STATUS REPORT

UNITED STATES V. PUERTO RICO 99-1435 (GAG/MEL)

MARCH 31, 2021

Benchmarks and Supplement Narrative

Alfredo Castellanos, Esq.
Joint Compliance Coordinator

Certification

I, Alfredo Castellanos, Esq, in my capacity as Joint Compliance Coordinator (JCC/Federal Monitor) hereby certify that the present Report has been prepared by the undersigned with the support of the members of the Federal Monitor's Office, and with the input and contributions of the following experts:

- Dr. Emily Lauer (UMass/CDDER);
- Dr. María Margarida Juliá;
- Dr. Serena Lowe;
- Dr. José Méndez Villarubia;
- Dr. José Blanco;
- Ret. Chief Justice, Federico Hernández Denton (Senior Advisor to the JCC);
- Dr. Dimaris García, Psy. D. (psychologist and co-monitor); and
- Dr. Carmelo Rodríguez, Psy. D. (psychologist and co-monitor).

Members of the Federal Monitor's Office:

- Ms. Diana Alcaraz, Esq./CPA (Special Investigator);
- Ms. Tirsa Sosa (Social Worker);
- Ms. Jeannie Castillo (Administrative Assistant);
- Mr. Salvador M. Carrión, Esq. (Legal Advisor to the JCC); and
- Mr. Javier González (Executive Director of the Office of the JCC).

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

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

I. Introduction

A. Methodology and Scope of the Report

The Federal Monitor's Office (JCC) hereby presents its fifth Semi-annual Status Report ("Report") regarding the Commonwealth of Puerto Rico's ("Commonwealth") and the Department of Health's Division of Services for Persons with Intellectual Disabilities (DSPDI for its Spanish acronym) compliance with the party-stipulated Benchmarks[1] and the Joint Compliance Action Plan ("JCAP").[2] As approved by the Parties, the method of illustrating our assessment consists of cross referencing the Benchmarks and indicating the level of compliance that the JCC and its team of experts has determined has been reached by the Commonwealth's previous administration **as of December 31, 2020.**[3] (See Benchmark Compliance Table, Attachment 1[4]). The JCC will make a general assessment of the Commonwealth's compliance as they relate to the Benchmarks, as well as an assessment of the compliance levels per each area of the JCAP.[5] The JCC, authorized to provide technical assistance as well as offer a guiding hand to the DSPDI (See Docket No. 2285), will also make recommendations to assist the Commonwealth in its effort to significantly improve its compliance levels for the most important matter at hand: ensuring the safety, protection, and well-being of all participants that receive services from the DSPDI program.

As it will be explained with particularity, **the Commonwealth is currently, in general terms, at a 9% compliance level, which represents the lowest level of compliance since the**

[1] See Docket No. 1998.
[2] See Docket No. 1185.
[3] The JCC will also reference matters that have transpired between January 1-15, 2021, including highlights related to the transition process of the new administration, as well as a few examples of specific initiatives, that, if implemented and maintained, should produce progress and result in benchmark compliance, which could be reflected in our September 2021 Report and Recommendations.
[4] The JCC's assessment for the present Report and the illustrative table follow the sequential order of the Benchmarks, which corresponds to the structure of the JCAP.
[5] The JCC will make a general assessment, not a weighted statistical analysis.

approval of the JCAP. Said level also represents a significant decline from the 24% that the Commonwealth had achieved in the JCC's September 2019 Report.[6]

The present Report was prepared relying on specific data furnished to the JCC by the DSPDI through numerous Court Orders, other first-hand sources of information obtained between the period of August 2019 to December 31, 2020, as well as in-person evaluations and remote monitoring conducted by the JCC. Our assessment includes input and analysis from the party-stipulated experts from the University of Massachusetts' Center for Developmental Disabilities Evaluation and Research (UMass/CDDER) and Dr. María Margarida Juliá,[7] the JCC team of experts, and other Court-appointed experts. The Report also includes an assessment as to other areas of paramount importance that have been agreed upon by the Parties with the endorsement of the JCC and the approval of the Court, such as the Joint Action Plan (JAP)[8] (Docket No. 2423).

B. Contextual Background

For purposes of the present assessment, it is impossible to quantify the negative impact of events that transpired during calendar year 2020 on the Commonwealth's overall compliance levels. Since September 2019, there have been a number of changes in the Government's administration and leadership, which led to: the addition of new legal counsel for the Commonwealth, three different Secretaries of Health, three different DSPDI directors, and the Commonwealth stopping almost all communications with the Office of the JCC. Additionally, the significant seismic activities that impacted the Island and the inception of the COVID-19 pandemic understandably shifted the focus of the Commonwealth's priorities.

The aforementioned events presented numerous derailments both for the DSPDI and the Federal Monitor's Office, but more importantly, they negatively impacted the population with intellectual disabilities/development disabilities (ID/DD) on the Island that receive services from the DSPDI. Moreover, the former Commonwealth Administration projected a deeply rooted, visceral reluctance to implement any of its commitments laid out in the Consent Decree. (See Docket No. 3046). Among many problems, the DD participants suffered significant setbacks due to the extremely poor transition period from the former Administration to the new one, characterized by the lack of communication and collaborative efforts of Dr. Joan Rivera, and the refusal of the DSPDI Director to provide its contact information until directed to do so by the Court. As such, one of the main reasons for the Commonwealth's low compliance levels was the lack of collaboration by the DSPDI and its former legal team, whose litigious approach to the

[6] The Parties did not object to the JCC's September 2019 report.

[7] Dr. Margarida Juliá is among the top experts in the field of neuropsychology with over 35 years of experience in the same.

[8] Said assessment will not be included in the overall percentage level of compliance that will be calculated by the JCC.

Consent Decree had the apparent intent of trying to nullify the JCC's monitoring duties and at times, the Court's orders. The former Administration's unwillingness to participate in useful joint working exercises with the JCC, including but not limited to the cancellation of the monthly meetings between the Commonwealth and the JCC's team of experts, hindered progress towards compliance and even caused regression in many areas. Instead of promoting discussions between agreed-upon experts and professionals from diverse fields that the JCC had retained to assist the DSPDI, the former Administration preferred counterproductive and adversarial exchanges through its lawyers who had never visited a day habilitation center or community home.[9] With this disagreeable dynamic, the Commonwealth caused the postponement of the JCC's September 2020 Report.

C. Postponement of the JCC September 2020 Semi-annual Report

Given that a year and a half has elapsed since the previous report, the JCC deems it important to clarify the reasons as to why the corresponding semi-annual Report and Recommendations were not filed in March and September 2020.

Shortly before the World Health Organization (WHO) declared COVID-19 a global pandemic, the Court issued an order pushing back the JCC's March 2020 Status Report to September 2020, due to the seismic activity that had affected the Island, as well as the numerous tasks that the Federal Monitor's Office was handling at the time with newly retained experts from UMass/CDDER. In said order, the Court noted that a comprehensive report with the input of the newly retained experts, "which will address clinical, as well as other health and DSPDI service areas, will be of greater benefit to the parties, family members and other stakeholders." (See Docket No. 2736).

Almost immediately, pursuant to the above directives, the JCC proceeded to request specific documents and information from the DSPDI in order to address a host of priority areas in need of a compliance assessment. However, despite numerous reminders, deadlines, and other attempts to obtain the relevant documents and information (including granting an enlargement of time), the DSPDI disregarded the JCC's requests and did not produce sufficient documents or information that would enable the JCC to prepare a comprehensive clinical report as mandated by the Court. (See Docket No. 3149 and 3230).

Due to the Commonwealth's obstructionist posture, the JCC had to seek the intervention of the Court in order to compel the production of the documents and information the DSPDI refused to furnish. The JCC later requested an enlargement of time to file the Report. (See Docket No. 3149). After considering the submissions of the JCC and the Parties (See Dockets Nos. 3154[10]

[9] The JCC is of the opinion that with proper communication channels between the JCC Office and the DSPDI, most of the regression in the DSPDI's compliance assessment could have been avoided.

[10] At the DSPDI's request, the Court granted the Commonwealth until September 30, 2020, to reply to the JCC's motion and ordered them to propose a realistic timetable to produce all outstanding data and information.

and 3159[11]), including USDOJ's assertion that that the Commonwealth "does not account for its own failure to provide the JCC with needed documents and information in a timely manner, which caused the instant JCC reporting delay,"[12] (see Docket No. 3223), the Court granted the JCC's extension request and ordered the DSPDI to produce the outstanding documents and information no later than November 6, 2020. (See Docket No. 3230). On November 5, 2020, the Commonwealth filed an unopposed motion for an extension of time, whereby the date for filing the outstanding documents and information would be extended until November 18, 2020. (See Docket No. 3273). The Commonwealth produced some documents and information by that extended deadline.

Once the JCC finished evaluating the production, it became evident that there was material information still missing, particularly in the critical areas of health care and mental healthcare. By this time though, there was already a newly elected gubernatorial administration, a transition process was in progress, and the designated incoming Secretary of Health had not yet appointed a new DSPDI director. Therefore, any additional requests for information to the outgoing DSPDI leadership would have proven futile at the time. Moreover, as JCC informed the Court in the in-chambers status conference that was held on February 25, 2021, the JCC had expressed to the designated Secretary of Health that no motions would be filed by the JCC before providing the Department of Health an opportunity to resolve outstanding issues. Given this, the dynamic during the transition period further limited the JCC's ability to obtain all relevant information to enable it to then issue a comprehensive clinical evaluation with a proper compliance assessment in the current report.

DSPDI is still in the process of providing the JCC with needed documents and information. After this is produced, in conjunction with the party-stipulated experts from UMass/CDDER, the JCC will issue a supplemental report on the very important health and mental healthcare areas of the present Report in advance of the JCC's September 2021 Report and Recommendations.

D. Overcoming Implications and Hurdles Resulting from the Seismic and COVID-19 Challenges

In addition to the unfavorable dynamic with the DSPDI, the JCC's ability to conduct needed monitoring was significantly limited by the COVID-19 pandemic. As confirmed by UMass/CDDER, similar COVID-19 limits negatively impacted monitoring operations in other jurisdictions across the country. Notwithstanding the above, the JCC office was still able to complete important projects for the benefit of the DSPDI participants, which included but were not limited to:

[11] The DSPDI informed the Court that it expected to be able to complete its production of the data and information by December 4, 2020.

[12] Said expression was made due to the fact that the Commonwealth did not address said failure in its motion.

a) Personal inspection of the areas affected by the seismic activity, including at the Instituto Psicopedagógico ("IPPR");
b) Providing assistance to the DSPDI with the party-stipulated experts from UMass/CDDER to establish a proper COVID-19 protocol with the information that was available at the time (Docket No. 2760);
c) Virtual visits to community homes, which included administering a questionnaire to determine if the service providers have the capacity to implement the established COVID-19 protocol, and also if there were isolation spaces in the residences to accommodate any participant who might contract COVID-19;
d) Remote monitoring to participants' well-being in biological homes;
e) An in-depth psychosexual evaluation and treatment plan for Participant INR #156 (one of the most challenging cases that the DSPDI is presently confronting) prepared by the Court-appointed expert, Dr. María Margarida Juliá and Dr. José Méndez[13] (Docket Nos. 3190, 3407 and 3434);
f) The comprehensive report prepared by UMass/CDDER with recommendations and observations to improve the Commonwealth's compliance with the JCAP (Docket No. 2942);
g) Dr. Roberto Blanco's comprehensive report regarding the use of polypharmacy among participants of the program (Docket No. 3052);
h) Monitoring reports regarding the DSPDI Dental Clinic (Docket Nos. 3175 and 3405) and a COVID-19 outbreak at Hogar Alma (Docket No. 3362);
i) Monitoring visits to the daily centers (CTS);
j) Emergency monitoring of participants that were abruptly transferred from the *Fundación Modesto Gotay Institution* (FMG) (See Docket No. 3477);
k) In-person monitoring of participants residing in the Shalom institution due to incidents and the COVID-19 contagion;
l) Intervention regarding the suspension of one-on-one services offered by the *Corporación de Amas de Llaves* ("COSALL" for its Spanish acronym) in biological and other community homes.
m) Timely intervention regarding a participant with Down syndrome who required emergency hospitalization;
n) Timely intervention to avoid what was considered by the party-stipulated experts to be a "super spreader" event (See Dockets Nos. 3298 and 3300); and
o) Establishing direct communications with the MRC Chairwoman, Dr. Yocasta Brugal, which then prompted her to create the Preventive Clinical Care Guidelines for the DSPDI, and to develop a plan to finish pending mortality reports and to monitor the implementation of the corresponding remedial plans by the DSPDI and the JCC.

In addition to the above, the JCC was also able to establish and maintain regular communications with service providers and parent organizations during the pandemic and

[13] This report included specific recommendations which have not yet been implemented by the DSPDI.

moved the Court to order the DSPDI to furnish twice-daily COVID-19 reports and twice-weekly incident reports. (See Docket No. 3048).

Moreover, at the request of the JCC, with the guidance of the party-stipulated experts, multiple efforts were carried out in order to: ensure that participants and caretakers were properly tested for COVID-19 and that they were properly inoculated as soon as possible (See Docket No. 3372); provide a safe and reasonable way to provide essential services and activities to participants while taking the necessary precautions to reduce the risk of contagion (See Docket No. 3085 and 3090); and establish the proper guidelines for re-opening of the daily centers and other services to participants (See Docket No. 3028).

Another situation that demanded the JCC's intervention on multiple occasions was the continuous delay in payments and reimbursements, as well as other contractual issues with service providers (including *Therap* platform), which compelled the JCC to seek the intervention of the Court on multiple occasions to ensure the continuation of essential services during the peak of the pandemic. The DSPDI failed to adhere to the directives of the Court and this threatened the solvency of the providers in the Program. (See Dockets Nos. 2944, 2947, 2975,2976, 3034, 3035, 3036, 3094, 3174, 3179, 3251, 3252, 3336, 3339, among others). After various interactions and meetings with the DSPDI and the Department of Health, as of December 31, 2020, the DSPDI fiscal area began issuing payments within 20 days of the receipt of valid invoices. However, the Commonwealth's problems in processing and issuing payments, directly affected the DSPDI fiscal area's ability to finalize and execute provider contracts for Fiscal Year 2020-2021, which occupied the JCC and the Court for months and was still an ongoing concern as of December 31, 2021. The JCC expects that the DSPDI and the Secretary's Office will establish a permanent mechanism for the uniform and effective processing and issuance of contract for essential services so that similar problems will not re-emerge.

Notwithstanding that the past year was plagued with numerous challenges, the JCC was able to continue its monitoring activities to ensure that the safety, protection, and well-being of all participants was monitored at all times and that the essential services that they receive were not interrupted or impaired in any manner. Due to the JCC's efforts and expert advice, only two participants passed away due to COVID-19 complications. At the outset of the pandemic, given the vulnerability of the ID/DD population and initial lack of preparation on the part of DSPDI, the JCC had serious concerns that the number of deaths would be significantly higher.

E. DSPDI Budget Concerns

As a result of an investigation by the JCC Office in 2019, the Court issued an order finding the Commonwealth in civil contempt for the "sweeping" of approximately $20M in DSPDI-allocated funds in violation of multiple Court orders. (See Docket No. 2664). After encouraging the Parties to resolve the present matter for the benefit of the participants (See Docket No. 2721), the Court vacated the finding of contempt following the Commonwealth's unopposed

motion agreeing to furnish the above funds during the next four fiscal years in $5M annual installments. (See Dockets Nos. 2738 and 2740).

In recent months, the Parties and the JCC have worked to establish a plan for the specific use of said funds and to avoid having unspent Court-ordered funds at the end of the fiscal year.[14] As part of the aforementioned efforts, the Parties and the JCC have participated in Court-ordered meetings to discuss the use of said funds, which the Parties and the JCC agree should be primarily destined for the opening of new community homes, reduce the number of participants in institutional settings, build capacity in the community to meet the needs of participants with complex conditions – both on the behavioral and health care ends of the spectrum – especially as individual participants experience a decline or crisis, and to improve other essential services and begin other projects. Said use will ultimately translate into better living conditions for participants, will foster independent living for many, and will reduce overcrowding in community homes. Although several ideas have been shared, **no concrete plan has been furnished as to the use of said funds as of the closing of the present Report.** This is mainly due to the pandemic and due to the transition to new DOH/DSPDI leadership. To help discipline efforts, on April 6, 2021, the Court ordered the Commonwealth, by April 16, 2021, to provide a status report on the DSPDI budget for next fiscal year. (See Docket No. 3484). The Court also ordered the parties, by May 4, 2021, to file a joint report on the use of funds next year.

The JCC looks forward to assisting the parties in 2021 in identifying the best use of the above funds and any roll-over funds (currently about $5.4M) which will carry over into fiscal year 2021-2022. The JCC's independent auditor/investigator will issue a short report around July 1, 2021, confirming the exact budget totals for next fiscal year, specifying the amount unspent during the current fiscal year, which will be carried forward to next fiscal year.

