Mr. Farano's impression that under the leadership of Secretary Mellado and Auxiliary Secretary, Dr. Cintrón, the Commonwealth has tried to put the interest of the participants first, and that the Commonwealth has strived to take a number of positive and sometimes difficult steps to better address their needs.

5. Mr. Rafael Barreto, Esq. (Counsel for the Commonwealth of Puerto Rico)

- Mr. Barreto expressed that when they took the case, they were given specific instructions that they needed to be facilitators so that the compliance process could take place. "*Since we started we have kept constant communication with USDOJ, the JCC and the Department of Health.*"
- "*The most important thing is for all of you to know that communication lines are always. Open and that any concerns you may have, be brought to the corresponding Department of Health officials who are here to serve you.*"

6. Dr. Marilú Cintrón Casado

- Dr. Cintrón expressed that the input that they have received from parents, providers, participants, and CTS staff has been vital for them to identify those areas that need to be revised, modified or where they simply need to start again.
- "*We recognize that there is much to cover and modify, but we have also had achievements and we aspire that the inclusion of all persons with intellectual disability become a reality.*"

7. Mr. Rafael Madera

- "*I have been in the Program since 1999. I was in the Ruiz Soler Hospital when Dr. John McGee, who may rest in peace, said that all participants needed to be removed and placed in a community home. So I was placed in the first community home called Casa Domenech in 2001.*"
- Mr. Madera expressed that when the providers asked him what he wanted, he said that he wanted an apartment. That was his first dream.
- "*I woke up very happy around 5:30 this morning. I made coffee, took a shower and got dressed and waited for my mother to bring me my suit. I have a coffee maker, a microwave and a big tv in my house.*"
- Mr. Madera has worked in about five McDonald's for seven years, but he is now unemployed. After McDonald's he worked for the municipality of Vega Baja.
- "*I would like to work at a car dealership, and I would like to take a workshop to learn how to work there. I would also like to learn to cook*".
- "*I am happy that we have new vehicles for the CTS.*"

8. Mr. Ismael Nieves

- Mr. Nieves is currently washing cars at the CTS and is training to open a car wash.
- "*I have good caretakers at the home and they have given me the opportunity to go to the CTS in Bayamón.*"
- Mr. Nieves expressed that he has had many issues in the past but since he's been in the Albert Ortiz home, it has been very good.
- "*I want to be able to help my family because my parents are over 90 and my sister is older as well and my brother, is in a home.*"
- "*If it was not for Albert and his wife I would not be here today. The treatment that we receive in the homes is very important and they treat me very well, and listen to my problems.*"
- Mr. Nieves expressed that he would not like to live by himself. "*I have had many problems in the past, including being in jail, and I feel safer in a home.*"

9. Mr. Miguel López

- Mr. López is taking art classes in Vega Baja and would like to sell his paintings.
- "*I enjoy working here today*". (Mr. López worked during the Town Hall Meeting assisting with general matters and was compensated for his time).

10. Ms. María Vilá

- Ms. Vilá thanked Dr. Cintrón and Mr. Soto for holding meetings with parents every trimester. "*They are very fruitful and give us the opportunity to express our concerns and find solutions in a collaborative manner.*"
- Ms. Vilá also thanks the Department for vaccinating participants against COVID-19 and requests that they be vaccinated against shingles as well.

- "*I encourage all providers to make exhaustive monitoring to ensure that all homes are treating participants gently. Daily monitoring by the interdisciplinary team is vital to avoid the closing of homes and to be able to correct and adjust the staff training with the participants' needs.*"
- Ms. Vilá would like that participants to attend the CTS at least five times a week. For participants to acquire independent life skills, as well as social and habilitative skills, they need to receive continuous and daily services. One or two days is not enough.
- Ms. Vilá stated that the daily centers have a dual function, because they not only provide important tools and skills for the participants, but also serve as respite for the parents and caretakers who need time to attend other responsibilities, go to medical appointments, or simply to recharge their batteries.
- "*We are very grateful that the respite program has begun and that it provides the opportunity for participants to spend the night. However, we would like that program to be expanded to cover daytime respite, so that parents are able to have that support during the daytime.*"

11. Ms. Carmen Vázquez

- Since Ms. Vázquez' parents passed away 9 years ago, she has been taking care of her brother and visiting him at the home constantly.
- "*I was able to observe that in his previous home, the participants were always overmedicated and at times, with multiple wounds.*"
- Ms. Vázquez stated that when her brother was transferred to another home, she had a negative experience given that they informed her by telephone the day before that he was going to be transferred to a home in Ponce, when she lives in Toa Baja.
- "*Thanks to the JCC's intervention, he was placed in a home in Dorado which is closer to me. The change has been very positive. I keep good communication with the provider and I visit him every Thursday and they keep me updated on every matter regarding his health and his behavior. I've never seen him overmedicated and he always looks happy.*"
- Ms. Vázquez highlights that the participants are taken outside regularly but they do not attend the CTS as frequently as they should. She would like for participants to go more often to the daily centers.