F. Re-evaluation of Participants

In the JCC's September 2019 Report (See page 22), the JCC reported that it sought the intervention of the Court to have 11 participants that the DSPDI deemed to no longer have ID/DD to be re-evaluated by an independent expert. (See Docket No. 2482 and 2499). Consequently, with the consent of the Parties, the Court appointed Dr. María Margarida Juliá, who evaluated four participants and identified important flaws in the scientific methodology that was being used by the DSPDI to evaluate said participants.[15]

[14] The JCC is concerned that notwithstanding the finding of contempt, the directives of the Court and the meetings between the Parties, we are about to enter a second fiscal year in which almost $5.4 million dollars have not been spent by the DSPDI to improve many areas that need to be addressed in order to comply with existing Court orders and improve the services that participants have long been waiting for.

[15] Neuropsychological evaluations were conducted by Dr. Margarida Juliá as follows: on July 15, 2019 (report issued on August 15, 2019), on July 26, 2019 (report issued on August 10, 2019), on October 19 and 21, 2019 (report issued on November 7, 2019), and on February 17, 2020 (report issued on March 1, 2020). Capacitation meetings between Dr. Margarida Juliá and the DSPDI were held on November 11, 2019 and February 26, 2020, after which efforts stalled.

Although a capacitation plan was established regarding the matter and meetings were held on November 2019 and February 2020, the DSPDI has failed to implement Dr. Margarida's recommendations as to the evaluation methodology and suspended the capacitation that she was providing as agreed by the Parties and approved by the Court. (See Docket No. 2538). There is no reason not to continue said capacitation process.

G. People with ID/DD Under the Local Jurisdiction

As previously reported, there are a number of people with ID/DD that have not been adequately diagnosed or treated and end up in the Commonwealth's Judicial Branch for actions that are deemed infractions or violations of the local Penal Code, which exposes them to potentially being incarcerated.

Since the previous report, the JCC had to intervene in a case where the DSPDI opted to initiate a criminal proceeding against a participant that was allegedly engaging in sexual misconduct, instead of finding alternate methods to address the participant' deficiencies and medical diagnosis.

Although this is one of the areas that has stalled due to the COVID-19 pandemic, the JCC reiterates its recommendation that an effective collaborative mechanism with law enforcement and the judicial branch must be established as soon as possible in order to properly handle participant contacts with the criminal justice system, including potential criminal cases that people with ID/DD could be facing. The JCC condemns the practice of pursuing criminal proceedings to resolve disability and health-related issues that pertain to participants' individual diagnoses. The JCC stands firm in the belief that no one with ID/DD should be subject to criminal proceedings because of a developmental disability or mental illness and is concerned that the DSPDI is not presenting the adequate defenses in the local courts regarding the nature of the JCAP (analogous to federal law).

II. Ratings of Compliance with Specific Provisions of the Agreement

The following section provides an in-depth assessment as to the Commonwealth's Compliance with respect to each area of the JCAP, as well as a brief progress analysis in comparison to the JCC's September 2019 Report and the JCC's remedial recommendations.

A. Community Placement from Institutions

BENCHMARKS: 4-12

In the September 2019 Report, the JCC expressed serious concerns with the fact that the Commonwealth was still using institutions for the placement of new participants, which in the

JCC's view, could constitute a direct violation of *Olmstead v. L.C.*, 527 U.S. 581 (1999) ("Olmstead").[16] Moreover, the JCC found that there was a 13% increase in the number of participants residing in institutions instead of community home settings. Thus, a regression in the compliance levels for this area was noted and remedial measures were recommended to increase the level of compliance by decreasing the number of participants residing in institutions.

For purposes of the JCC's assessment of this area of the Report, it is recognized that expanding community services and supports to meet the needs of participants during the COVID-19 pandemic has been a challenge for the DSPDI.

The abrupt closing of the Fundación Modesto Gotay institution (FMG) and the immediate community placement of 41 participants residing in said facility significantly impacted the assessment of this area of the Report.[17]

Closing of FMG

As reported by the previous DSPDI Director, Dr. Joan Rivera, Río Grande CTS personnel were providing services to the participants that resided at FMG due to a contractual issue with the *Corporación de Amas de Llaves* ("COSALL" for its Spanish acronym). According to Dr. Rivera, said personnel noticed a series of irregularities that put the safety, protection, and well-being of the residents at risk, such as poor hygiene of participants, poor diet, dirty clothes, and no hot water available in the showers, among others.

Following an interagency investigation which lasted less than one day, the Department of Health ordered the closure of FMG on August 6, 2020, and the immediate transfer of the participants that resided therein. The investigation was carried out by the Auxiliary Secretariat for Environmental Health (SASA for its Spanish acronym); the Auxiliary Secretariat for Regulations and Accreditation of Health Facilities (SARAFS for its Spanish acronym); the Office of Investigations; and the DSPDI, which presented an administrative complaint regarding the matter.[18]

According to the information analyzed by the JCC, participants were transferred to unfamiliar community-based settings in the middle of the night without prior notice, in many instances without the knowledge of their guardians, and without their personal items, including

[16] In said case, the United States Supreme Court held that, under Title II of the Americans with Disabilities Act (ADA), jurisdictions are required to place persons with mental disabilities in community settings rather than in institutions when community placement is appropriate (the individual can handle and benefit from community living) and the transfer from institutional care to a less restrictive setting is not opposed by the affected individual.

[17] Although the closing of FMG and subsequent transfer of the participants that resided therein, is the subject of a separate court-ordered investigative report [add a cite here], the JCC deems it important to provide context regarding the matter for purposes of the corresponding analysis of this area of the Report.

[18] In response to this complaint, an order for immediate action was issued by the Secretary of Health on August 9, 2020, validating the FMG closure and scheduling an administrative hearing on the matter.

clothes, medication, and required assistive equipment, among other important and/or vital belongings.

Moreover, Individualized Transition Plans (ITPs) for participants had not been completed as required, so the receiving providers were not properly trained on each individual's service and support needs. Moreover, there was no evidence of an integration of the different service components in the process allowing the DSPDI to identify and take action to avoid events classified as emergencies.

In conclusion, the transfer of the participants was carried out in an improvised, accelerated, and deficient manner, which failed to safeguard the participants' safety, protection, and well-being, and was carried out with complete disregard for the mandates set forth in the CBSP and the JCAP. As of the preparation of the present Report, four of the participants have regrettably passed away since their transfer. In at least one death, there was an allegation that the receiving provider was using mechanical restraints to manage the participant without a safety plan or human rights oversight, in conflict with DSPDI's own policies on restraint use.[19] Further, in using Hacienda Don Luis as a community home after the closing of FMG, the DSPDI deprived the program of a residence that was specifically designed to serve as an isolation unit during the peak of the COVID-19 pandemic to help support the numerous community homes that lacked an available isolation space to place participants that showed signs or symptoms of COVID-19 and/or became infected with COVID-19. The JCC is of the opinion that the reckless calculus is a reflection of the way the DSPDI and the previous administration handled it affairs leading up to December 31, 2020.

Distribution of Participants by Institution

As the following analysis will demonstrate, the closing of FMG and the transfer of the participants that resided therein have significantly impacted the numbers of participants that are still residing in institutions as of August 20, 2020:

Table I: Distribution of participants by institution:

	March 2019	April 2019	August 2020*
Fundación Modesto Gotay	44	47	0 (Closed August 6, 2020)
Instituto Psicopedagógico	33	39	38
Shalom	46	55	58
Total	**123**	**141**	**96**

[19] As of the preparation of the present Report, the JCC has still not received a copy of the autopsy report for this participant in order to finish a Court-ordered investigative report related to the participants' death.

* Based on Census report furnished by the DSPDI revised on August 20, 2020.

As of August 20, 2020, the Commonwealth still has 96 out of 635, or 15% of the population served by the DSPDI, living in institutions.

As referenced, unfortunately, this change was mainly due to the abrupt closing of FMG rather than as part of an individualized, interdisciplinary assessment process with individualized transition plans using person-centered planning principles, as required by the CBSP. This irresponsible and dangerous process should never happen again for anyone who is to transition from an institutional setting.

Spaces Available in Community Homes

The Commonwealth began to track open beds in existing community homes in the hopes of filling them with other participants moving from somewhere else. As of December 17, 2021, the Commonwealth identified about a dozen open beds in existing homes. But the JCC is compelled to state that the transfer of participants to already overcrowded community homes does not meet the mandated requirements for this particular area. As the JCC and his team of experts agree, overcrowded community homes are the equivalent to "institution-like" settings which make it more difficult for the participants to then possibly transition into independent living. As of December 31, 2020, the Commonwealth had failed to create an adequate plan regarding the deinstitutionalization of participants that are in institutions or institution-like settings. As a result, no progress is evident in finding proper living units for both participants living in institutional settings and new participants coming into the Program.

Remedial Recommendations

The JCC recommends that the DSPDI develop a Strategic Plan for regularly and continuously:

- solidifying and expanding the individualized integrated services and supports for participants to successfully transition from institutionalization to community living, including services and supports that improve individuals' social determinants of health (including health & wellbeing, employment, transportation, recreation, housing, education, and social connectivity);
- assuring transitions of participants to the community adhere to the ITP so as to meet individualized needs;
- training new service providers on how to implement the ITP and the Individualized Service Plan (ISP) more generally to meet individual participant needs; and
- monitoring participants adequately after transition to ensure that they are receiving services and supports to ensure their health, safety, and welfare.

The planning for the opening of new homes should correspond with proximity to family

members (whenever appropriate) and individuals' support circles, anticipated service volume needs from current participants, as well as those aging in place and those newly applying for services. New placements to institutions should be avoided except in rare circumstances where this placement would be a solution of last resort. Failure to create new community placements should not be a justification for new institutional placements or for transferring a participant between institutions, as was the case with the closing of FMG.

Due to the COVID-19 pandemic, initiatives to provide guidance and inform parents and relatives of participants living in institutions about the benefits of transferring said participants to community homes have stalled. There is little evidence of the establishment of alternate methods to communicate with the parents and/ or family members, despite the availability of technological resources to support such communication safely during the pandemic.

Family members oppose the transfer of participants from institutions to community homes mainly due to the great geographical distance between the proposed community home and the family residences, which limit family members from visiting the participants on a regular or consistent basis. This situation can be remedied, whenever appropriate, by providing family members with nearby community home options for placement. Families also lack confidence in the quality of day services and care offered by the DSPDI. With proper reform of DSPDI's current disability service delivery system and greater transparency regarding the services and choice of providers/direct support professionals, families will learn to trust DSPDI again and may even become community champions as they see their family members with ID/DD successfully live, work, and thrive in community settings. However, DSPDI must eliminate the present culture of low expectations for the target population, as well as its overreliance on archaic models of service delivery to focus on the personalization of services, integration of individuals with ID/DD in all aspects of community life, and a commitment to providing services and supports that assist individuals to pursue their dreams and attain maximum self-sufficiency and independence This will greatly improve the integration process of said participants and will advance the Commonwealth's compliance with the JCAP.

B. **Provider Capacity Expansion in the Community**

BENCHMARKS: 13-16

The JCC finds that there is significant work to be done in this area of the JCAP in which the objective is to increase options for community living for persons with ID/DD and to try to reduce the census size of existing and future community homes.

In the previous Report, the JCC was expecting the Commonwealth to finalize an agreement with Burns and Associates, Inc.,[20] in order to carry out a rate assessment study to evaluate the costs of all relevant services provided by the DSPDI. Additionally, the JCC recommended that the Commonwealth adopt a four participant per community home standard, for which the pending rate assessment would serve to assist the Commonwealth to better utilize scarce resources to open new community homes to properly place all participants.

Although said contract was duly executed, and Burns worked on the project, there **was a delay in meeting the party-agreed timelines for the creation and implementation of the corresponding rate adjustments due to the COVID-19 pandemic. As of December 31, 2020, the DSPDI had not provided any information as to the work that had been performed by Burns and Associates[21].** The information that the JCC has been able to obtain regarding the matter was the product of our monitoring duties and not as a disclosure by the DSPDI.[22]

Notwithstanding the above, the JCC notes that during the period that is covered in the present Report, a total of six community homes were opened; four group homes and two substitute homes. This represents a total of 32 living units in the DSPDI system.

One additional home opened as an isolation facility in response to the COVID-19 pandemic (Hacienda Don Luis), which is dedicated exclusively for short-term stays for COVID-related isolation of participants. Some other residences opened as a result of the abrupt closure of FMG. Thus, **86% of the new community homes were opened on an expedited manner as a result of reactionary activity due to the pandemic and the emergency closure of FMG, and not as a result of intentional and well thought-out expansion plan.**

The JCC is unable to draw any positive conclusions here, especially given that millions of dollars had been available to the DSPDI between August 2019 and December 2020, and yet few new homes were opened.

The following is a breakdown of newly opened homes, none of which are located in the southern part of the island where a significant number of participants reside:

Table II. Community Homes opened during 2020

[20] Burns and Associates is a healthcare consulting firm that specializes in approaches to the financing and delivery of health care and human services.

[21] The JCC notes that Burns and Associates has completed its report and the Commonwealth sent a final report in Spanish on April 9, 2021.

[22] The current DSPDI administration has embraced the idea of discussing all matters related to budget allocation and plans with the party-stipulated experts and USDOJ. We expect that the rate adjustment plan and its implementation will be the subject of the next JCC Report given that the DSPDI expects to have the same ready for full implementation by June 2021.

	Home	Date	Municipality	No. of spaces available
1	Ágape Mitchell II	September 2020	Morovis	6
2	Brisas del Paraíso	August 2020	Aguadilla	6
3	Hacienda Don Luis (COVID-19 Isolation Facility)	August 2020	Vega Alta	6
4	Hogar Comunitario Freiden	August 2020	Corozal	6
5	Rayitos de Amor	August 2020	Adjuntas	5
6	Sustituto Eric Rios	June 2020	San Juan	1
7	Sustituto Ilarraza	August 2020	Luquillo	2
	Spaces available			**32**
8	Shalom Adonai	Approved for opening since August 2020 but not yet opened.	Aguadilla	6

It is still unclear whether the community homes that opened under such rushed circumstances were, in fact, ready and/or able to provide appropriate and safe services and supports to the displaced participants. This is evidence that the DSPDI had become complacent in its efforts to open new homes and needs to set forth and implement a clear strategy for attracting new providers and opening new homes that provide adequate and appropriate care to participants and allow participants to live as independently as possible. The opening of new community homes will allow the relocation of participants who are still in institutions, are in overcrowded community homes, and on the DSPDI's waiting list, as well as those interested in receiving services from the DSPDI.

In addition to the above, the prospect of new residential spaces provides an opportunity to reevaluate the location of participants who are currently distant from their family members and support system, whose needs are not being adequately met, and to decrease the size of current community homes – **at least 16 of which house seven to eight participants.**

Early identification will allow for appropriate planning and relocation in accordance with the needs of the individual, as well as the provisions of the JCAP. Said evaluation should take into consideration the analysis of the relocation of the participants who, at present, continue to reside in institutions. This will allow the DSPDI to plan in an orderly manner, establishing priorities and reducing situations or events that can be classified as "emergencies" or ones that put the participants' "life at risk."

During the period from September to December 2020, there were about 12 transfers of participants between community homes (not taking into consideration the emergency transfer

from FMG, which occurred in August 2020). Some of the findings regarding such transfers were the following:

1. There is no evidence in the participants' electronic file in the *Therap* platform of up-to-date information on the transition process, its results and/or recommendations. In some instances, the transitions had been carried out the same day of placement or the next day, limiting the participants to a one-day period of observation and adjustment to their new environment; and
2. Gaps have also been identified with regard to services and supports vital to the participants' health and well-being. For example: (i) a transfer was made without identifying the participant as blind, thus, issues related to visual impairment were not taken into consideration, (ii) assistive and/or orthotic equipment of a participant were not transported to the new home (e.g. transferred without their positioning bed or orthopedic mattress among others) until days after the new placement, (iii) a participant was transferred without medication for epilepsy, (iv) parents were notified after the transfer and later objected to the new location due to distance from the family, and (v) providers were not given adequate information about participants placed in their residences.

According to the evidence available to the Office of the JCC, there were incidents and/or situations with participants in community homes that ultimately led to the eventual transfer of the participant to other community homes. However, it was not evident that such transfers were effected pursuant to the details set out in a proper ITP. Rushing transfers without an ITP impacts the participant's quality of life and increases the likelihood of: (i) increased incidents in the new home, (ii) psychiatric hospitalizations, (iii) impairment of the participant, (iv) destabilization of the home environment, (v) lack of knowledge of and poor tools for meeting the needs of the participant by the home employees, (vi) lack of information sharing with the participant's family, (vii) frustration from the participant's family, (viii) provider refusal to continue to provide services to the placed participant, (ix) contact with clinical hospitals, and (x) physical and psychological harm or even death, among others.

Moreover, despite the opening of new community homes, as of December 31, 2020, 26% of community homes house more than six participants, which is a home that is overcrowded with participants. Although this has been a recurring practice in the past, it has been identified that the abrupt placement of the FMG participants worsened the overcrowding predicament previously mentioned in the JCC's September 2019 Report (See pages 7-8, and 14) as there were not enough community homes and living units available to address the participants' needs, which had the effect of placing them in "institution-like" settings. **Hence, the JCC finds that the compliance level as to this area of the Benchmarks has regressed**. See Illustrative Table IV.

Table IV. Community Group Homes with seven or more participants.

Community Home		No. of Participants
1	Hogar Olám II	7
2	Nueva Vida	7
3	Hacienda Isaí	7
4	Casa Rayo de Luz	8
5	Alma Inc.	8
6	Erickmar	7
7	Luz Divina Mia	7
8	Jehová Yireh	8
9	Abimar	7
10	Mekaddesh	7
11	Dulce Amanecer II.	7
12	Kairos	7
13	Pacto de Amor	7
14	Janick	7
15	Nueva Esperanza	7
16	Abimar 2	7
Total Community Homes with overcrowding: 16		

*Based on Movement Report furnished by the DSPDI revised on December 17, 2020.

Remedial Recommendations

As previously mentioned in this Report, a plan for the increase of physical locations for community-based group homes must be promoted by the DSPDI's Community Homes and Private Institution Unit and the CITE, with projections, goals, objectives and activities for the opening of homes by geographic zones as used by the DSPDI in Puerto Rico. This will facilitate the identification of the areas of greatest need for the expansion of community homes. Once the Burns Rate adjustments are implemented and additional significant funding becomes available a plan should be developed to maintain the homes with a census of no more than six participants with a goal for a census of four, which offers the opportunity to provide individualized services according to the needs of the participant. It is important to emphasize both the participants' needs, and the changes provoked by the COVID-19 pandemic. The DSPDI has an important opportunity to use the $20 million in previously unused funding to make substantial and lasting investments in the accelerated opening of new physical locations for community-based services. It is critical that these resources be used effectively and efficiently with a long-term vision on sustainable infrastructure development.

The efforts to increase service capacity must also go hand-in-hand with the transparent use and application of fair provider rates based on the findings of the forthcoming provider rate

assessment from Burns and Associates, as referenced in UMass/CDDER's June 2020 report of Preliminary Recommendations:

> *Currently, providers are paid at different rates for similar services, and reimbursement rates appear to be underfunding certain service offerings. Additionally, the annual provider rate negotiation process with DSPDI reportedly does not provide sufficient time for the negotiation prior to the rates being set for re-contracting resulting in stagnation of rates over years. This climate produces real barriers to recruiting new community-based service providers and the sustainability of existing providers. It also results in workforces that have not experienced any pay increases over many, many years, which hinders workforce retention and recruitment. As a result, any efforts to grow or further stabilize residential service offerings have dependencies on improving the rate consistency and alignment with costs of service provision for providers. Additionally, substitute home providers experience occasional delays in monthly provider payments, as well as incur cost burdens from extensively delayed medical-cost reimbursements (#24.b) presenting and compounding the financial burdens for these providers.*

It is also important to mention that upon comparing the JCC's September 2019 Report and the data furnished by the DSPDI up to December 2020, the JCC finds that there is a reduction of 10 participants in regard to the total population served by the DSPDI from a total of 645 participants in September 2019, to 635 as of December 2020. It concerns the JCC that, although evidence points to an increase population of ID/DD in Puerto Rico, the number of people serviced by the DSPDI has decreased. A more thorough investigation into the existing program waiting list should be expected by the DSPDI from the JCC.

C. **Integrated Employment and Day Activities**

BENCHMARKS: 17-39

The current reality experienced as a result of the COVID-19 pandemic has significantly impacted the population served by the DSPDI in their search for employment and job retention. From the data furnished by the DSPDI as of December 31, 2020, it was noted that out of a total of six hundred and thirty-five (635) participants, only 20 participants (3%) of the total population served), are potentially employed.[23]

This level of potential employment is substantially below Benchmark 29's target rate of 25%. In comparison to the JCC September 2019 Report, this represents an increase of one

[23] In the context of this Report, "potentially employed" means participants previously employed who, since March 2020, have been excused from work by their employers but for which the DSPDI has no guarantee of job retention.

participant (See page 15). However, it is important to note that out of 20 potentially employed participants, we identified the following:

- Four participants are currently working which represents 20% of the potentially employed participants or 1% of the total population. These participants reside in biological homes;
- Thirteen of the potentially employed participants residing in community homes, equivalent to 65% of the potentially employed participants, have been excused by their employers from work due to the COVID-19 pandemic, various Governors Executive Orders, and most recently, because they have not completed their vaccination cycle. According to a conference held with Ms. Linoshka Bernardi, coordinator of ASCERV, once the second dose of the COVID-19 vaccine is administered, ASCERV will begin a process of on-site reevaluation and retraining for the gradual integration of these participants into their respective employments. For the record, the JCC had accessed correspondence sent by DSPDI excusing participants. However, the JCC did not have access or was provided with the replies submitted, if any, by employers;
- Two participants, equivalent to 10% of the potentially employed participants, previously employed by a maintenance services company subcontracted by DSPDI are now in the process of negotiating an employment contract with the new hired maintenance services company; and
- For the remaining one participant, we were informed that the employer had initially agreed to excuse the participant from work and reserve employment until January 2021. ASCERV is currently in communication with the employer to confirm that the employment opportunity is still available for the participant.

The challenges faced by participants residing in community homes once they are cleared for reentry into employment will be significant. Some of the challenges faced, to list a few, will be: the hours available for work (sub-employment due to employer opportunities), re-evaluation of the necessary skills, tolerance of participants to their essential tasks, use of basic personal protection equipment (e.g., proper use of masks), the uncertainty and fluctuation in the labor market, the reluctance of employers to allow the presence of trainers in the workplace due to their protocols for COVID-19, self-employment opportunities, access to referral to employment-related agencies, and participation in pre-vocational or vocational workshops, among others.

According to ASCERV, their staff has been in virtual communication with participants offering services and observing the participant in the performance of tasks in order to ensure the maintenance of skills. To this end, they have also developed programs, workshops and activities to be carried out by the participants in their homes. From the observations made by DSPDI personnel, events or behaviors are identified that could affect the use or integration of the information presented by the participants. Among these, it can be highlighted that: (i) some of the participants did not have the necessary electronic equipment to access the workshops, thus,

the workshop was done by telephone; (ii) in some cases, both participant and caregiver expressed lack of knowledge in the use of electronic equipment or how to access the workshops; and (iii) that the participants were distracted and inattentive.

When exploring the process carried out by the DSPDI with providers or household staff, it was noted that, although they validate the communication and the importance of the workshops, (i) there was no continuity and / or monitoring in the implementation of the activities or clear goals in the process, and (ii) the DSPDI failed to identify their inclusion in the implementation process, to name a few. Due to the above, it is not clear whether participants have been able to maintain the skills that are essential to their job retention. Further, the JCC found no evidence in the information and documents furnished regarding the above virtual communications of an actual plan or workshops geared towards maintaining skills in the areas of independent living or self-employment, academics, the arts, among others. Although each CTS has a calendar of planned activities prepared by ASCERV, there is no evidence of uniformity or information as to whether these activities respond to the actual needs and goals of the participants and of how progress is being measured. This lack of uniformity, fragmented information and details makes it impossible to measure any progress and/or regress in this area.

As highlighted by the employment area of the DSPDI, the JCC recognizes that there is a need to conduct in-person evaluations in basic areas such as: essential skills necessary for participants to return to previous employment (in the case of employer holding employment for participants), new clean and safety procedures and protocols necessary due to the pandemic and tolerance in the use of masks among other particular aspects. In addition, although there has been a commitment by employers to hold employment for previously employed participants, it is uncertain how many will, in fact, be able to return to their past employment in light of the above. **The JCC has hope that the above important matter necessary for the aspiration of independent living is addressed effectively in the early part of 2021, for which the Office of the JCC has retained the services of Dr. Serena Lowe, who will assist the DSPDI in this endeavor.**[24] Dr. Lowe will work with DSPDI on developing and implementing strategies related to:

- identifying federally-funded opportunities for the Commonwealth and its partners to receive technical assistance, training and professional development support focused on building the capacity of direct support professionals and disability service providers to implement evidence-based practices (i.e. customized employment[25] and supported

[24] Dr. Lowe is a government relations, public policy and global advocacy expert. Dr. Lowe has over 25 years' experience in furthering public policies that promote the socioeconomic advancement of individuals with disabilities, and other at-risk populations.

[25] As defined in the Workforce Innovation and Opportunity Act (P.L. 113-128, Title IV, Section 404(7)), the term 'customized employment' means competitive integrated employment, for an individual with a significant disability, that is based on an individualized determination of the strengths, needs, and interests of the individual with a significant disability, is designed to meet the specific abilities of the individual with a significant disability and the

employment[26]) known to support individuals with ID/DD and other most significant disabilities seek, obtain, and maintain competitive integrated employment[27]; designing value-based payment methodologies to incentivize and reward outcomes-based service

business needs of the employer, and is carried out through flexible strategies, such as— ''(A) job exploration by the individual; ''(B) working with an employer to facilitate placement, including— ''(i) customizing a job description based on current employer needs or on previously unidentified and unmet employer needs; ''(ii) developing a set of job duties, a work schedule and job arrangement, and specifics of supervision (including performance evaluation and review), and determining a job location; ''(iii) representation by a professional chosen by the individual, or self-representation of the individual, in working with an employer to facilitate placement; and ''(iv) providing services and supports at the job location.'' Retrieved at: https://www.govinfo.gov/content/pkg/PLAW-113publ128/pdf/PLAW-113publ128.pdf

[26] As defined in the Workforce Innovation and Opportunity Act (P.L. 113-128, Title IV, Section 404(38)), the term 'supported employment' means competitive integrated employment, including customized employment, or employment in an integrated work setting in which individuals are working on a short-term basis toward competitive integrated employment, that is individualized and customized consistent with the strengths, abilities, interests, and informed choice of the individuals involved, for individuals with the most significant disabilities— ''(A)(i) for whom competitive integrated employment has not historically occurred; or ''(ii) for whom competitive integrated employment has been interrupted or intermittent as a result of a significant disability; and ''(B) who, because of the nature and severity of their disability, need intensive supported employment services and extended services after the transition described in paragraph (13)(C), in order to perform the work involved. ''(39) SUPPORTED EMPLOYMENT SERVICES.—The term 'supported employment services' means ongoing support services, including customized employment, needed to support and maintain an individual with a most significant disability in supported employment, that— ''(A) are provided singly or in combination and are organized and made available in such a way as to assist an eligible individual to achieve competitive integrated employment; ''(B) are based on a determination of the needs of an eligible individual, as specified in an individualized plan for employment; and ''(C) are provided by the designated State unit for a period of not more than 24 months, except that period may be extended, if necessary, in order to achieve the employment outcome identified in the individualized plan for employment.''; (23) in paragraph (41), as redesignated by paragraph (17), by striking ''as defined in section 101 of the Workforce Investment Act of 1998'' and inserting ''as defined in section 3 of the Workforce Innovation and Opportunity Act.

[27] Public Law 113–128; Title IV, Section 404(5) COMPETITIVE INTEGRATED EMPLOYMENT.—The term 'competitive integrated employment' means work that is performed on a full-time or part-time basis (including self-employment)— ''(A) for which an individual— ''(i) is compensated at a rate that— ''(I)(aa) shall be not less than the higher of the rate specified in section 6(a)(1) of the Fair Labor Standards Act of 1938 (29 U.S.C. 206(a)(1)) or the rate specified in the applicable State or local minimum wage law; and ''(bb) is not less than the customary rate paid by the employer for the same or similar work performed by other employees who are not individuals with disabilities, and who are similarly situated in similar occupations by the same employer and who have similar training, experience, and skills; or ''(II) in the case of an individual who is selfemployed, yields an income that is comparable to the income received by other individuals who are not individuals with disabilities, and who are self-employed in similar occupations or on similar tasks and who have similar training, experience, and skills; and ''(ii) is eligible for the level of benefits provided to other employees; ''(B) that is at a location where the employee interacts with other persons who are not individuals with disabilities (not including supervisory personnel or individuals who are providing services to such employee) to the same extent that individuals who are not individuals with disabilities and who are in comparable positions interact with other persons; and (C) that, as appropriate, presents opportunities for advancement that are similar to those for other employees who are not individuals with disabilities and who have similar positions.''
https://www.govinfo.gov/content/pkg/PLAW-113publ128/pdf/PLAW-113publ128.pdf

delivery strategies that support people with ID/DD secure and sustain competitive integrated employment;

- engaging with employers on their capacity to rehire, recruit, train and hire workers with disabilities in the aftermath of the COVID pandemic; and
  educating and meaningfully engaging self-advocates and families in designing and eventually participating in community-based employment training and placement programming offered by the Commonwealth.

While conducting the evaluation of the factors identified that need to be addressed in respect to underemployment and to increase the likelihood of employment and independent living, positive changes have been identified in several of the indicators listed in previous reports that have been partially or fully addressed to increase the likelihood of compliance.

These positive changes observed include:

1. Hiring of Vocational Rehabilitation Counselors (VRC): Six VRCs have been hired. Such professionals will be key in providing services to achieve employment and independent living goals. Each CTS (with the exception of Cayey and Aibonito which share a VRC) and the Central Office has a full-time (37.5 hours per week) VRC. These recruitments are positive; the challenge may be in retaining the VRCs on a long-term basis since the hiring was done through a temporary employment agency.

2. Hirings by ASCERV: ASCERV currently has 21 employees, which represents an increase of four employees. Although this increase is positive, the number of hiring is still not sufficient to meet the participant's needs per the CTS Census;
   For example:
   - The Vega Baja CTS has a Census of 112 participants and they have:
     - Trainers: 02
     - Promoters: 00
   - The Ponce CTS has a Census of 59 and they have;
     - Trainers: 04
     - Promoters: 01

3. Professional trainings: The addition of VRCs to the ASCERV team increases access to the necessary tools and strategies that apply to the demands of the current labor market. However, as mentioned in the previous JCC Reports, professional training and technical assistance in the implementation of evidence-based practices that lead to employment and independent for individuals with ID/DD need to be provided to develop and support the capacity, skills and competencies of the hired professionals necessary to strengthen the Commonwealth's compliance around employment and to achieve compliance with the JCAP.

4. Scientifically validated vocational tools. There have been positive changes in the evaluation process aimed at individualized evaluation. For example: Interview A for verbal participants and Interview B for participants with greater severity (based on images). Also, the fact that licensed professionals will be managing the evaluation process added to the acquisition of scientifically validated tools will increase the likelihood that participants will find employment consistent with their strengths, resources, priorities, abilities, interests, residual functional capacity, and informed choice. However, the DSPDI is still in the process of evaluating and purchasing tools, that will allow the personnel to have adequate evaluation mechanisms. At this time, the Skills Assessment Module (SAM) has been purchased and is in use. However, it is of utmost importance that ASCERV continues its efforts to obtain all scientifically validated tools to support the work of the CRV and its working group. The status of acquisition by the DSPDI of tests that they have identified as necessary for the offer of evaluative services continues to be uncertain. These include: Inventory of Vocational Interest Free of Reading (RFVII-3); Harrington O'Shea level one in Spanish among others.

5. The Puente Project: On November 2019 the *Development of the Vocational Rehabilitation Counseling Section of the Services to Persons with Intellectual Disability Division of the Department of Health* was issued. This report was the result of the Puente Project, a collaborative agreement between the University of Puerto Rico and the Department of Health. The purpose of the Puente Project was to analyze the organizational structure of the Vocational Rehabilitation Counseling Area of the DSPDI, conduct an analysis of the functions and duties of the personnel of ASCERV, evaluate the ASCERV eligibility determination processes and procedures to identify deficiencies and/or inefficiencies and carry out an assessment of the services directed to independent living, social-community reintegration, work and employment. Some of the recommendations of this study have already been implemented (e.g., the hiring of professionals from the Rehabilitation and Counseling Professionals Association). However, as mentioned in the previous JCC Reports, collaboration with other agencies (for example, through the Commonwealth's workforce system via the implementation of the Workforce Innovation and Opportunity Act (WIOA), as well as leveraging the federally-funded DD network managed by the U.S. Department of Health & Human Services' Administration for Community Living), would increase the possibility of participants obtaining employment.[28] Effective and coherent collaboration agreements would allow the DSPDI to work with other entities focused on employment/vocational preparation to maximize fiscal and human resources, thus increasing the probability of favorable employment results. Other than the Puente Project, the JCC has not seen evidence of collaboration efforts, formal or integrated,

[28] Recommendation aligns with UMass/CDDER's mid-term recommendation #56: "Leverage existing resources to offer greater career and financial counseling to assist participants, parents, and service providers, such as One-Stop Career Centers, SSA Ticket-to-Work (WIPA & Employment Networks), & other resources." See Docket No. 2962, page 17.

between the DSPDI and other governmental agencies or interested external stakeholder entities.