12. Ms. Mary Irizarry

- She is the mother of participant Gustavo Velázquez. He works at the Luis Muñoz Marín park in a plant nursery.
- "*Finally, our population is recognized and we can see hints of inclusion and opportunities for our children.*"
- Ms. Irizarry would also like that participants attend the CTS more regularly.
- Although the centers have acquired new vehicles, there is still the need for assistance ramps for participants who need a wheelchair.
- For many participants, these activities are the only opportunity they have to visit places and socialize with their peers.

- "*I am also concerned about the lack of food storage in the daily centers. There is no food menu planning for the week and snacks and lunches are improvised.*"
- The Bayamón CTS is also a hazard, not only for cars, but for people walking. There is a lot of debris and there are holes in the pavement.

13. Mr. Erick Ríos

- He is the President of the Service Providers Association
- "*I have to say that in 21 years in the Program, I have not seen an administration that works so hand-on-hand like Danniel and his team.*"
- Mr. Ríos is concerned about the economic situation of the homes. Inflation is at 25%. When the rates and the tiers were established, it was done considering the conditions of that time, which have changed. Although they have been able to manage through time, things are getting very complicated.
- They also have issues with recruitment. "*We need to begin talks with the administration to see how we can address these needs by next year. We need more specialized personnel to be able to provide the services that participants require*."
- Mr. Ríos expressed that there needs to be a revision of all matters related to payments to providers so that we can maintain the quality of services.

14. Ms. Ginaydie Ramos (recorded message)

- She is the Clinical Coordinator for the Vega Baja CTS.
- "*We have solidified relations with providers and parents of participants, holding continuous meetings with them*".
- Ms. Ramos stated that they have faced challenges at times with a lack of electricity and that they need to strengthen the clinical team at the Vega Baja CTS. Inconsistent electricity and other concerns have presented an infrastructure challenge, but they appear to have been able to obtain a space that previously belonged to the Vega Baja CTS at may resolve the issues.
- They have also faced challenges with the recreation areas, related to the deep cleaning of the basketball court, paint, etc.
- "*We have various projections for next year, including the increase of the frequency of services to participants, as well as increasing the number of community activities and employment for participants.*"

15. Mr. Héctor Rodríguez

- "*We would like to expand services and receive more participants, but we have an issue with available space in the Rio Grande CTS.*"
- They have basically a hospital setting, there are two hallways and that is where they do all the activities.

- "*One of our missions is to be able to move the CTS to another location. We continue to identify possible spaces but there are issues with the municipality and other matters that interfere in this process.*"
- They have issues with the air conditioners, personnel recruitment, and receiving food in time.

16. Ms. Laida Plá

- She has been the Bayamón CTS Director since last year.
- "*We have had an increase in our census. We had 90 participants when I started and now we have 129. 92 of those attend personally to the activities [at the CTS] and the rest receive services at their homes*".
- They have also had participants from specialized homes which are a big challenge because they come from hospital settings where they have spent a lot of time.
- They have a group that comes twice a week and they continue to expand.
- "*We have a [service-delivery] limitation [based] on staff recruitment [concerns] such as [difficulty hiring] occupational therapists and other professionals.*"
- Their elevator is not working and they are renovating the basement for offices, storage or habilitative uses.
- They have seven employed participants.
- They have multiple participants with difficulties eating and with aspiration risks.

17. Mr. Frank de la Torre and Ms. María López

- *"We are parents of a participant who attends the Rio Grande CTS. We share the concerns about the space and other matters raised by other parents."*
- They also agree that they need daytime respite services.

18. Ms. Paz Catalina Salas

- "*I am the mother of a participant with Down syndrome, behavioral problems, and Alzheimer's.*"
- They have received much help from the Program, especially regarding support for his social adaptation and emotional stability.
- However, her son is only attending the CTS once a week.
- She recommended that ramps be added to the buses, as they were not included when they were purchased.
- She reported that the CTS encounters occasional difficulties with the electricity generator. These issues affect water services and have forced biological participants to return to their homes.
- She noted that increasing support staff is necessary to prevent fatigue among employees who constantly injure themselves, and that it would also allow the CTS to serve more participants from the biological homes.
- She reported roof leak repairs as insurance matters, and she mentioned that the repair or purchase of a new elevator has been pending for a long time.

- At the program level, she noted that the Respite program was not well-known among the families, and she proposed that more information be gathered and disseminated.
- She identified hiring specialists, especially in occupational therapy and psychology, was identified as an important need for the centers.
- She discussed creating more CTSs to make services more accessible to participants and offering more accessible services for people with disabilities, closer to their homes.
- The group submitted a medium-term project for consideration to develop biological home services focused on a geriatric population, given the high number of participants in late adulthood between 45 and 60 years old who will require another level of care within the next 10 to 15 years. The group expressed hope that the Program will not abandon parents who are unable to care for their children and allow their children to remain in their family environment even when the children will present the greatest need.