6. Activation of a module in *Therap* Services known as "Employment History". In this module the DSPDI can upload into the participant's electronic file updated information related to the area of employment or relevant date pertaining to independent living. It also provides for the incorporation of intervention plans and other documents relevant to the assessment process. Additional efforts could be conducted overtime to strengthen the person-centered planning process to allow for an evidence-based approach known as Discovery, which focuses on identifying a participant's skills, experiences, preferences and support needs so as to better plan for and successfully match the individual with a prospective employer.

It is important to note that in order to access and maximize the use of the electronic module mentioned above, the CTS needs to have the necessary services and equipment available for its use. The following is a breakdown by CTS of the number of personnel, the number of computers available, services or equipment available, and the services or equipment required.

Table V: Personnel and equipment resources per CTS.

CTS	Staff (including handlers, promoters and CRV)	Number of computers available	Service or equipment available	Service or equipment needed
Bayamón	4	1	Internet	Scanner and Printer
Rio Grande	4	3	Internet, Scanner and Printer	
Cayey	4	2		Internet, Scanner and Printer
Ponce	6	2	Internet	Scanner
Aibonito	3	2	Internet Scanner; Printer	
Vega Baja	3 (0 job promoter)	1	Internet	Scanner and Printer
Aguadilla	4	3	Printer	Internet (area where they are located) and Scanner

The lack of the services and equipment detailed in the table above is very concerning and significantly hinders the capacity of the ASCERV personnel to perform their duties in a diligent

and efficient manner to the detriment of the participant. Although there is access to specific modules for the area of employment in the *Therap* platform, such lack of the necessary equipment for the ASCERV personnel to perform their tasks results in deficient and incomplete records, thus not maximizing the utilization of the *Therap* platform. It also increases inadequate work practices and puts at risk the privacy of the participants' information. Among these are: use of personal equipment (cell phones, computers) and personal services.

When exploring the platform through which the virtual or remote services are being offered, the common use of the Zoom platform was identified. It was noted that the accounts used are personal to the staff and not official accounts established by the DSPDI, which raises serious concerns regarding the privacy and confidentiality of participant information mentioned above. Pursuant to the DSPDI, the official platform authorized is Microsoft Teams; however, the personnel have not been trained in its use.

As a closing observation, the DSPDI must urgently integrate strategies that support participants with ID/DD to take advantage of the increased employment opportunities available as a result of the COVID-19 pandemic, as well as opportunities for obtaining more hours of work. To be successful, DSPDI must design a robust, multi-faceted systems change model focused on the following objectives:

- Transformation of its disability service provider network to focus on and prioritize the provision of services aimed at supporting individuals with ID/DD to work, live and thrive in the community;
- Establishment of value-based payment models that incentivize and reward providers who support individuals with ID/DD secure and obtain employment, maximize their self-sufficiency and achieve desired independent living goals;
- Leveraging of and collaboration with other partners inside the Commonwealth government and externally (for example, employers), to braid resources and coordinate services to support the target population in achieving optimal employment in the community and socioeconomic advancement in the community;
- Investments in capacity building of the VRCs and other direct support professionals in implementing evidence-based practices used to support individuals with ID/DD to secure and maintain employment; and
- Improvements to the person-centered planning processes to prioritize employment as a key goal of all publicly financed supports.

Combined, these efforts will significantly address the underemployment problem among the target population of individuals with ID/DD and set the Commonwealth on a very different path in terms of its recognition and utilization of the talents and contributions of this constituency, which we previously address in our last report. Consequently, because the previous DSPDI leadership did not take proactive steps to capacitate participants to be able to return to work or

secure alternative employment opportunities for those that were not employed prior to the pandemic, much work must be done to increase the Commonwealth's compliance in this area.

We take the opportunity to highlight that, although the documents and information furnished by the DSPDI for purposes of this report were lacking and incomplete in this area, the DSPDI personnel was very forthcoming with the information once directly approached by the JCC. We found that documents had been prepared by the different areas of the DSPDI with important information pertaining to participant employment, which had not been furnished to the office of the JCC. For future reports, this information should be included in the documents submitted for purposes of showing compliance with the mandates of the JCAP.

D. Safety and Restraint Issues

BENCHMARKS: 40-52

Since the year 2016, the DSPDI has been in the process of implementing the *Therap Service*s electronic platform to respond to the mandates of the JCAP. The DSPDI submitted the "Therap Services Implementation Plan", dated August 24, 2020, detailing its efforts since October 2019. The stage of the initial plan of implementation was delayed due to earthquakes in Puerto Rico and the COVID-19 pandemic. Despite the situation, the DSPDI made an effort to continue offering support and guidance to providers via telephone and trainings through the use of "Google classroom" platform.

As of August 2020, the *Therap* Services platform, has 974 active users and only one coach to provide training and support on how to use the platform. With the objective of accelerating the implementation of the implementation plan, the JCC continues to recommend that additional coaches are necessary.[29]

It is very concerning that the *Therap* platform, which should always have fundamental information of all participants, continues to have outdated participant's profiles, unreported incidents and reports no action plan and/or follow-up. This platform has still numerous challenges to overcome in order to achieve full implementation. The JCC deems necessary to contract trained personnel to update the information on the *Therap* platform in order for it to be a reliable source of data for use in the analysis of incidents and its multiple functions.

Incident Reports

[29] This recommendation coincides with UMass/CDDER recommendation #23.d: "Institute a *Therap* team lead per CTS, institution, and region for home providers for technical assistance, as well as ensuring timely and quality data entry and completion of backlog project." See Docket No. 2962, page 10.

As of December 31, 2020, the analysis and investigation of incidents as required by the JCAP is not evidenced in the *Therap* platform. Given this ongoing lack of compliance and as a result of the COVID-19 pandemic, on April 2, 2020, the JCC requested that the DSPDI notify participants' incident reports on bi-weekly basis (Continued Request for Information Report), with the intention of monitoring and guaranteeing that the required attention is being offered for all incidents that participants may confront in the program and to verify if said incidents are being investigated. Furthermore, the JCC followed-up on the relocations of the participants and requested to review the individualized transitional plans.

In the reports delivered by the DSPDI on August and November 2020 for the JCC Report, the DSPDI did not submit reports from the **quality control** area relating to the number and type of incidents, statistics, investigation reports and corrective plans. Further, the vast majority of the reported incidents in the *Therap* platform do not have the required **corrective plan and the corresponding follow-up information**. Incidents that provide data are missing the analysis that would assist in understanding the root cause of the incident and the measures necessary to prevent future recurrences. (See Section III, 4-A (2) of the JCAP, Docket No. 1185, at page 11). Said problem and serious shortcoming should be remedied without delay.

Restraint Practice – Use of physical and chemical restraints. The JCC recognizes that the practice of physical restraints mechanism has been virtually eliminated, and the use of "as needed" (PRN) medication continues to be prohibited. However, it is imperative to investigate the reason behind the variety of psychiatric medications used by participants in the absence of a medical diagnosis. During 2020, Court-acknowledged expert, Dr. Roberto Blanco[30] conducted a study and issued the first phase of his Polypharmacy Report (the "Polypharmacy Report"), which includes his analysis and recommendations on the matter that should be addressed by the DSPDI on this important matter. Dr. Blanco explained that medications are often improperly used to treat behaviors because alternatives non-pharmacological treatments, such as behavioral planning, positive interventions, educational programming and communication supports are not being used adequately. See Docket No. 3052.

In accordance with the mandates of the JCAP, the incident reports should analyze patterns and trends; show the causes that triggered the incident and develop and implement remedies for prevention in the future. Although the JCC is aware that the DSPDI has protocols in place for responding to incidents, the results of the same and the prevention action plans **have not been furnished to our office nor it is available in the *Therap* platform**. Likewise, the analysis of the data on incidents in the area of quality and the action plan is also, as of today, unknown.

[30] Dr. Blanco is an expert retained by the JCC Office who has been assisting the present case for over five (5) years. As of today's date, Dr. Blanco's contributions have been welcomed by the parties, the Court and the JCC throughout the above-mentioned years. Dr. Roberto Blanco, M.D. is also an Associate Professor at the University of North Carolina School of Medicine and Medical Director at the NC START Central.

The Office of the JCC faced several challenges in the evaluation of this area due to: (i) lack of information in the in the participant's electronic file, (ii) participants electronic file in *Therap* was not updated once the transfer took place, (iii) lack of ITPs, (iv) progress notes lacked essential details and follow-ups, (v) notes that invite the reader to review the participant's physical file, (vi) notes reference efforts made with the participant, but are not supported by evidence, (vii) lack of analysis of the results found and a corrective action plan.

Remedial Recommendations

The JCC is of the opinion that part of the additional $20 million dollars in the DSPDI's budget could be invested in providing community homes a laptop and internet access as needed to ensure connectivity, particularly to the *Therap* platform. Ensuring this access would help facilitate consistent and timely *Therap* data entry and delivery of remote day services and clinical check-ins. A technology needs assessment would need to be conducted in order to gauge the technology needs of the community. Also, a provider's Internet costs should be considered as part of the rates provided.

The JCC also shares the recommendation of UMass/CDDER in regards to the creation of a *Therap* team lead per CTS, institution, and region for home providers for technical assistance, as well as ensuring timely and quality data entry and completion of backlog projects.

It is unclear how DSPDI's Organizational Development & Quality Unit (*Unidad de Calidad y Desarrollo Organizacional* – unit charged with information management) operates, but it would be ideal to have a QA/QI lead assigned to each CTS to ensure quality measures are being consistently implemented; this person would also be the CTS' *Therap* Team Lead in charge of training and technical assistance, as well as quality monitoring for *Therap* data entry, e.g. ensuring that corrective action and follow-up plans are also documented with the initial incident report submitted in the *Therap* platform.

In addition to the above, the JCC does not have the adequate information to establish if the reduction of chemical and physical restraints is attributable to the lockdown of participants in their homes and the absence of daily activities, or if its attributable to a change in the practice of restraints used by the DSPDI. The JCC recommends that the DSPDI work in a collaborative manner with Dr. Blanco in order to address the issues set forth in his report and proceed to implement his recommendations in a sustainable manner.

E. Health Care and Mental Health Care

BENCHMARKS: 53-65
BENCHMARKS: 66-99

Since the JCC issued the previous report, he was committed to submitting a more comprehensive evaluation of this area, among other clinical matters that should be addressed in

every report. However, the total disregard to the Court's directives regarding the production of information that would place the JCC's team of experts in a position to conduct evaluations as to these areas, as well as the impact of the COVID-19 pandemic, deemed the task of making proper scientific evaluations impossible.

Notwithstanding the above, the JCC acknowledges the fact that other ID/DD programs in other jurisdictions of the mainland have also not been able to properly assess these areas due to the challenges confronted by the COVID-19 pandemic. Regardless of said reality, the JCC is committed to producing a comprehensive clinical evaluation as to these matters in the upcoming months, for which we have begun the process of requesting the corresponding information with the purpose of supplementing the present Report before the September 2021 assessment. The JCC is confident that said information will serve to assess the impact that the pandemic has represented to the participants' health and mental health.

It is important to note that if it were not for the service providers and parent organizations, the JCC would be in the dark ages regarding the issues that the community homes were confronting, such as un-wanted visits from DSPDI personnel and lack of proper preventive measures, lack of proper capacitation and information, among others. The JCC is optimistic that for his next report, the total disregard for the Court's orders and the JCC's requests for information would be a thing of the past if the new administration continues to work in a collaborative manner between the parties and the Office of the JCC, and that we would be able to render a proper comprehensive clinical assessment as to all matters related to this area.

DSPDI and JCC's Response to the COVID-19 Pandemic

The arrival of COVID-19 pandemic has greatly impacted the health services to the intellectual and developmental disability population. This pandemic has changed our way of living, forcing us to take unprecedented, and at times uncomfortable, and extreme social measures in order to preserve the physical health of the participants. According to the nation's health protection agency, the "Centers for Disease Control and Prevention" (CDC), at this moment integrating both mental and physical health should be a main strategy for the prevention and transmission of this disease.

One of the first efforts realized by DSPDI to address this pandemic was the "***COVID-19 Action Plan and Protocol,"*** approved by the Court on March 20, 2020 ("COVID-19 Protocol") (See Docket No. 2767). This protocol was reviewed and commented on by a team of experts, the JCC Office, family members, employees, contractors and subcontractors of the DSPDI and may be updated as necessary by the agreement of the parties, the JCC and the subsequent approval of the Court. Since the beginning of the COVID-19 pandemic, the JCC has been monitoring and assisting in the implementation of the COVID-19 Protocol.

In addition, the DSPDI formed a "COVID-19 Task Force" to respond to the emergency that impact the participants. In view of the new reality, the DSPDI continued offering mental and physical services in remote modality with a few exceptions that required on-site visits from interdisciplinary team from CTS (nurses, social workers, psychologist, among others). The participant case discussions between interdisciplinary teams of CTS were also performed remotely as establish in the COVID-19 Protocol. The *Therap* platform has been an important and pivotal tool for gathering participants' data such as: case notes, incident reports, and medical data, to name a few. Nevertheless, the *Therap* platform is still in the implementation phase and the JCC continues to find that important information has not been updated and recent events are not timely recorded.

The JCC Office continued its independent monitoring efforts throughout the year in order to guarantee the safety, support, and protection of the DSPDI participants. For instance, the JCC Office followed up the physical and mental services through: phone calls, remote visits (using Facetime, WhatsApp and Zoom) and on-site visits to homes and institutions following the established personal safety COVID-19 Protocol, CDC guidelines and UMass/CDDER expert recommendations, participating in remote case discussions and through the review and analysis of the bi-weekly Continued Request for Information Report submitted by the DSPDI as requested by the JCC. The JCC has also continued to engage in multiple conference meetings with DSPDI staff and consultants. Furthermore, in various incidents with participants, the intervention of the JCC and its team has been necessary to follow up on cases that required urgent attention such as the closure of FMG, deaths in the Shalom Institution, Inc., among others.

The following list is to mention some of the JCC's efforts to continue its independent monitoring of the mental and physical health of the participants:

1. The JCC established that DSPDI had to report daily incidents of the participants with the goal of knowing and guaranteeing that health and mental care was offered, also providing pertinent follow-up to urgent cases;
2. In addition to engaging the services of Dr. Blanco (as mentioned above), the JCC office also engaged the services of UMass/CDDER and their team of experts to provide recommendations and observations to advance compliance with the JCAP. On March 2020, the team of UMass/CDDER visited Puerto Rico to conduct site visits including direct observations and interviews with various stakeholders, and to research and review documents related with DSPDI and JCC Reports. On June 2020, UMass/CDDER submitted a report entitled "Preliminary Recommendations and Observations for the Commonwealth of Puerto Rico to Improve Supports for People with Intellectual and Developmental Disabilities" (UMass/CDDER Report, See Docket No. 2942). Since this report, UMass/CDDER has remained actively engaged in providing consultation regarding the evolving COVID-19 public health crisis, and emerging events within the DSPDI service system;

3. As of today, the JCC Office continues with the consultation service of Dr. Margarida, clinical neuropsychologist, with vast expertise in the field of psychological assessment;
4. The JCC Office engaged the services of forensic psychologist Dr. José Mendez with expertise in sex offending evaluations and treatments and count with experience with neurological challenge patients; and
5. The JCC participated in several meetings with the DSPDI staff, mortality committee, Puerto Rico's epidemiologist conference calls meeting, UMass/CDDER and interdisciplinary team of CTS in the discussion of participants' cases.

a. CEEC

The intervention of the CEEC for consults and support is not evidenced with any detail and accuracy. However, use of CEEC consulting services may be inferred from other DSPDI documents where the CEEC is mentioned, as well as in case notes in the *Therap* platform regarding attendance to conference call meetings and consults in the fields of psychology and nursing. Nevertheless, as required by the JCAP, the CEEC should be carrying out a more active role with greater participation and should serve as a mobile crisis team. The above has simply not been the case.