19. Ms. Yolanda Rosado

- She is the new provider for Casa Salud of Quality Assisted Care, located in Manatí.
- She referenced clinical situations regarding the management of participants that they are working on with their doctor.
- She mentioned that the DSPDI team has been attending to their needs and that they are happy to work with the clinical management of the participants since ensuring the health, safety, and welfare of participants is their main goal at Casa Salud.
- They have heard some concerns regarding medication management, specifically cases of polypharmacy and excessive medication. They have identified these cases and have been working on them for the past three months. They have seen positive changes in their participants. The team's goal is to work on the clinical management of their participants, and they appreciate the opportunity to do so.

20. Mr. Kenneth Román

- He is the provider of Casa Salud, a group home established in Corozal. Has been operating for around seven months now with participants.
- "*The Division has been working hand in hand with me since day one and I have no complaints. On the contrary, what I want to do is extend my gratitude to all of you because you are always there to support me, my team, and the participants 24/7.*"

21. Mr. Alberto Ortiz

- The Division should minimize the amount of staff that goes to participants' homes during monitoring visits as too many staff members can create a difficult dynamic for the participants and invade their personal space.
- "*Advance notice would also be appreciated given that said visits also focus on administrative matters, which not all staff are privy to.*"

22. Mr. Richard Farano

- "*We need to continue collaborating and working together to tackle outstanding issues, such as delivering effective healthcare and mental health care services in a timely manner to ensure the health, safety, and welfare of people in integrated settings.*"

23. Mr. Rafael Barreto Sola

- Mr. Barreto expressed that the goal is not to end the case, but to reform the system. The communication with the Monitor's Office has been excellent and he thanked Mr. Farano for his availability and input.
- There have been few controversies, and those that arose were resolved between the parties without needing to go to court.
- "*I encourage anyone with concerns to bring them forward. We are committed to carrying out the necessary steps for compliance.*"

24. Mr. Danniel Soto

- Has been the interim DSPDI director since May, and he acknowledges that there are pending projects from previous administrations. He invites all stakeholders to work together to facilitate the process of addressing these issues.
- He emphasizes the importance of focusing on results and not just on the process. They are open to dialogue and taking action to transform the system.
- He acknowledges the progress that has been made and assures the audience that there is a functional system in place.

EXHIBIT #2: AGUADILLA TOWN HALL MEETING MINUTES

Date: February 17, 2023
Location: Punta Borinquen Resort, Aguadilla, Puerto Rico
Time: 11:00 a.m.

Appearances:

Mr. Alfredo Castellanos, Esq. – JCC/Federal Monitor (Office of the JCC)
Mr. Richard Farano, Esq. – Legal Counsel for the United States Department of Justice
Mr. Rafael Barreto Solá, Esq. – Legal Counsel for the Commonwealth of Puerto Rico
Hon. Carlos Mellado – Secretary of Health of the Commonwealth of Puerto Rico
Dr. Marilú Cintrón Casado – Auxiliary Secretary of Health of the Commonwealth of Puerto Rico
Mr. Danniel Soto – Interim Director of the DSPDI

Guest Speakers:

Mr. José Luis Morales Lopez
Mr. Christian Orengo Pacheco
Mr. José Berríos
Ms. Amneris Rivera
Mr. Harry Lamberty
Ms. Sandra Cerezo
Dr. Juan Molina
Ms. Esther Caro
Ms. Eileen Llavina
Ms. Iniabel Peña
Ms. Zoila Roca
Ms. Margaret Sanders
Ms. Magda Ramos

Proceedings

1. **Recorded Message from Hon. Silvia Carreño-Coll, United States District Court Judge.**
2. **Opening Statement from Mr. Alfredo Castellanos, Esq. and rules of proceedings.**
3. **Opening statement from Mr. Richard Farano, Esq. (USDOJ).**

- Mr. Farano recognized the many partnerships that have contributed to the success of the case, including participants, families, community providers, Commonwealth leadership, the federal court, and the JCC.

- He specifically recognized the contributions of the current Secretary of Health, Dr. Carlos Mellado López, and the Auxiliary Secretary of Health, Dr. Marilú Cintrón, for putting the interests of the participants first and taking positive steps to better address their needs.
- Mr. Farano thanked Mr. Castellanos for his work as the JCC and for his instrumental role in protecting the Program from adverse actions.

4. Dr. Marilú Cintrón Casado

- It is important for us to note that this exchange of information is not just an obligation we have, but it is driven by a genuine interest of our Division to address the needs of the adult population with intellectual disabilities.
- As a team and agency, we aspire for our services to improve in every instance. We know that we have a difficult road ahead and that there is room for improvement, but I want to let each and every one of you know that we will take on this commitment and continue to do so.