Over time, the information offered to the JCC pertaining to the CEEC services has diminished and there is little information available in order for the JCC to analyze the services and measure compliance within this area of the JCAP. As has been stated above, upon receipt of DSPDI's September 2020 documents compiled for purposes of the JCC Compliance Report, the JCC apprised the Court of the lack of information furnished (See Docket No. 3149). The DSPDI was granted additional time to collect and produce information and documents for the JCC to assess compliance with the JCAP. However, when reviewing the documents, it was found that documents and reports submitted do not show sufficient relevant, measurable, or useful data with regard to the CEEC. The JCC is very concerned by the lack of human resources and level of expertise and capacitation of existing personnel to be able to adequately furnish the types of services that participants need. Below is a short summary of the limited information provided:

- Some of the reports provided are basically **Attendance Tables specifying the service provided** such as Psychiatric services, Occupational Therapy, and social work, among others, reporting the date the service was provided and the participant control number. For example, the Psychology area included a report titled "Monthly Statistical Report" but the information provided was basically a table with "x" marks assigned to the service offered, thus lacking any statistical interpretations. Likewise, the Nursing Report submitted was a table only presenting the participant's medical information, again, with no clinical interpretation.
- Another document filed to show compliance was a "flowchart" titled "Implement Efficient Measures to Address Risk Factors Among Peers to Prevent Damage."

Although we understand that a flowchart's purpose is to present "steps of management as a guideline", it lacks evidence of actual implementation of such guidelines.

- Various documents titled "Certifications" with a table referencing the benchmarks (BM) and detailing how the DSPDI is allegedly complying, is presented without any supporting evidence of implementation and/or compliance. This type of Certification was present for the BMs: #43, #44, #45, #46, #47, #57 # 59, #94, # 95. It should be noted that these certifications appear dated June 30, 2020 but are signed on June 28, 2019.
- The status of the use of the CEEC Crisis Line continues to be unknown (number of calls received by the emergency line, type of intervention provided, and the follow-up plan).
- No evidence was provided regarding the "Genesight Test"[31] and how the results that were used during the years 2019 are still being used.
- The DSPDI agreement with the "*Sociedad Puertorriqueña de Epilepsia*" is valid until June 30, 2021. Thus, it will be important to know the implementation of the agreement and its outcome since DSPDI reported having 251 participants with a diagnosis of epilepsy. Further, the work plan that is part of the agreement has not been formally documented.

As mandated by the JCAP, the DSPDI must provide a list of **high-risk participants.** The following table illustrates the number of high-risk participants between the years **2018 – 2020:**

Table VI: High risk participants:

Year	Physical Condition	Behavioral	Choking Risk	Diagnose with Epilepsy
2020	---	23	132	251
2019	359	16	101	250
2018	410	90	138	252

(---) The list of participants at high physical risk was not provided by the DSPDI.

The DSPDI submitted a "**High Risk and Longitudinal Report of Medications"** as part of the compilation of information of treatment, intervention, and data of the participants from the high-risk list. As previously emphasized in the past JCC Report, the JCC Office recognizes the value and usefulness of the information compiled in said report. However, this "longitudinal" report does not present a ***summary of the analysis of the information compiled*** **through time**; thus, it does not comply with what it is expected in a longitudinal evaluation (See Docket No. 2610, page 20). It is important to present the final number of participants who have had changes in their

[31] The GeneSight test is a pharmacogenomics test that analyzes how a person's DNA may affect its response to depression medications.

medication (adding or discontinuing prescriptions as well as dosages changes) and provide the number of participants that are under polypharmacy.

The objective of the JCAP is to use this information to help the participant, and to implement measures that meet the individual physical and mental needs so the CEEC can issue recommendations to the community physicians.

b. Dental Health

Despite the pandemic, the DSPDI Dental Clinic has continued offering dental services to participants and bedridden patients. During a visit to the Dental Clinic by a team from the JCC office, the following needs were identified: installation of telephones and institutional computers at the central level, internet service, electrical generator for the clinic, adequate air circulation system conditioners in the hallways and the correction of defects in the windows and no access door to the basement ramp. Some of the items are still pending to be addressed (See Docket No. 3405).

DSPDI did not procure any of the dental services that were offered during the year for participants. If it were not for Dr. Molina's initiatives, the participants would have been deprived of their corresponding dental services. The JCC takes this opportunity to commend Dr. Molina, whose honesty, commitment and integrity allowed us to bring the deficiencies in the dental clinic to the attention of the Court for immediate resolution.

c. Nutrition

During the first quarter of 2020, the then JCC Office licensed nutritionist conducted various visits to the DSPDI CTS sites. In such visits, the cooks were interviewed and the menu, food shopping list, food stores, kitchen temperature record were reviewed and recommendations for the improvement of food preparation according to the needs of people with intellectual disabilities were provided. In addition, the licensed nutritionist visited homes and institutions, reviewed the menus and performed nutritional assessments on the participants. In addition, training and orientations on diabetes management, and patients with pica disorder, among others, were offered to employees and home providers. Several meetings were held with the DSPDI nutritionist to share and discuss findings and offer nutrition recommendations. It is imperative to continue efforts to offer training on nutritional plans, prevention of aspirations, dysphagia, and training to employees of DSPDI about this topic.

d. Mortality Review Committee (BM 86)

During 2020, the JCC had serious concerns regarding the Mortality Review Committee (MRC) chairperson's independence given that the DSPDI had furnished a list of the MRC members that included DSPDI personnel. Moreover, the JCC became aware that the previous counsel of

record for the Commonwealth was reviewing the MRC's reports prior to furnishing them to the JCC. The above practice was an express violation of the independence that the JCAP mandates for the MRC chairperson.

However, after meeting with the MRC chairperson, Dr. Yocasta Brugal, the JCC deems that there has been significant progress in this area. The furnished reports reflect the exercise of the independence required by the MRC chairperson, and as of December 31, 2020, eight mortality reports for years 2017 to 2020[32] are pending (with the exception of those waiting for autopsy results). The MRC has also been receptive in working collaboratively with the party-stipulated expert (UMass/CDDER) and we have agreed to reduce the terms for the pending mortality reports to those corresponding to the year 2017 forward. This will enable the MRC to comply with the 30-day deadline for producing the mortality reports. The JCC commends the efforts made by Dr. Brugal, which have led to the DSPDI achieving significant progress in this area.

Notwithstanding the above, as it pertains to the content of the mortality reports, the MRC has found factors contributing to deaths that present likely targets for systemic quality improvement. Across the finished mortality reports, there have been issues regarding over medication, side effects of medications, delays in medical care, and gaps in management of chronic conditions including constipation that have contributed to deaths.

One of the recommendations made by the past chairperson, Dr. Rodríguez Llauger, was to incorporate a community nurse in all institutions, and to provide follow-up services to the participants in this service model. Likewise, in a meeting held between Dr. Rodríguez Llauger, the members of the JCC and the directors of DSPDI, the JCC expressed the importance of establishing regulations and a protocol to conduct "root cause analysis" or review of each death to identify preventable deaths. (BM 89 & 90, JCAP III.5.N.5). Dr. Rodríguez Llauger indicated by that time, that he was expecting to implement the analysis system by the end of November 2019. As of today, this analysis has not been done.

The JCC is currently awaiting information as to how the DSPDI will implement the findings and recommendations set forth in the mortality reports. As mandated by the JCAP, "the Commonwealth shall ensure the prompt and effective implementation of all the committee's recommendations whenever appropriate. The MRC shall continue to monitor all recommendations for remedial action until they are implemented (JCAP N. 7.) The DSPDI should present "actionable plans" to have clear and measurable strategies and timelines and start assigning adequate personal and/or experts who will be in charge and oversee the implementation of the remedial action plan, which currently does not exist.

[32] All eight (8) reports have been filed as of March 26, 2021.

As for reaching sustainable compliance regarding the MRC's member's qualifications, the JCC recommends that in future, the DSPDI director and the MRC chairperson provide a certification as to the qualifications of the MRC members.

Mortality Rate

During 2020, 26 deaths have been reported to the JCC. They occurred in biological, group homes and institutions. Of these 26 deaths, 54% happened at an institution, 33% of which resided in the Shalom Facility Group Institution.

Table VII: Mortality Rate

Year	Deaths	Population	Mortality Rate (per 1000)
2018	20	647	30.9%
2019	15	635	23.6%
2020	26	635	40.9%

As shown in the table above, the mortality rate per one thousand (1,000) participants ranges from 23.6 per thousand in 2019 to 40.9 per thousand in 2020. The increased mortality rate in 2020 is, in part, affected by the COVID-19 pandemic.

Upon examining the mortality rates in the DSPDI prior to the pandemic, the party-stipulated experts (UMass/CDDER) found that the average rate across 2018-2019 is at least **40% higher** than other service programs that serve people with ID/DD, even though the population served by the DSPDI tends to have a lower prevalence of severe health needs compared to most ID/DD populations served in the U.S. Additionally, while the mortality rate in the general population of Puerto Rico tends to be slightly higher (about 6% higher than the U.S. overall), this context does not fully account for the higher rates of mortality observed in the DSPDI participant population.

The JCC is particularly concerned with the number of deaths from the Shalom institution. It is the JCC's opinion that ITPs should be established to transfer participants from Shalom to community homes. Throughout the current transition, we have gathered information that new plans (tempered to other jurisdictions of the United States) will be implemented in the DSPDI. The JCC recommends that all pending mortality reports should be limited from 2017 up to the present. The above will allow the DSPDI to accomplish the root cause analysis of the mortality report related to the above timeline and allow the mortality committee to establish and implement remedial plans that will assist the DSPDI in avoiding preventable deaths, among other important matters.

F. System Wide Reforms

BENCHMARKS: 100-106

a. *Therap* Service Platform

Since the year 2015, the DSPDI has been in the process of implementing the *Therap* Service platform. The deadline set forth in the JAP for full implementation of *Therap* was October 2019. As of today, the DSPDI has not reached full implementation (only 50% of the platform's capacity is being used).[33] For the JCC it is of paramount importance that the DSPDI achieve full operation, which will certainly assist the DSPDI to be in compliance with the JCAP.

Further, on a review conducted by UMass/CDDER of the information recorded in the *Therap* platform it was found that:

1. The volume of reported incidents seems low. For example, there was only one General Event Report (incident report) entered for the first three months of this year;
2. In some incidents there appears to be a very large gap in time between when the event occurred, and the event was reported. These patterns occurred across providers;
3. The descriptions provided in the incident reports are very minimal. Typically, only a sentence or two is provided in the description. It is typically the "Quality Associate" that provides more information about the incident in the comment sections;
4. A substantial proportion of the incident reports appear to be entered into the system after the receipt of a paper report. There appear to be some challenges in reading what is written on numerous reports by the person entering the information (often a quality associate);
5. The investigations module appears to be underutilized. From 04/01/2020 – 12/31/2020, only one investigation is listed; and
6. The case note section does appear to be used regularly across numerous participants and by multiple roles/reporters.

It is the JCC's recommendation that a new timeline should be developed for the full implementation of *Therap* throughout the entire DSPDI system. In addition, it is recommended that the DSPDI re-educate providers and DSPDI personnel on proper incident report documentation, as the information included in *Therap* is lacking and inconsistent.

b. Respite Program and Crisis Hotline

[33] Pursuant to information furnished upon request by the DSPDI, as of February 22, 2021, there are twenty-four (24) group homes and tow (2) institutions not documenting in the *Therap* platform.

Lastly, although a respite program was in its incipient stages, its implementation was delayed due to the COVID-19 pandemic. The implementation of such plan will be important in order to reach full compliance in this area of the JCAP, as has been done with the crisis Hotline. Although said program has not been properly implemented, the JCC will remain vigilant (as things get back to a certain form of normality), on how ultimately the respite program operates and services the beneficiaries of the program. The JCC is confident that once it is viable, the DSPDI will implement the same for the benefit of the parents and caretakers who have a full-time job of taking care of their loved one with ID/DD with little to no time for themselves or to get a proper rest.

III. CONCLUSION

In summary, the JCC is aware of the numerous challenges that mankind faced during the year 2020 and the impact they had on the proper implementation of various Benchmarks and the JCC's suggested remedial actions that were included in the September 2019 Report. However, the JCC has high expectations (premised on numerous videoconferences, telephone conversations, letters from the Secretary, Administrative Orders, and meetings) that we have before us a team with a vision and commitment that the undersigned has not witnessed in all the years working in the present case. The JCC looks forward to continuing to work with the DSPDI in the collaborative manner that has prevailed since the new administration assumed their duties in January 2021, for the benefits of the entire ID/DD population in the Island. The JCC will never relinquish its obligation to keep the Court informed as to any matter that may place the safety and well-being of any participant at risk and to furnish the new administration a helping hand to assist them in overcoming the past challenges that they inherited from the previous administration. If any matter that arises that is in conflict with the directives of the Court or with the disclosure of documents, our next report will show if our optimism is grounded and confirmed.

As for the lack of clinical information related to the health care and mental health area of the present Report, the JCC acknowledges the fact that other ID/DD programs in other jurisdictions of the mainland have also not been able to properly assess these areas due to the challenges confronted by the COVID-19 pandemic. However, the JCC is committed to producing a comprehensive clinical evaluation as to these matters in the upcoming months, for which we have begun the process of requesting the corresponding information with the purpose of supplementing the present Report before the September 2021 assessment. The JCC is confident that said information will serve to assess the impact that the pandemic has represented to the participants' health and mental health.

As with previous reports, the JCC is confident that the present Report will serve as a valuable working instrument to measure the Commonwealth's current compliance level and as

a guide on how to properly address outstanding issues with the purpose of achieving full and sustainable compliance with the Benchmarks and the mandates of the JCAP.

ATTACHMENT 1:

No.	BENCHMARK	Compliance	Remedial Recommendation (s)
1	Translate this benchmark document, as well as any updated versions, into Spanish	IN COMPLIANCE	
2	Disseminate both the English and Spanish versions of these benchmarks to all pertinent personnel	IN COMPLIANCE	
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	SUBSTANTIAL COMPLIANCE	During 2020 the JCC did not receive the "Master List" or Census quarterly or all other lists from the DSPDI. Thus, the JCC has no evidence of compliance. **REC**. Update the Master List Quarterly.
	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 Psicopedagogico, Modesto Gotay, Centro Shalom)	SUBSTANTIAL COMPLIANCE	The latest version of the sublist of institutionalized participants furnished to the JCC is dated April 23, 2020. Thus, the JCC has no evidence of compliance. **REC.** Update the Master List Quarterly It is recommended that this sub-list be submitted once changes are made in the institutions, such as relocations and deaths.
5	Issue a policy directive that all institutionalized participants can live in the community with adequate supports/services (JCAP III.1.A) (all cites below are to JCAP)	IN COMPLIANCE	
6	Develop a written individualized community transition plan for each participant in an institution using person-centered planning techniques (III.1.A, E)	PARTIAL COMPLIANCE	The JCC needs to see all participant's plans. **REC**. Provide all written individualized community transition plans. We recommend the use of Therap.
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)	PARTIAL COMPLIANCE	The JCC needs to see all participant's plans. REC. Provide all written individualized community transition plans. We recommend the use of Therap.
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)	PARTIAL COMPLIANCE	The JCC needs to see all participant's plans. REC. Provide all written individualized community transition plans. We recommend the use of Therap.
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)	PARTIAL COMPLIANCE	The JCC does not have the information that was provided to the families, and/or guardians of participants. **REC:** Provide information**.**
10	Take the opposed families/guardians on tours of prospective, successful community residences (III.1.C)	PARTIAL COMPLIANCE	**REC:** Provide Information.

No.	BENCHMARK	Compliance	Remedial Recommendation (s)
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)	PARTIAL COMPLIANCE	**REC:** Provide Information.
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)	PARTIAL COMPLIANCE	
	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	
14	Develop a system wide plan to increase the number of community residential providers to meet participants' individualized needs (III.2)	IN COMPLIANCE	
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-to-day (III.2); each participant shall have a private or semi-private bedroom	NO COMPLIANCE	There are still Homes with 7 or more participants. **REC**: No more than 6 participants per home.
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)	PARTIAL COMPLIANCE	There are still participants living without the necessary equipment and services for their specific condition. **REC:** Provide information
	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	IN COMPLIANCE	
18	For those working in the community, develop individualized action steps to ensure no one working in the community is underemployed (III.3.A)	PARTIAL COMPLIANCE	**REC:** Provide evidence of individualized plan focuse on participant and individualized action steps. We recommend the use of Therap.