5. Mr. Jose Luis Morales López

- He informed the group that he was planting and that right now he has his harvest; he is also playing volleyball.
- He is going to church and doing well.
- The plants are making him money.

6. Mr. Christian Orengo Pacheco

- Mr. Orengo Pacheco greeted everyone and informed them that he was in good health. He also mentioned that he enjoyed practicing sports, especially basketball.
- The Monitor asked him if he liked the Indios de Mayagüez. He said he liked them but had not been to a game in Mayagüez. He mentioned that he used to go to the Yauco stadium and that he had listened to baseball games on the radio.

7. Mr. José Berríos

- Mr. Berríos expressed that he was doing well and that he likes to listen to music and play the "guiro."
- He proceeded to play and sing two songs.

8. Ms. Amnerys Rivera

- She reported that she likes to paint and make jewelry and crafts.
- *"I like to sing Christian music and paint my nails."*

9. Mr. Harry Lamberty

- He lives in Hogar Puerta de Sol. He likes to eat chicken and fries.
- *"I am grateful for the home providers because they help me a lot and listen to my problems. I listen to music when I am sad, mad, or when things are not going well."*

10. Hon. Carlos Mellado, Secretary of Health

- Secretary Mellado explained that he was there because he had made a commitment from the beginning of the Program to exchange ideas and receive input from Monitor Castellanos.
- Secretary Mellado emphasized that they were working hard in a complex environment where execution was often challenging. However, he stated that they were committed to working with the participants (who he referred to as "special human beings") to help them integrate and learn, while also learning from them. He expressed his willingness to listen to everyone's input.

11. Sandra Cerezo

- She is the Secretary of APIADI, an organization that connects together parents and other family members of adults with intellectual disabilities; she also serves as the Secretary of the Aguadilla chapter of parents.
- She commended the organization for its progress but expressed concern for the less functional participants and their future after their parents are no longer able to care for them.
- She also suggested the need for more transitional service centers for individuals with intellectual disabilities.

- **Monitor Castellanos: He s**hared information about collaborative agreements established by the Office of the Monitor with the Department of Education and the Department of the Family, which have identified potentially hundreds of citizens with intellectual or developmental disabilities that may receive services from the Department of Health.

- He referred to efforts being made between the Department of Health and the Department of Education to build a bridge to DD services for individuals aged 18 to 21, so that the skills they have acquired during their education are not lost, and so they can become citizens who can work and have their own homes and jobs. The Monitor was positive about the progress made in addressing the needs of the population with developmental disabilities appearing before local courts, and he mentioned that they are working to ensure that individuals with developmental disabilities are properly processed and diverted away from the criminal justice system whenever possible in both civil and criminal matters. He also shared information on the number of citizens with developmental disabilities in Puerto Rico and the ongoing efforts to provide services to those in need. The Monitor asked Ms. Cerezo about the services being provided by the CTS of Aguadilla, and whether she believed that more days and access to workshops are needed.

- Ms. Cerezo discussed the current two-day service schedule and agreed that it is too little to provide the necessary follow-up and support for their less functional participants who require

more reinforcement in their therapies. Additionally, she mentioned that with the pandemic, it was difficult for parents to take their children to medical appointments and offices.

- Ms. Cerezo raised concerns about the lack of visibility of these programs, and the need for more centers across the island. She acknowledged that the waiting lists are long, which presents challenges in meeting unmet needs. She suggested that there should be more centers and a better transportation system.

- The Secretary requested time to speak and shared their experience in restructuring the Department of Health. He discussed his goals of creating a better structure to improve the program and the importance of having sub-secretaries for public policies to promote their independence. He also discussed his visits to participants with independent lives and to agencies that employ participants to do competitive work; he said he was surprised by the limited number of participants and centers given the demand.

12. Dr. Juan Molina (via video)

- Dr. Molina started the meeting by greeting everyone and apologizing for not being there in person due to a shortage of dentists for people with "special needs." He expressed his gratitude to the Department of Health for their support in providing dental space to develop non-pharmacological dental interventions that complement pharmacological ones. He also thanked all the parents, the JCC, and everyone working with them.
- He referenced that the Medical Sciences Campus is also on board in trying to find more professionals sensitive to proper pharmacological management.
- Secretary Mellado also greeted Dr. Molina and praised him as an excellent dentist and human being. The Secretary talked about the challenges they faced in finding medical specialists in different disciplines, such as urology, psychiatry, and internal medicine. He mentioned the issue of polypharmacy and the need for pharmacies to educate patients or their families to avoid interactions with other medications. He also emphasized the importance of avoiding the use of multiple medications, especially in adult centers.

13. Ms. Esther Caro

- *The Asociación Mayagüezana de Personas con Impedimentos* (AMPI) provides daytime services aimed at promoting the improvement of the quality of life of adults with developmental disabilities. In 2008, she reported that they opened the first of three assisted living homes for adults with developmental disabilities, two of which serve residents with mild to moderate DD and promote their capacity for independent living. The third home provides 24-hour housing and support services to residents with severe intellectual disabilities.
- She referenced that they have been submitting proposals to the Department of Health since the end of 2018 to fill the available spaces in her homes with adults with intellectual disabilities presently under the custody of the Department of Health, but she reported that her proposals have been rejected on the grounds that, as a home affiliated with HUD, they cannot offer services.