No.	BENCHMARK	Compliance	Remedial Recommendation (s)
19	Implement the action steps to ensure that no one working in the community is underemployed (with the understanding that the Commonwealth cannot guarantee optimal employment, but nonetheless will continue its efforts to avoid underemployment) (III.3.A, B)	PARTIAL COMPLIANCE	**REC:** Provide evidence of individualized plan focuse on participant and individualized action steps. We recommend the use of Therap.
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	SUBSTANTIAL COMPLIANCE	**REC**: Provide the Updated list.
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)	PARTIAL COMPLIANCE	**REC:** Provide evidence of assessment or re-assessment for community employment of all participants who are currently not working in the community. Present evidence of the use of scientifically validated instruments and the professional training of staff. We recommend the use of Therap.
22	Develop individualized, concrete action steps with timeframes to maximize their community employment (III.3.C)	PARTIAL COMPLIANCE	**REC:** Provide evidence regarding the development of individualized concrete action steps. We recommend the use of Therap.
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 (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)	PARTIAL COMPLIANCE	**REC:** Provide evidence regarding the development of individualized concrete action steps. We recommend the use of Therap.
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**	SUBSTANTIAL COMPLIANCE	**REC:** Provide the Updated list. Present evidence of the use of scientifically validated instruments and the professional training of staff 20.
25	Professionally assess or re-assess for community employment all of these other participants who are not currently working in the community (III.3.C)	PARTIAL COMPLIANCE	**REC:** Provide the Updated list. provide evidence of the use of scientifically validated instruments and the professional training of staff
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)	SUBSTANTIAL COMPLIANCE	**REC**: Provide the Updated list.

No.	BENCHMARK	Compliance	Remedial Recommendation (s)
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)	PARTIAL COMPLIANCE	**REC:** Provide evidence of implementation
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.	PARTIAL COMPLIANCE	**REC:** Provide evidence of the develop and implement a program to promote self-employmen
29	System wide, work to implement the goal of having at least 25 percent of all participants of working age 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 that the Commonwealth cannot guarantee employment, but nonetheless will continue its efforts to find paid employment and avoid underemployment)	PARTIAL COMPLIANCE	**REC:** Provide evidence to implement the goal o having at least 25% participants of working in the community. At present, there are only 4 participant employees.
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)	PARTIAL COMPLIANCE	**REC:** Provide update evidence of individualized plans of meaningful and functional community activities that foster their independent living.
31	Implement the plans (III.3.E)	PARTIAL COMPLIANCE	**REC**: Provide evidence of the plan.
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 according to his/her individualized needs; ensure that staffing, transportation, and other resources are adequate to meet individualized needs; ensure that buses have ramps and other needed accessibility supports	PARTIAL COMPLIANCE	**REC:** Provide evidence of the services in "remote modality and if these were in accordance to the participant needs.

No.	BENCHMARK	Compliance	Remedial Recommendation (s)
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)	IN COMPLIANCE	**REC:** Provide the Updated list.
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	PARTIAL COMPLIANCE	**REC:** Provide update evidence of individualized plans with meaningful, functional community activities.
35	Implement the plans (III.3.F)	SUBSTANTIAL COMPLIANCE	**REC:** Provide update evidence of implementation of the plans.
36	Develop a system wide 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)	PARTIAL COMPLIANCE	**REC:** Present evidence of the action plan for all participants.
37	Implement the plan (III.3.G)	PARTIAL COMPLIANCE	**REC:** Provide evidence of the implementation plan.
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	PARTIAL COMPLIANCE	**REC:** Provide evidence of adequate staffing, transportation and other resources regarding participants individualized needs.
39	Ensure there are sufficient job coaches and job trainers to meet individualized needs in the community (III.3.I)	PARTIAL COMPLIANCE	**REC:** Provide evidence of the adequate staffing vs participants and the professional training of staff.
	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)	PARTIAL COMPLIANCE	**REC**: Provide the update of "Therap Services Implementation Plan": 1. Stable internet system 2. More Laptops and computers in all CTS. 3. All providers and employees should use Therap system consistently and as part of standard method of data entry. 4. Using data from Therap combined with onsite assessments, conduct a safety and welfare analysis of all individual participants and their residences (III.4.A).
41	Implement measures to ensure participant safety and welfare based on this analysis (III.4.A)	PARTIAL COMPLIANCE	**REC:** Provide information.

42	Using data from Therap combined with first-hand accounts, analyze peer-to-peer interactions that create risk of harm (III.4.A.1)	PARTIAL COMPLIANCE	**REC:** Provide Operational Reporting; results driven means of tracking, measuring and analyzing data from Therap.

No.	**BENCHMARK**	**Compliance**	**Remedial Recommendation (s)**
43	Implement effective measures to address peer-to-peer risk factors to prevent harm (III.4.A.1)	PARTIAL COMPLIANCE	**REC**: Improve DSPDI quality Control Area and provide evidence of Implement effective prevention plan.
44	Using data from Therap combined with first-hand accounts, identify vulnerable participants at risk of harm (III.4.A.2)	PARTIAL COMPLIANCE	**REC:** Provide evidence of Implementation using data from Therap combined with first-hand accounts, identify vulnerable participants at risk of harm (III.4.A.2).
45	Implement effective measures to minimize/ eliminate their risk factors (III.4.A.2)	PARTIAL COMPLIANCE	**REC:** Provide evidence of action plan to implemented effective measures to minimize/ eliminate their risk factors (III.4.A.2)
46	Using data from Therap combined with first-hand accounts, identify aggressor participants (III.4.A.3)	SUBSTANTIAL COMPLIANCE	**REC:** Provide the Updated list.
47	Implement effective measures to minimize/eliminate aggressor risk triggers (III.4.A.3)	PARTIAL COMPLIANCE	**REC:** Provide evidence of individualized plans.
48	Informed by data from Therap, develop a system wide 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)	PARTIAL COMPLIANCE	Quality Control Area of DSPDI **REC:** Provide evidence of data from Therap and develop a system wide plan to ensure that serious incidents are reported promptly and investigated within 45 days.
49	Informed by data from Therap, develop a system wide plan to analyze incident patterns and trends to prevent incidents in the future (III.4.B)	PARTIAL COMPLIANCE	**REC:** Provide evidence of the plan.
50	Implement these system wide 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)	PARTIAL COMPLIANCE	Quality Control Area and CEEC **REC:** Provide evidence of the system wide plans and the remedial measures from the investigations and incident analysis. Continue to work with with Dr. Blanco for the implementation.
51	Implement effective measures to minimize/eliminate use of all restraints on participants (III.4.C)	PARTIAL COMPLIANCE	**REC:** Provide evidence of the measures taken to eliminate the use of ALL restrants.
52	Prohibit use of standing PRN or "stat" orders for chemical restraints on participants (III.4.C)	PARTIAL COMPLIANCE	**REC:** provide evidence of the measures taken to prohibit the use of PRN.
	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)	IN COMPLIANCE	

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)	PARTIAL COMPLIANCE	**REC**: Provide information.

No.	BENCHMARK	Compliance	Remedial Recommendation (s)
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	PARTIAL COMPLIANCE	**REC:** Provide evidence that appropriate treatment and other measures are provided promptly to meet the individualized needs of the participant
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	PARTIAL COMPLIANCE	**REC:** Provide evidence of system plan or action plan to gather and provide to pertinent community clinical personnel all individual participant information for use in monthly or more frequent appointments.
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)	SUBSTANTIAL COMPLIANCE	**REC:** Provide evidence of effective communication with community clinicians.
58	Ensure participants receive necessary health care in a timely manner to meet their individualized needs in the community (III.5.G)	SUBSTANTIAL COMPLIANCE	**REC:** Provide evidence of follow-up to the treatment plans, evaluation and reassessment and communication with community doctors. We recommend the use of Therap.
59	From the Master List, create sub-lists of priority at-risk participants in the community, per JCAP criteria, that require heightened, enhanced attention and focus (III.5.H); priority at-risk condition criteria are set forth in JCAP III.5.H	SUBSTANTIAL COMPLIANCE	**REC:** Provide the Updated list.
60	Through Therap and other means, implement a system wide 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)	PARTIAL COMPLIANCE	**REC:** Provide evidence through Therap the implement of the system wide plan. The Therap platform remains with important information that has not been updated in the participant's profiles, also unreported incidents and no action plan and/o follow-up is evidenced.
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)	PARTIAL COMPLIANCE	**REC:** Provide evidence. At the present, the report was a table limited to present the participant's medical information no clinical interpretation.

No.	BENCHMARK	Compliance	Remedial Recommendation (s)
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	PARTIAL COMPLIANCE	**REC:** Provide evidence of the action plan to Strengthen program of traveling nurses from the CEEC and/or the CTS sites. Develop a educational training program to nursing staff and develop critical thinking.
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)	PARTIAL COMPLIANCE	**REC:** Provide evidence of using data from Therap.
64	Regularly share this information with community clinicians (III.5.J)	PARTIAL COMPLIANCE	**REC:** Provide evidence in clinical records and on the Therap platform.
65	Maintain effective communication with community clinicians to determine if they utilize this information to implement measures to meet individualized participant needs (III.5.J)	PARTIAL COMPLIANCE	**REC**: Provide information.
	Neurological Care		
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	**REC:** Provide the Updated list.
67	Ensure that neurologists provide participants with a seizure disorder with comprehensive neurology evaluations as needed, at least annually (III.5.K)	SUBSTANTIAL COMPLIANCE	**REC:** Provide the Updated list.
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)	PARTIAL COMPLIANCE	**REC:** Provide evidence of using data from Therap and other sources to compile a sub- list of those participants.
69	Ensure that neurologists provide effective care for those having 10+ seizures per year (III.5.K.1)	SUBSTANTIAL COMPLIANCE	**REC:** Provide recently information.
70	Ensure that neurologists provide effective care for those who have not had a seizure in the past two years (III.5.K.1)	PARTIAL COMPLIANCE	**REC:** Provide information.
71	Ensure that neurologists weigh the benefits of medication use and adequately document the rationale for anticonvulsant medication (III.5.K.2)	PARTIAL COMPLIANCE	**REC:** Provide evidence.

72	Ensure the use of intra-class polypharmacy is minimized and fully justified (III.5.K.2)	PARTIAL COMPLIANCE	**REC:** Provide evidence that intra-class polypharmacy is minimized and fully justified.

No.	BENCHMARK	Compliance	Remedial Recommendation (s)
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)	SUBSTANTIAL COMPLIANCE	**REC:** Provide evidence to know the implementation of the agreement and its outcome since DSPDI reported having 251 participants with a diagnosis o epilepsy and is not formerly documented.
	Aspiration Risks		
74	From the Master List, create a sub-list of those participants at risk of aspiration and/or aspiration pneumonia	SUBSTANTIAL COMPLIANCE	**REC:** Provide the update list.
75	Implement individualized plans to eliminate unsafe mealtime practices, per JCAP criteria, to minimize risk of aspiration/pneumonia (III.5.L)	PARTIAL COMPLIANCE	**REC:** Provide evidence of the individualized implementation plan.
76	Implement individualized plans to keep non-ambulatory individuals in proper alignment to minimize risk of aspiration/pneumonia (III.5.L)	PARTIAL COMPLIANCE	**REC:** Provide evidence of the individualized implementation plan.
	CEEC		
77	Ensure CEEC regularly evaluates all participants (III.5.C); compile list of ongoing evaluations	PARTIAL COMPLIANCE	**REC:** Provide evidence that CEEC regularly evaluates all participants and the list of ongoing evaluations.
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	PARTIAL COMPLIANCE	**REC:** Provide evidence and the list of ongoing reviews
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	PARTIAL COMPLIANCE	**REC**: Provide evidence and listed of ongoing instances in contacting community clinicians to rais red flags/advocate for participants, summarizing result of contact. We recommend the use of Therap
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	PARTIAL COMPLIANCE	**REC:** Provide evidence of ongoing instances where CEEC informed community clinicians and summarizing result of contact

81	Develop and implement effective system wide plan for CEEC to promptly communicate concerns to community clinicians that improve outcomes (III.5.E); compile list of improved outcomes after CEEC intervention	PARTIAL COMPLIANCE	**REC:** Provide evidence of an effective wide system plan and evidence of list of improved outcomes after CEEC intervention.
82	Implement a system wide protocol to alert licensing, ombudsman agencies of community clinician improprieties (III.5.F); compile list of alerts	PARTIAL COMPLIANCE	**REC:** Provide information of the Implement a syster wide protocol.

No.	BENCHMARK	Compliance	Remedial Recommendation (s)
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 to meet individualized needs on a 24/7 basis (III.5.C); compile list of mobile crisis team visits/interventions, summarizing result	PARTIAL COMPLIANCE	**REC:** Provide Evidence that CEEC serves as a mobile crisis team and compile list of mobile crisis team visits interventions.
84	Ensure CEEC mobile crisis team is comprised of multi-disciplinary group of DD professionals (III.5.D)	PARTIAL COMPLIANCE	**REC:** Provide Update list of DD professionals.
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	PARTIAL COMPLIANCE	**REC:** Provide evidence CEEC mobile crisis services maximize individuals' ability to live successfully in the community and compile list of mobile crisis team visits interventions.
	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	**REC:** The Director of the DSPDI, in consutation with Chairman of the Commitee should establise the qualifications for the members of the Committee.
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	PARTIAL COMPLIANCE	**REC:** Provide update information and the list of MRC meetings and death reviews.
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)	PARTIAL COMPLIANCE	**REC:** Create a pathway so that the MRC performs a root-cause analysis to identify any preventable causes of illness and death.

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)	NO COMPLIANCE	**REC:** Create a pathway so that the MRC issues a final report on each death promptly, per JCAP criteria, with root-cause analysis and recommendations to address outstanding issues.
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	NO COMPLIANCE	**REC:** Provide evidence of implementation of all MRC recommendations and continue to monitor until full implementation; compile tracking table of recommendations and implementation status.
92	Monitor to ensure MRC process is effective to avoid preventable illnesses, deaths for similarly situated individuals (III.5.N)	NO COMPLIANCE	**REC**: Provide evidence of action plans and its result that guarantee that the MRC process is effective in avoiding preventable illnesses, morbidities and mortalities.
	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)	PARTIAL COMPLIANCE	**REC: Provide the sub-list of all participants with mental illness, specifying their mental illness diagnosis. We recommend the use of Therap platform.**
94	Ensure participants receive necessary mental health care in a timely manner to meet their individualized needs in the community (III.5.G)	PARTIAL COMPLIANCE	**REC: Provide evidence.**
95	Ensure that all mental illness diagnoses are consistent with DSM criteria and justified in the record (III.5.M)	NO COMPLIANCE	**REC: Provide evidence.**
96	Ensure that no participant receives psychotropic medication in the absence of a clinically justifiable diagnosis of mental illness (III.5.M)	PARTIAL COMPLIANCE	**REC: Provide evidence that Psychotropic medicine reconciliation by a PharmD and/or Psychiatrist.**
97	Ensure that type, dosage of psychotropic medication are appropriate and needed for each participant, per JCAP criteria (III.5.M)	NO COMPLIANCE	**REC: Provide evidence Psychotropic medicine reconciliation by a PharmD and/or Psychiatrist. Take into consideration the recommendations in the polypharmacy report of Dr. Blanco.**

98	Minimize use of typical/first generation psychotropic medication (III.5.M)	PARTIAL COMPLIANCE	**REC: Provide evidence. Take into consideration the recommendations in the polypharmacy report of Dr. Blanco.**
99	Minimize use of intra-class psychotropic medication polypharmacy (III.5.M)	PARTIAL COMPLIANCE	**REC: Provide evidence of Psychotropic medicine reconciliation by a PharmD. Plan to Minimize use of intra-class psychotropic medication polypharmacy (III.5.M). Take into consideration the recommendations in the polypharmacy report of Dr. Blanco.**
	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)	PARTIAL COMPLIANCE	**REC: Full Implementation of the Therap Service and ensure that the information in the system is kept up- to-date in a sustainable way.**
101	Implement prompt and effective measures to address patterns and trends that adversely impact participant safety, welfare, health, and mental health (III.6.A)	PARTIAL COMPLIANCE	**REC: Full Implementation of the Therap Services and ensure that the information in the system is kept up- to-date in a sustainable way.**
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	PARTIAL COMPLIANCE	**REC: Provide evidence.**
103	Work with family members of participants on a plan to address quality issues that impact participants	PARTIAL COMPLIANCE	**REC: Provide evidence of the plan and the Full implementation of Respite program.**
104	Create and maintain toll-free crisis hotline, staffed 24/7 by qualified professionals that can effectively help to resolve issues (III.6.B)	SUBSTANTIAL COMPLIANCE	**REC: Provide evidence.**
105	Create and maintain a system wide email system to facilitate prompt communication to all pertinent individuals, per JCAP criteria to resolve outstanding issues (III.6.C)	PARTIAL COMPLIANCE	**REC: Provide evidence.**

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 and with prior authorization in private homes	PARTIAL COMPLIANCE	**REC: Provide evidence of the plan and the Full implementation of Respite program.**

ATTACHMENT 2:

Executive Summary

The Federal Monitor's Office (JCC) presents its fifth Semi-annual Status Report ("Report") regarding the Commonwealth of Puerto Rico's ("Commonwealth") compliance with the party-stipulated Benchmarks[34] and the Joint Compliance Action Plan ("JCAP")[35] covering the period between August 1, 2019 and December 31, 2020, which covers the incumbency of the Commonwealth's previous administration. The JCC will also reference matters that have transpired up to January 15, 2021, that pertain to the new administration.

This report will also cover the DSPDI's response to the COVID-19 pandemic and JCC's efforts to assist the Commonwealth in establishing proper protocols and safety measures to reduce the risk of contagion among ID/DD participants, including testing frequencies and vaccination objectives (See Docket No. 3442). It is imperative to mention that both the services provided by the DSPDI as well as the JCC's monitoring activities were significantly impacted due to the mandatory and extraordinary measures that had to be implemented in order to guarantee the safety and well-being of all DSPDI participants, service providers, caregivers, contractors and employees.

In addition to the historical challenges faced in 2020, the JCC also faced countless challenges due to the Commonwealth's litigious approach in handling a consent decree with the intent of nullifying the same, which included JCC duties and at times Court directives, most of which pertained to matters that had been reached by consent of the Parties. This resulted in DSPDI's refusal to furnish vital information to JCC through most of 2020, which led to unavoidable delays in JCC's filing its September 2020 Court Monitor Report.

As the present report will illustrate, **the DSPDI's overall compliance level decreased from 24% to 9% in comparison to the JCC's September 2019 Report, which is the lowest level of compliance since the approval of the JCAP.**

The following summary provides an overview of our compliance assessment for each area of the Agreement.

A. DSPDI Budget Concerns

As a result of an investigation conducted by the JCC in 2019, the Court issued an order finding the Commonwealth in civil contempt for the "sweeping" of approximately $20m in DSPDI-allocated funds in violation of multiple Court orders. (See Docket No. 2664). However, the Court vacated the finding of contempt following the Commonwealth's unopposed motion agreeing to

[34] See Docket No. 2049.
[35] See Docket No. 1185.

furnish the above funds in the DSPDI during the next four fiscal years in $5m annual installments. (See Dockets Nos. 2738 and 2740). Even though the Court has issued stern directives as to the use of the approved budget funds, JCC emphasizes the importance of establishing the necessary mechanisms to avoid a reoccurring event of unspent Court-ordered funds.

As part of the efforts carried out to comply with the above, the Parties and JCC have participated in Court-ordered meetings to discuss the use of said funds and mutually agree that they should be prioritized toward funding the opening of new community-based homes, reduce the number of participants in institutional settings, build capacity in the community to meet the needs of participants with complex conditions – both on the behavioral and health care ends of the spectrum – especially as individual participants experience a decline or crisis, and to improve other essential services and begin other projects. **Although several ideas have been shared, no concrete plan was furnished as to the use of said funds as of the closing of the present Report. The JCC looks forward to the continuation of the monthly meetings with the objective of assisting the Parties in identifying the best use of the above funds and the additional $5.4m (approximately) of roll-over funds which will carry over into Fiscal Year 2021-2022.**

B. Re-evaluation of Participants

The JCC was informed of 11 participants that the DSPDI deemed to no longer have ID/DD and sought the intervention of the Court in order to have said participants re-evaluated by an independent expert. (See Docket No. 2482 and 2499). With the consent of the Parties, the Court appointed Dr. María Margarida Juliá[36] to evaluate four participants[37]. During this process, Dr. Margarida Juliá identified important flaws in the scientific methodology that was being used by the DSPDI to evaluate said participants.

Although a capacitation plan was established regarding the matter and meetings were held in November 2019 and March 2020, the DSPDI has failed to implement Dr. Margarida's recommendations as to the evaluation methodology and suspended the capacitations that she was providing as agreed by the Parties and approved by the Court. (See Docket No. 2538). With available low-cost technological communication options, there is no reason why the capacitation plan could not have continued even during the pandemic. **Thus, it is recommended that the capacitation process should be renewed as soon as possible.**

C. People with ID/DD Under the Local Jurisdiction

[36] Dr. Margarida Juliá is among the top experts in the field of neuropsychology with over 35 years of experience in the same.

[37] Neuropsychological Evaluations were conducted by Dr. Margarida Juliá as follows: on July 15, 2019 (report issued on August 15, 2019), on July 26, 2019 (report issued on August 10, 2019), on October 19 and 21, 2019 (report issued on November 7, 2019) and on February 17, 2020 (report issued on March 1, 2020). Capacitation meetings between Dr. Margarida Juliá and the DSPDI were held on November 11, 2019 and February 26, 2020 after which efforts stalled.

There are a number of people with ID/DD that have not been adequately diagnosed or treated who have ended up in the Commonwealth's Judicial Branch for perceived infractions or violations of the local Penal Code, which exposes them to potential incarceration. The JCC had to intervene in a case where the DSPDI opted to initiate a criminal proceeding against a participant that was allegedly engaged in sexual misconduct, instead of finding alternate methods to address the participant's behavioral deficiencies and medical diagnosis. Exposing participants to criminal proceedings should never be an option, and certainly not an option of first resort. **JCC recommends that DSPDI be required to exhaust all other available options for the rehabilitation of a participant and focus on participants' safety and well-being before ever considering initiating criminal proceedings against the individual.**

The JCC reiterates its recommendation that an effective collaborative mechanism with law enforcement and the judicial branch must be reestablished as soon as possible in order to properly handle participant contacts with the criminal justice system, including potential criminal cases that people with ID/DD could be facing. The JCC stands firm in its belief that no individual with ID/DD should be subject to criminal proceedings due to their cognitive deficits, and it is concerned that the DSPDI is not presenting the adequate defenses in local courts regarding the nature of the JCAP and the implications of not abiding to what is analogous to federal law. Through its Senior Advisor, Ret. Chief Justice Federico Hernández Denton, the JCC intends to reach out to Hon. Sigfrido Steidel, the Director of the Court Administration Office (OAT for its Spanish acronym), to renew the discussions initiated prior to the COVID-19 pandemic to address the challenges that the local jurisdiction faces in relation to cases involving people with ID/DD.

D. COMMUNITY PLACEMENT FROM INSTITUTIONS

BENCHMARKS: 4-12

The Commonwealth still has 96 out of 635 participants (15% of the population served by the DSPDI) residing in institutions. Although this appears to represent a seven percent decrease from the 22% outlined in the JCC's previous report, the decrease was attributed to the abrupt closing of the *Fundación Modesto Gotay* institution (FMG) and not part of any individualized, interdisciplinary assessment or individualized transition plans using person-centered planning principles, as required by the Community Based Service Plan ("CBSP")[38]. Thus**, the JCC cannot attribute any actual progress as it pertains to compliance with this particular area of the JCAP premised on the above facts. A specific report as to the closing of FMG has been filed by the JCC as ordered by the Court (See Docket No. 3477).** Even though the aspiration of the Consent Decree in great measure is to transfer participants that reside in institutions into community-based home settings, the JCC hopes that an event such as the abrupt closing of FMG never occurs again for reasons elaborated in the Report. (See also Docket No. 3263).

[38] **As will be explained in detail further in the present Report, the transfer of said participants was carried out at late hours of the night without informing the participants' guardians; without the participants' personal belongings; and without proper capacitation to the receiving providers, among other concerning deficiencies.**

E. PROVIDER CAPACITY EXPANSION IN THE COMMUNITY

BENCHMARKS: 13-16

As of December 31, 2020, there was a delay in the party-agreed timeline for the creation and implementation of the corresponding rate adjustments study that is being prepared by Burns and Associates, Inc.[39], the DSPDI had not provided any updates on the work that is being performed by Burns and Associates or the status of the pending rate assessment study to either the JCC or the U.S. Department of Justice (USDOJ). However, Burns has since completed its report and the Commonwealth sent out a final report in Spanish on April 9, 2021.

During the period covered in this Report, a total of seven community homes, five group homes, and two substitute homes were opened. This represents a total availability of 32 new community-based living units. However, it is important to note that one of the homes was opened as an isolation facility in response to the COVID-19 pandemic (Hacienda Don Luis) and five due to the abrupt closure of FMG. The JCC does not believe the increased units should be characterized as an improvement in the Commonwealth's focus on creating community homes for the target population. The fact is that despite DSPDI having millions of dollars between August 2019 and December 2020, no new living units became available.

Moreover, despite the opening of new community homes, as of December 2020, 26% of community homes harbor more than six participants, which represents a serious overcrowding problem for the participants and DSPDI. Although this has been a recurring practice in the past, the abrupt placement of the FMG participants worsened the overcrowding predicament previously mentioned in the JCC's September 2019 Report (See pages 7-8, and 14). The urgency to place FMG participants in existing community-based housing, magnified with an inadequate pre-existing supply of available community homes and living units to address the participants' needs, the JCC finds that the compliance level as to this area of the Benchmarks has regressed.

F. INTEGRATED EMPLOYMENT AND DAY ACTIVITIES

BENCHMARKS: 17-39

Out of a total of 635 participants, only 20 participants (3% of the total population served), are employed. This level of potential employment is substantially below Benchmark number 29's target rate of 25%. In comparison to the last JCC's September 2019 Report (see page 15), this represents an increase of one participant.

[39] Burns and Associates is a health care consulting firm that works with states on policy analysis, financial modeling, rate setting, program design, implementation and evaluation and stakeholder engagement.

As for participants that were employed prior to the COVID-19 pandemic, the JCC recognizes that in order for participants to return to work, there is a need to conduct in-person evaluations in several areas. In addition, although there has been a commitment by employers to hold employment for previously employed participants, it is uncertain how many will, in fact, be able to return to their past employment in light of the above. **The JCC has hope that the above important matter for the participants aspiration towards independent living is addressed effectively in 2021, and the JCC has retained the services of Dr. Serena Lowe to assist the DSPDI in this endeavor[40].** Dr. Lowe will work with DSPDI on developing and implementing strategies related to:

- identifying federally-funded opportunities for the Commonwealth and its partners to receive technical assistance, training and professional development support focused on building the capacity of direct support professionals and disability service providers to implement evidence-based practices (i.e. customized employment and supported employment) known to support individuals with ID/DD and other most significant disabilities seek, obtain, and maintain competitive integrated employment; designing value-based payment methodologies to incentivize and reward outcomes-based service delivery strategies that support people with ID/DD secure and sustain competitive integrated employment;
- engaging with employers on their capacity to rehire, recruit, train and hire workers with disabilities in the aftermath of the COVID pandemic; and
- educating and meaningfully engaging self-advocates and families in designing and eventually participating in community-based employment training and placement programming offered by the Commonwealth.

G. SAFETY AND RESTRAINTS ISSUES

BENCHMARKS: 40-52

Incident Reports

The practice of analyzing and investigating incidents as required by the JCAP is not evidenced in the *Therap* platform.[41] Given this lack of compliance, the JCC requested that the

[40] Dr. Lowe is a government relations, public policy and global advocacy expert. Dr Lowe has over 25 years' experience in furthering public policies that promote the socioeconomic advancement of individuals with disabilities, and other at-risk populations.

[41] During 2017, the Commonwealth entered into a contract with *Therap* Services to design and implement an electronic incident and recordkeeping system to routinely compile better and more timely information system-wide about the current health, safety, and welfare of individual participants. The expectation was that this database enabling the Commonwealth to proactively identify individual participant crises or declines and then to mobilize more quickly to provide needed services and supports to help address situations of concern before they worsen. Further, the data from the electronic system was expected to reveal overall trends and discrete problem areas,

DSPDI notify participants' incident reports on a bi-weekly basis, with the intention of knowing and guaranteeing that the required attention is being offered for all incidents that participants may confront in the program.

However, in the reports delivered to the JCC, the DSPDI did not submit reports from the **quality control** team regarding the number and type of incidents, statistics, investigation reports and corrective plans. Furthermore, the vast majority of the reported incidents in the *Therap* platform do not have the required **corrective action plan and corresponding follow-up information**. Although the DSPDI has protocols in place for responding to incidents, neither the investigation results nor the prevention action plans have not been furnished to our office, nor are they available in Therap.

The reason for the missing data is unknown. These information gaps and procedural shortcomings should be remedied without delay. All conversations that the JCC has held with the Secretary of the Department of Health and its team of advisors generate high hopes that all of the deficiencies regarding the use and reporting of the Therap platform are going to be expediently addressed and promptly resolved in 2021.

Restraint Practice – Use of physical and chemical restraints

The JCC recognizes that the practice of physical restraints mechanism has been significantly diminished and the use of "as needed" (PRN) medication continues to be prohibited. However, it is imperative to investigate the reason behind the variety of psychiatric medications used by participants in the absence of a proper medical diagnosis. During 2020, Court-certified expert, Dr. Roberto Blanco[42] conducted a study and issued the first phase of his Polypharmacy Report, which includes his analysis and the recommendations that should be addressed by the DSPDI on this extremely important matter.

Notwithstanding the above, the JCC does not have the adequate information to establish if said reduction is attributable to the lockdown of participants in their homes and the absence of daily activities, or if its attributable to a change in the practice of restraints. The JCC recommends that the DSPDI work in a collaborative manner with Dr. Blanco in order to address the issues set forth in his report and proceed to implement his recommendations in a sustainable manner.

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making system-wide reform easier and more effective. (See Section II of the JAP, Docket No. 2426, page 5 and Section IV-B of the JCAP, Docket No. 1185, at page 11).

[42] Dr. Blanco is an expert retained by the JCC Office who has been assisting in the present case for over five (5) years and is familiar with the DSPDI participants and the numerous issues that the program confronts. As of today's date, Dr. Blanco's contributions have been welcomed by the parties, the Court and the JCC throughout the above-mentioned years. Dr. Roberto Blanco, M.D. is also an Associate Professor at the University of North Carolina School of Medicine and Medical Director at the NC START Central.

H. HEALTH CARE AND MENTAL HEALTH CARE

BENCHMARKS: 53-99

Although we have made evaluations that will allow us to express ourselves in regards to the healthcare and mental healthcare area, at this moment the JCC has not been placed in a position to conduct any form of evaluation as to the potential impact that the COVID-19 pandemic has had on the mental health of the participants.

It is important to note that, if it were not for service providers and parent organizations, the JCC would be in the dark regarding the many issues that the community homes were confronting, such as un-wanted visits from DSPDI personnel and the lack of proper preventive measures proper protocol, capacitation and other updated information. The JCC is optimistic that for its next report, the total disregard for the Court's orders and the JCC's requests for information will become a thing of the past.

Notwithstanding the above, the JCC acknowledges the fact that other ID/DD programs in other jurisdictions of the mainland have also not been able to properly assess these areas due to the challenges confronted by the COVID-19 pandemic. Therefore, the JCC is committed to producing a comprehensive clinical evaluation as to these matters in the upcoming months, for which we have begun the process of requesting the corresponding information with the purpose of supplementing the present Report.

a. CEEC

The intervention of the CEEC's availability for consults and support is not evidenced with any detail and accuracy. The use of CEEC consulting services may be inferred from other DSPDI documents when the CEEC is mentioned in the same, as well as in case notes in the *Therap* platform regarding attendance to conference call meetings and consultants in the fields of psychology and nursing. Nevertheless, as required by the JCAP, the CEEC should be carrying out a more active role with significantly greater participation. The above has simply not been the case.

Since September 2019, the information offered to the JCC pertaining to the CEEC services has diminished and there is little information available in order for the JCC to analyze the services and measure compliance within this area of the JCAP. Although we cannot conclude our assessment, the JCC is very concerned by the apparent lack of human resources and required level of expertise and capacitation of existing personnel to be able to adequately furnish the types of services that participants need. **The JCC has high hopes that the above deficiency and the need to be proactive in all areas of capacitation will be property addressed and effectively resolved by the new administration**.

b. Dental Health

Despite the pandemic, Dr. Juan Molina and Dr. Jazmín Rosado have continued offering dental services to participants and bedridden patients. During a visit to the Dental Clinic by a team from the JCC office, several areas required attention, some of which as of December 31, 2020, were not finished. The JCC is compelled to commend Dr. Molina, whose long-time commitment in assisting the ID/DD population has never proven more genuine than during the COVID-19 pandemic.

c. Nutrition

During the first quarter of 2020, the JCC Office's licensed nutritionist conducted various visits to the different CTS sites, community homes and institutions. In such visits, the nutritionist interviewed the cooks and reviewed the menu, food shopping list, food stores, and kitchen temperature records. Additionally, recommendations for the improvement of food preparation according to the needs of people with ID/DD were provided, as well as training and orientations on diabetes management, and patients with pica disorder, among others. It is imperative to continue efforts to offer training on nutritional plans, prevention of aspirations, dysphagia, and training to employees of the DSPDI about this topic. The JCC foresees that the new administration is committed to addressing all nutritional needs of participants in a manner consistent with the mandates of the JCAP.

d. Mortality and Comorbidity Committee

The JCC deems that there has been significant progress in this area. The furnished reports reflect the exercise of the independence required by the MRC chairperson, and only four mortality reports for 2020 are pending (with the exception of those waiting for autopsy results). The MRC has also been receptive in working collaboratively with the party-stipulated expert (UMass/CDDER) and we have agreed to reduce the terms for the pending mortality reports to those corresponding to the year 2017 forward. This will enable the MRC to comply with the 30-day deadline for producing the mortality reports. The JCC commends Dr. Yocasta Brugal in her efforts to resolve the past challenges that the mortality committee has historically faced and the achievements she is currently accomplishing.