- Mr. Soto responded by saying that they respect AMPI's services and work, and that they responded to their proposal in a formal meeting where they discussed each point in detail. They even made a counteroffer, including their rates, in an effort to reach an agreement. However, they did not receive any further response from AMPI after that meeting.

14. Ms. Eileen Llavina

- Ms. Llavina introduced the Association of Providers of Homes for People with Intellectual Disabilities to those who were unfamiliar with it and passed the floor to the vice president.
- She referenced that the association was founded in March 2020 and has more than 26 staff members and 39 community homes, representing over 50% of the established homes served by the program.
- She reported that the association is also part of ACORN, an organization of disability providers based in the United States.
- She mentioned that the association's mission is to advocate for the rights of residents in developmental disability homes and for the providers in charge of their direct services. She added that their vision is to offer the best services to their participants and to set an example for providers, complying with all the requirements of the Division with which they maintain a contract and its regulations.
- She referenced that some of the association's achievements include providing documentation for COVID protocols, getting contractual vocabulary implemented to improve services, improving communication with the Division and the JCC in the JCAP compliance area, and providing a list of all homes and addresses to FEMA for disaster management. They also distributed N95 surgical masks and food boxes to providers and APIADI family members.

15. Ms. Iniabel Peña

- Ms. Peña mentioned that she has been collaborating and serving as a community home provider in Aguadilla for 16 years. She expressed her pleasure in providing respite services, which she considers a wonderful service that has greatly helped family members in need.
- Ms. Peña mentioned that they started an association in 2020 due to the aftermath of Hurricane Maria and the onset of COVID-19. She referenced that the group decided to form because working as independent groups was not effective. She reported that the association has grown since then, not only because they became an association, but also because they have had communication with the Program's administration group.
- She emphasized that communication has been critical to the association, and they have quarterly meetings with the director. She praised the open-door policy and described how they are heard, are taken seriously, and that they see results. She added that the communication within the CTS has been excellent, and that payments are now being made on time.
- She concluded by saying that the emergency response has been satisfactory, and they have not seen such prompt responses before. She expressed her satisfaction with how things are going, and she believes that the association is growing in the right direction.

- Secretary Mellado expressed his belief that the challenge being discussed was a challenge for the entire government. He mentioned a study from 2021 which showed an increase and suggested evaluating processes in the short, medium, and long-term to address concerns.
- Mr. Soto praised the work of providers during Hurricane Fiona and discussed the expenses involved in operating the homes. He also mentioned a formal letter sent by the attendees last week and their ongoing conversations with Burns & Associates to establish a contractual review agreement. Finally, he stated that they were also evaluating the expense on emergency reimbursement and could intervene during the renewal period.

16. Ms. Zoila Roca

- Ms. Roca talked about her experience at the Aguadilla CTS since 2006, and how she fell in love with the participants and the processes. She mentioned that she would be leaving in about two months, but had not yet decided on a specific date.
- She then went on to explain the objectives of the Aguadilla CTS, which includes developing skills for independent living and integrating participants into the community. Currently, the center has 147participants, with 107 located in community homes, 8 in substitute homes, 6 in specialized homes, and 26 in biological homes. She referenced that one participant is located in a private home, and that they would have a home for him by the end of the week.
- She provided a breakdown of the homes, with 18 community homes, 4 substitute homes, 1 specialized home, and 3 biological homes, in addition to the private home.
- She did not go into detail about the workshops offered at the center, as she said they were well-known. Instead, she focused on the center's response to the COVID-19 pandemic. The center became a vaccination site for DSPDI, and SRA. Roca reported that 107 participants, or 73%, were fully vaccinated, with 146, or 99%, having received both doses. Additionally, 109 participants, or 74%, had received the influenza vaccine.

17. Ms. Margaret Sanders

- She is the mother of a 17-year-old boy and spoke about the present systemic problems that exist. She expressed her opinion on the issue and stated that the present problems do not affect her. She mentioned that parents like her have been working towards the development, full life, and dignified life of their children since 2005.
- She emphasized the importance of self-determination, which goes beyond the rehabilitation paradigm. She pointed out that we should talk about people with disabilities rather than as patients.
- She provided an example of her son's disability and how he can communicate verbally to a certain extent, but that he still faces notable barriers to social participation in the community.
- She explained that in 2020, the definition of disability changed and stated the new definition of disability. She further added that the lack of integration is a barrier to those people who want to have dignified and self-determined participation.
- She expressed her gratitude for a letter that she considers to be an important legal document based on the United Nations' new charter for the rights of people with disabilities. She also

highlighted the importance of Puerto Rico's own charter, which she believes is more comprehensive. She emphasized the need to move beyond just knowing about the rights of people with disabilities and actually practicing inclusion. She noted that Puerto Rico still lags some jurisdictions in the United States in terms of progress towards inclusion and encouraged strong mobilization efforts to be made on the island.

18. Ms. Magda Ramos

- She introduced herself as a member of the *Grupo de Madres Innovadoras de Niños con Síndrome de Down*, a group of mothers who have been fighting for the rights of their children since 2004. She stated that she has nothing more to add to what her colleague had just expressed. She mentioned that their group has always tried to be ahead of the curve, and that they are constantly questioning, which has resulted in the positive development of their children.
- Magda has an 18-year-old daughter with Down syndrome who attends a regular school, the *Escuela Vocacional Doctor Heriberto Domenech*. Magda does not believe in segregating her daughter and wants her to be included. She added that despite the difficulties her daughter faces in school, such as exhaustion and arm pain due to writing, she is visible and that is important. Magda believes that the typical students who are with her daughter will remember her when they see someone with Down syndrome in the future.
- Magda shared that her daughter has expressed her desire to go to university, work, earn money, have a house, get married, and have children like her other siblings. Magda sees this as a challenge and is determined to help her daughter achieve these goals. She acknowledged that there are many good intentions, but it takes more than that to support individuals with intellectual disabilities.

19. Mr. Richard Farano

- Mr. Farano expressed his appreciation for everyone who participated in the event, specifically mentioning the participants and the free concert from Harry and José. He also expressed support for the last few speakers and their interests and emphasized the importance of individual support plans and person-centered planning.
- He then thanked Secretary Mellado and Auxiliary Secretary Cintrón for their contributions and leadership, and noted the positive comments made about them during the event. He acknowledged that there is still work to be done and expressed his commitment to addressing outstanding issues.

Exhibit #3: PONCE TOWN HALL MEETING MINUTES

Date: April 13, 2023
Location: Aloft Hotel, Ponce, Puerto Rico
Time: 11:00 a.m.

Appearances:

Mr. Alfredo Castellanos, Esq. – JCC/Federal Monitor (Office of the JCC)
Mr. Richard Farano, Esq. – Legal Counsel for the United States Department of Justice
Mr. Rafael Barreto Solá, Esq. – Legal Counsel for the Commonwealth of Puerto Rico
Hon. Carlos Mellado – Secretary of Health of the Commonwealth of Puerto Rico
Dr. Marilú Cintrón Casado – Undersecretary of Health of the Commonwealth of Puerto Rico
Mr. Danniel Soto – Interim Director of the DSPDI
Ms. Emily Lauer – University of Massachusetts Center for Developmental Disabilities Evaluation and Research (CDDER)

Guest Speakers:

Mr. Enrique Biascochea Goglad
Ms. Rocío Sepúlveda Sotomayor
Mr. Roel Gardeslen Colón
Mr. Nelflen Rivera López
Ms. Gloria Rodríguez Pagán
Ms. Adriana Sofía Méndez Ramos
Ms. Vilma Vega
Ms. Madeline Cintrón
Ms. Haydeé Ramos
Ms. Milagros Alvarado
Ms. Martha Gracia
Ms. María Cristina Quevedo
Ms. Nidia Martínez
Ms. Olga Avilés
Mr. Frank Santiago
Ms. Joyce Santiago
Ms. Luz Torres Ríos

Proceedings

1. **Opening Statement from Mr. Alfredo Castellanos, Esq. and rules of proceedings**
2. **Recorded Message from Hon. Silvia Carreño-Coll**
3. **Opening statement from Mr. Richard Farano, Esq. (USDOJ)**

4. **Opening statement from Dr. Marilú Cintrón Casado**
5. **Message from Hon. Carlos Mellado, Secretary of Health**

- The past Town Hall Meeting was very beneficial for me because we heard different perspectives on the matters that were discussed. I am in the best disposition to help improve the services, take care of the IDD population, and to address the issues and concerns that were raised in the last meeting. The Department of Health is committed to keep working for the benefit of the participants, expand the program and improve the services as all participants deserve.

1. **Mr. Enrique Biascochea (participant)**

- Has been working at McDonald's for a few years and also graduated high school around 13 years ago.
- Works 20 hours a week and receives services from the CTS at his home.
- Likes to work with plants and animals.
- Went to Ireland for vacation.

2. **Ms. Rocío Sepúlveda (participant)**

- Has been working as a receptionist in the Department of Health's Ponce Regional Director's Office since January, from 8am to 12pm.
- Would like more help controlling her emotions. She has a prescription, and the neurologist says she's doing fine, but she would like more help with her emotions because she is very sentimental.

3. **Mr. Roel Gardeslen (participant)**

- He would like to work at Sam's Club and would like to receive more services from the CTS to help him with that.
- He only receives services twice a week but wants to go more often and be able to go out more and be with other people because he feels very lonely.

4. **Ms. Gloria Rodríguez (participant)**

- Currently working at the Ponce CTS from Monday to Friday, from 8am to 12pm. Very grateful for her job and to be working with people she loves.
- She has 2 dogs that she loves very much.
- She went to Disney World, and they take her shopping so she can buy her things.
- Wants to go to Dominican Republic.

5. **Ms. Adriana Sofía Méndez (potential future participant)**

- Student at Dr. Heriberto Domenech Vocational High School. She is currently in the 11th grade. She is 18 years old.
- Her dream is to go to college once she graduates high school. She wants to be able to get a good job, buy a house and get married at age 30. She wants to live independently like her brother and sister.
- "I would like to ask all that are present here to help us achieve that dream, because we all have the right to a meaningful and dignified life, with the same opportunities, with no barriers or limitations".

6. Mr. Neflén Rivera (participant)

- He would like to go to the CTS every day. He currently goes twice a week.
- Would also like to have more physical activities like running and playing sports, as well as going to the beach, music concerts and shopping.
- Would like to have a job, although he makes hammocks and sometimes sells them.

7. Ms. Vilma. Vega (mother of participant in biological home)

- She is very happy to see a lot of positive changes and progress, but her main concern is that there is no guarantee that this will continue if there is a change of government administration or changes in personnel.
- She would like to receive more assistant from Amas de Llaves to help with her daughter's needs, because she does not receive enough help.
- Would also like to receive some assistance regarding social security benefits for her daughter, as well as nutritional assistance, among other available government services.

8. Ms. Ivonne Sabater (mother of participant)

- My son has been going to the Ponce CTS since he was 20 years old.
- He has severe intellectual disability and cannot express himself. He is a very difficult case, and as such, is constantly subject to negligent treatment in hospitals and medical facilities. Nobody wants to treat him or take care of him when they see him or when they read his diagnosis.
- The most recent case was a doctor that asked her why did she take him (her son) to the doctor and not just take the medical record. The purpose of the visit was to check a skin condition that looks very bad, but the doctor did not even order any tests.
- She is very concerned that she cannot find the formula that he consumes (since he cannot consume milk and most foods).
- She is very saddened by the fact that her son does not get invited to outings and other outdoor activities like other participants. She feels like her son is discriminated in the hospitals, in the program, and in the general population.

9. Ms. Madeline Cintrón (mother of participant)

- Wishes that participants assist the CTS more frequently.
- Concerned about the Ponce CTS infrastructure (parking needs pavement, among others).
- However, it is positive that they have fixed the bathrooms, the dining room, and the green areas are being maintained.
- She is pleased with the services received. Participants have improved their social and emotional skills.

10. Ms. Haydeé Ramos (mother of participant)

- Her daughter has been attending the CTS for many years. She recognizes that there have been many ups and downs, but mostly, she is grateful for the services that her daughter receives there.
- She is currently receiving combined services from the CTS and from Amas de Llaves.
- She hopes that the Program can expand CTS services given that 7 centers and 3 days of services are not enough for the IDD population.
- Would also like a music program for her daughter.

11. Ms. Milagros Alvarado (mother of participant Christian Román)

- Her son is in a Sor Isolina Ferré center. He has a special education teacher, but she needs to spend over 2 hours with him every day to help him study. She would like a special education tutor to help him.
- He wants to read and write and wants to be able to get his driver's license.
- He works with his father, and I pay for private swimming lessons, as well as in special education basketball clinics.
- There used to be a special education teacher in the CTS but not anymore.
- He has not had a psychological evaluation in 18 years. I asked the CTS if the psychologist from central level could go to Ponce to evaluate him, but they have cancelled the 2 appointments that have been made for this.

12. Ms. Martha Gracia (sister-in-law of participant)

- My husband and I have been taking care of my sister-in-law for 23 years.
- When she first started living with us, she couldn't do much, but I wanted more for her, so with the help of the CTS and all the people that helped, she was able to learn a lot of things.
- She has been bedridden for the past 7 years, so she no longer goes to the CTS.
- The center needs a thanatologist (to help when we lose a participant or a loved one dies) and a speech therapist.

13. Mr. Alejandro Rodil (Ponce CTS)

- Throughout the pandemic the CTS provided synchronous and asynchronous therapies to participants. We also remained doing collaborative work in the employment area, which we did with various agencies and universities.
- We have students that provide services and do their practice in our center, mainly in the areas of psychology and occupational therapy, among others.
- We have also initiated various pilot programs with agencies such as the Department of Education.

14. Ms. Nilda Martínez (service provider)

- Has been a service provider for 20 years.
- One of her main concerns is the time that it takes to place a participant in the home, which currently takes around 10 months.
- Another thing that has been very difficult is obtaining the social security card for her participants, which is needed for passports, food stamps, and other important services.
- She also needs to have some sort of authority to be able to sign on behalf of the participants in medical emergencies.

15. Ms. Olga Avilés (service provider)

- Participants in her home are all bedridden and do not attend the CTS, but she takes them to community activities, centers, festivals and integrates them to the community.

16. Mr. Frank Santiago (service provider)

- He takes his participants to community activities and basketball games, where they have their VIP seats. They are well known in the community and people help them a lot.
- He suggests that more awareness has to be created in the community by the providers and the Program, given that a lot of people don't know the nature of the homes.

17. Mr. Alfredo Castellanos (Special Master/JCC)

- Closing remarks and farewell

Exhibit #4: Addendum for Integrated Employment and Day Activities Section

Updating Departmental Policies and Protocols to Support Employment and Community Integration

- Clarify Rules and Procedures on Individualized Support Services: Standard #3, Page 7 (Specific Objectives) of the Manual states, "*To ensure that participants receive the individualized support services they need for job placement and retention, ongoing work experiences, and independent living."* This standard should be clarified to include the various support services that participants may require to successfully attain and retain employment (i.e., Nursing, Occupational Therapy, Psychology, Social Work, Service Mediator, Nutritionist, Speech Pathology, Psychiatrist, Neurologist, other in-home and community behavioral supports, independent skills development, transportation, assistive technology, etc.).

- Revisit Process Flows for Vocational Rehabilitation Staff to Allow and Encourage Implementation of Customized Employment Practices: Vocational Rehabilitation Counseling ("VRC") staff need more time to conduct their evaluations and observations of participants in their day-to-day (home or community) settings, as well as to effectively introduce and implement customized employment strategies related to discovery, exploration, employer engagement/relationship cultivation, and job development.[1]

- Improve Therap System Accessibility for the Vocational Rehabilitation Counseling Services Area (ASCRV) Staff: Improve the ability of ASCRV staff to upload information in the Therap platform to guarantee that all findings completed as a result of personalized assessment, discovery and exploration processes are embedded into the participant's member file and used for the development of the person-centered service plan.

- Reform Policies with Community Home Providers to Encourage and Incentivize Focus on Supporting Employment, Independent Skills Development and Community Inclusion:

  a) Update current DSPDI policies to increase number of required community outings from two community outings per month to 3-5 outings per week with a goal of daily community exposure, depending upon participant preferences as outlined in their person-centered ISPs;
  b) Create financial incentives within existing reimbursement model for providers to increase outings in the community (group and individual), and revisit transportation reimbursement amounts and procedures to support adequate mobility for all participants;
  c) The DSPDI's current mileage benefit should be expanded to contract staff to help defray gas expenses for community visits so that transportation expenses are no longer an obstacle to increase participants' access to and engagement with the community;

[1] These observations shall be conducted through 3-4 visits which should be carried out within 60 days, depending on each individual's particular case.

d) Transportation supports are not being effectively utilized across programs (for example, between the community home and CTS providers), and transportation access and coordination should be fully documented and resolved within participants' ISPs; and
e) Consider requiring 85% of all outings to include one or more of the following components: rehabilitation, independent skill development, or employment exposure.

- Improve Quality of Person-Centered Service Planning Implementation: The JCC reaffirms its previous recommendations from the past several reports regarding the importance of implementing person-centered planning (see Docket No. 3510) and practice in the initial service planning and ongoing service coordination. Embedding some of the learnings from Discovery and Exploration could greatly improve the quality of the existing person-centered planning practices taking place across disciplines. As such, we recommend orienting and training as many other professionals from the interdisciplinary team, providers, and families as possible to these evidence-based strategies to help build a more robust approach to person-centered planning and service delivery.

- Enhance Coordination of Decisions/Actions between ASCRV and the Interdisciplinary Teams: Coordination between various professionals of the interdisciplinary team seems inconsistent, thus minimizing the opportunity for improved resource leveraging and service coordination around each participant's goals as outlined in the person-centered service plan.

  In addition to fragmentation in ISPs, there are also gaps in information being shared and coordination of responses among various professionals when dealing with critical incidents and the potential implications on employment. For example, a participant had a behavioral situation in the workplace that prompted the EID to compel the participant to resign from the job, when instead, the proper action would have been to develop a plan to address these behavioral issues and find alternatives that did not involve resigning from the job. There are employment situations that require tuning the participants' skills. Often, a referral is made to ASCRV, but not with the promptness that the situation warrants. As a result, effective coordination between ASCRV and the EID appears to be absent. This happened with Participant #1123 who was placed in a SCH with a recommendation for vocational rehabilitation services and independent living services from occupational therapy, recreational therapy and psychology and, but the recommendations were not implemented.

  Involving the ASCRV personnel in ongoing exchanges and sharing information and decision-making pertaining to changes to the ISP is critical to success. The JCC recommends training other professionals within the Interdisciplinary Teams, as well as staff of the CTS system, community home and other service providers, family members and other stakeholders, on the critical role of the CRV in supporting the employment and community integration goals of participants.