Mortality

Of the 26 participant deaths that occurred in 2020, 54% happened at an institution, 33% of which resided in the Shalom Facility Group Institution. This data is extremely concerning to the JCC.

Upon examining the mortality rates of the DSPDI prior to the pandemic, the party-stipulated experts (UMass/CDDER) found that the average rate across 2018-2019 is at least **40%**

higher than other service programs that serve people with ID/DD, even though the population served by the DSPDI tends to have a lower prevalence of severe health needs compared to most ID/DD populations served in the U.S. Additionally, while the mortality rate in the general population of Puerto Rico tends to be higher (about 6% higher than the U.S. overall), this context does not fully account for the higher rates of mortality observed in the DSPDI participant population.

I. SYSTEM WIDE REFORMS

BENCHMARKS: 100-106

The DSPDI has not reached full implementation of the TherapServices platform. The JCC has found that currently the DSPDI is only using 50% of the platform's capacity. For the JCC it is of paramount importance that the DSPDI achieve full operation, which will certainly assist the DSPDI to be in compliance with the JCAP. We look forward to working with the new administration in achieving his extremely important objective.

Lastly, although a respite program was in its incipient stages, its implementation was delayed due to the COVID-19 pandemic. The implementation of such plan will be important in order to reach full compliance in this area of the JCAP as it has been done with the crisis Hotline. Although said program has not been properly implemented, the JCC will remain vigilant (as things return to a certain form of normality), on how ultimately the respite program operates and services the beneficiaries of the program.

J. CONCLUSION

In summary, the JCC is aware of the numerous challenges that mankind, the United States, Puerto Rico and the world faced during the year 2020 and the impact they had on the proper implementation of various Benchmarks and the JCC's suggested remedial actions that were included in the September 2019 Report. However, the JCC has high expectations (premised on numerous videoconferences, telephone conversations, letters from the Secretary, Administrative Orders, and meetings) that we have before us a team with a vision and commitment that the undersigned has not witnessed in all the years working in the present case. Notwithstanding the above, the JCC will never relinquish its obligation to keep the Court informed as to any matter that may place the safety and well-being of any participant at risk and to furnish the new administration a helping hand to assist them in overcoming the past challenges that they inherited from the previous administration. If any matter that arises that is in conflict with the directives of the Court or with the disclosure of documents, our next report will show if our optimism is grounded and confirmed.

As for the lack of clinical information related to the health care and mental health area of the present Report, the JCC acknowledges the fact that other ID/DD programs in other

jurisdictions of the mainland have also not been able to properly assess these areas due to the many challenges that were confronted during 2020 in relation to the COVID-19 pandemic. However, because of the importance of the same for the benefit of the parties, caretakers and stakeholders, the JCC is committed to producing a comprehensive clinical evaluation in the upcoming months. The JCC has already requested the corresponding information and documentation with the objective of supplementing the present Report with the assistance of his team of experts, particular UMass/CDDER.

As the Commonwealth moves forward, it is the JCC's hope that the new Administration will prioritize its obligations under the Consent Decree, and use the opportunity and available funds to ignite transformative, lasting, comprehensive systems-change that will significantly improve the opportunities of Puerto Ricans with ID/DD to excel in all aspects of community life, as well as establish a new visionary framework for the future of the Commonwealth's commitment to this important subpopulation. Such efforts will require bold, courageous, and dedicated leadership, and this population deserves no less than that of its government leaders. JCC stands firmly committed to support the Commonwealth in any way possible should it demonstrate legitimate, genuine commitment to reform.

ATTACHMENT 3:

Resumen Ejecutivo

La Oficina del Monitor Federal (JCC) presenta su quinto Informe Semi-anual de Situación (Informe) sobre el nivel de cumplimiento del Estado Libre Asociado de Puerto Rico (ELA) con los indicadores de cumplimiento[43] estipulados por las partes y el Plan de Acción de Cumplimiento Conjunto (JCAP [por sus siglas en inglés])[44] para el período comprendido entre el 1 de agosto de 2019 y el 31 de diciembre de 2020, el cual cubre la incumbencia de la administración anterior del ELA. El JCC también hará referencia a asuntos ocurridos hasta el 15 de enero de 2021 con la nueva administración.

Este Informe también cubre la respuesta de la División de Servicios para las Personas con Discapacidad Intelectual (DSPDI) a la pandemia del COVID-19 y los esfuerzos del JCC para apoyar al ELA en establecer protocolos adecuados y medidas de seguridad para reducir el riesgo de contagio entre los participantes del Programa, incluyendo las frecuencias de las pruebas y los objetivos de vacunación (Véase Dkt. 3442). Es imperativo mencionar que tanto los servicios prestados por la DSPDI como las actividades de monitoreo del JCC se vieron significativamente afectados debido a las medidas obligatorias y extraordinarias que se implementaron para garantizar la seguridad y el bienestar de todos los participantes de la DSPDI, los proveedores de servicios, los cuidadores, los contratistas y los empleados.

Además de los desafíos históricos enfrentados en el año 2020, el JCC también enfrentó innumerables retos debido al enfoque litigioso del ELA en el manejo del decreto de consentimiento con la intención de anular el mismo, incluyendo los deberes del JCC y en ocasiones las directrices de la Corte, la mayoría relacionados a asuntos sobre acuerdos que fueron alcanzados con el consentimiento de las Partes. Esto resultó en la negativa de la DSPDI en proporcionar información vital al JCC durante gran parte del año 2020, lo que resultó en retrasos inevitables en la presentación ante la Corte del Informe del JCC de septiembre de 2020.

Como se ilustrará en el presente informe, **el nivel de cumplimiento general de la DSPDI disminuyó de 24% a 9% en comparación con el Informe de septiembre de 2019 del JCC, siendo este el nivel de cumplimiento más bajo desde la aprobación del JCAP.**

El siguiente resumen provee una visión general de nuestra evaluación de cumplimiento para cada área del JCAP.

A. ASUNTOS SOBRE EL PRESUPUESTO DE LA DSPDI

[43] Véase Dkt. 2049.
[44] Véase Dkt. 1185.

Como resultado de una investigación del JCC durante el 2019, la Corte emitió una orden declarando al ELA en desacato civil por el "barrido" de aproximadamente $20 millones en fondos asignados a la DSPDI en violación a múltiples órdenes la Corte. (Véase Dkt. 2664). Sin embargo, la Corte anuló la declaración de desacato tras la moción sin oposición del ELA en la que se comprometió a suministrar los fondos mencionados a DSPDI durante los próximos cuatro (4) años fiscales en partidas anuales de $5 millones. (Véanse los Dkts. 2738 y 2740). A pesar de que la Corte ha emitido ordenes estrictas en cuanto al uso de los fondos presupuestarios aprobados, el JCC enfatiza la importancia de establecer los mecanismos necesarios para evitar que se continúe la practica de que los fondos ordenados por la Corte no sean utilizados en su totalidad.

Como parte de los esfuerzos realizados para cumplir con lo anterior, las Partes y el JCC han participado en reuniones ordenadas por la Corte para discutir el uso de dichos fondos y se ha acordado que dichos fondos deben ser priorizados hacia la apertura de nuevos hogares comunitarios, mejorar los servicios esenciales (tales como mejoras del equipo), y aumentar el acceso a otros servicios relacionados al empleo y la vida comunitaria. **Aunque se han compartido varias ideas, no se ha proporcionado un plan concreto sobre el uso de dichos fondos al cierre del presente informe. El JCC espera que continúen las reuniones mensuales con el objetivo de asistir a las Partes a identificar el mejor uso de los fondos asignados y los $5.4 millones adicionales (aproximadamente) de fondos sobrantes y a ser transferidos al año fiscal 2021-2022.**

B. REEVALUACIÓN DE LOS PARTICIPANTES

El JCC fue informado de once participantes que la DSPDI determinó ya no tenían ID/DD y solicitó la intervención de la Corte para que dichos participantes fueran reevaluados por un experto independiente. (Véanse los Dkts. 2482 y 2499). Con el consentimiento de las partes, la Corte designó a la Dra. María Margarida Juliá[45] para evaluar a 4 de dichos participantes.[46] Durante este proceso, la Dra. Margarida Juliá identificó importantes fallas en la metodología científica utilizada por la DSPDI para evaluar a dichos participantes.

Si bien se estableció un plan de capacitación al respecto y se realizaron reuniones en noviembre de 2019 y marzo de 2020, la DSPDI aún no ha implementado las recomendaciones de la Dra. Margarida en cuanto a la metodología de evaluación y suspendió las capacitaciones que estaba brindando según acordado por las Partes y aprobado por la Corte. (Véase Dkt. 2538). Dada la disponibilidad y opciones tecnológicas de comunicación de bajo costo, no hay razón para que

[45] La Dra. Margarida Juliá se encuentra entre los mas destacados expertos en el campo de la neuropsicología con más de 35 años de experiencia en el mismo.

[46] Las Evaluaciones Neuropsicológicas fueron realizadas por la Dra. Margarida Juliá como sigue: el 15 de julio de 2019 (informe emitido el 15 de agosto de 2019), el 26 de julio de 2019 (informe emitido el 10 de agosto de 2019), el 19 y 21 de octubre de 2019 (informe emitido el 7 de noviembre de 2019) y el 17 de febrero de 2020 (informe emitido el 1 de marzo de 2020). Las reuniones de capacitación entre la Dra. Margarida Juliá y la DSPDI se celebraron el 11 de noviembre de 2019 y el 26 de febrero de 2020, tras lo cual las gestiones se paralizaron.

el plan de capacitación no haya podido continuar incluso durante la pandemia. **Por lo tanto, se recomienda que el proceso de capacitación se renueve lo antes posible.**

C. PERSONAS CON ID/DD BAJO LA JURISDICCIÓN LOCAL

Hay un número de personas con ID/DD que no han sido diagnosticadas o tratadas adecuadamente y que han terminado bajo rama judicial del ELA por supuestas infracciones o violaciones al Código Penal local lo que los expone a un potencial encarcelamiento. El JCC tuvo que intervenir en un caso en el que la DSPDI optó por iniciar un proceso penal contra un participante que supuestamente estaba involucrado en una conducta sexual inapropiada. Esto en lugar de identificar métodos alternativos para abordar las deficiencias de comportamiento y el diagnóstico médico del participante. Exponer a los participantes a un proceso penal nunca debería ser una opción, y ciertamente no una opción de primer recurso. **El JCC recomienda que se exija a la DSPDI que agote todas las opciones disponibles para la rehabilitación de un participante y que se centre en la seguridad y el bienestar de los participantes antes de considerar la posibilidad de iniciar un proceso penal contra el individuo.**

El JCC reitera su recomendación de que lo antes posible se debe restablecerse un mecanismo de colaboración eficaz con la rama judicial para el manejo adecuado de los casos penales a los que se enfrentan las personas con ID/DD. El JCC se mantiene firme en su opinión de que ninguna persona con ID/DD debe ser sometida a un proceso penal debido a sus deficiencias cognitivas, y le preocupa que la DSPDI no esté presentando las defensas adecuadas ante los tribunales locales sobre la naturaleza del JCAP y las implicaciones de no cumplir con un acuerdo que es análogo a ley federal. A través de su asesor legal, el pasado Juez Presidente del Tribunal Supremo de Puerto Rico, el Juez Federico Hernández Denton, el JCC tiene la intención de dirigirse al Honorable Sigfrido Steidel, Director de la Oficina de Administración de Tribunales (OAT), para reanudar las discusiones iniciadas antes de la pandemia del COVID-19 para atender los retos que enfrenta la jurisdicción local en relación a los casos que envuelven a personas con ID/DD.

D. UBICACIÓN EN LA COMUNIDAD A PARTICIPANTES EN INSTITUCIONES

INDICADORES DE CUMPLIMIENTO: 4-12

El ELA todavía tiene 96 de 635 participantes (15% de la población atendida por la DSPDI) que residen en instituciones. Aunque esto parece representar una disminución del 7% con respecto al 22% señalado en el informe anterior de la JCC, dicha disminución se atribuye al cierre abrupto de la institución Fundación Modesto Gotay (FMG) y no como resultado de una evaluación individualizada e interdisciplinaria ni de planes de transición individualizados que utilicen los principios de planificación centrados en la persona, tal como lo exige el Plan de

Servicio de Base Comunitaria (CBSP [por sus siglas en inglés])[47]. **Por lo tanto, el JCC no puede atribuir ningún progreso real en cuanto al cumplimiento de esta área particular del JCAP. El JCC ha presentado un informe específico sobre el cierre de FMG, tal y como ordenó la Corte (véase el Dkt. 3477).** Aunque la aspiración del Decreto de Consentimiento en gran medida es transferir a los participantes que residen en instituciones a entornos domiciliarios basados en la comunidad, el JCC espera que un evento como el cierre abrupto de FMG no vuelva a ocurrir por razones elaboradas en el Informe. (Véase también el Dkt. 3263).

E. CAPACIDAD EXPANSIÓN DE LOS PROVEEDORES EN LA COMUNIDAD

INDICADORES DE CUMPLIMIENTO: 13-16

Actualmente existe un retraso en el calendario acordado por las partes para la creación y aplicación del correspondiente estudio de ajustes tarifarios que está preparando Burns and Associates, Inc. Al 31 de diciembre de 2020, la DSPDI no había proporcionado ninguna actualización sobre el trabajo que está realizando Burns and Associates[48] o el ELA del estudio de evaluación de tarifas pendiente ni al JCC ni al Departamento de Justicia de los Estados Unidos (USDOJ)[49].

Durante el período cubierto por este informe, se abrieron un total de siete hogares comunitarios, cinco hogares de grupo y dos hogares sustitutos. Esto representa una disponibilidad total de 32 nuevas unidades de vida en la comunidad. Sin embargo, es importante señalar que uno de los hogares se abrió como instalación de aislamiento en respuesta a la pandemia de COVID-19 (Hacienda Don Luis) y cinco debido al cierre abrupto de FMG. El JCC no cree que el aumento de unidades deba ser caracterizado como una mejora en el enfoque del ELA en la creación de hogares comunitarios. El hecho es que, a pesar de que la DSPDI dispuso de millones de dólares entre agosto de 2019 y diciembre de 2020, no hubo nuevas unidades de vivienda disponibles.

Además, a pesar de la apertura de nuevos hogares comunitarios, a diciembre de 2020, el 26% de los hogares comunitarios albergan a más de seis participantes, lo que representa un grave problema de hacinamiento para los participantes y la DSPDI. Aunque esta ha sido una práctica recurrente en el pasado, la colocación abrupta de los participantes de la FMG empeoró el problema de hacinamiento mencionado anteriormente en el Informe de septiembre de 2019 del

[47] **Como se explicará en detalle más adelante en el presente Informe, el traslado de dichos participantes se realizó a altas horas de la noche sin informar a los tutores de los participantes; sin las pertenencias personales de los participantes; y sin una adecuada capacitación a los proveedores de los hogares comunitarios, entre otras deficiencias preocupantes.**

[48] Burns and Associates es una empresa de consultoría en el área de salud que trabaja con los Estados en el análisis de políticas, la elaboración de modelos financieros, el establecimiento de tarifas, el diseño, la ejecución y la evaluación de programas y la participación de las partes interesadas.

[49] El 9 de abril de 2021, el ELA suminsitró una copia en español del informe de Burns and Associates.

JCC (Ver páginas 7-8, y 14). Dada la urgencia de ubicar a los participantes de la FMG en hogares comunitarios existentes, añadido a una cantidad inadecuada de hogares comunitarios y unidades de vivienda disponibles para atender las necesidades de los participantes, el JCC determina que el nivel de cumplimiento en cuanto a esta área de los indicadores de cumplimiento ha retrocedido.

F. EMPLEO INTEGRADO Y ACTIVIDADES DIURNAS

INDICADORES DE CUMPLIMIENTO: 17-39

De un total de 635 participantes, sólo 20 participantes (el 3% de la población total atendida), tienen empleo. Este nivel de potencial empleo está sustancialmente por debajo de la tasa objetivo de 25% del indicador de cumplimiento número 29. En comparación con el último Informe de septiembre de 2019 del JCC (ver página 15), esto representa un aumento de 1 participante.

En cuanto a los participantes que estaban empleados antes de la pandemia de COVID-19, el JCC reconoce que para que los participantes vuelvan a su empleo, es necesario realizar evaluaciones en persona en varias áreas. Además, aunque los patronos se han comprometido a mantener la plaza disponible para los participantes que estaban empleados anteriormente, no hay certeza sobre cuántos podrán, de hecho, volver a su empleo a la luz de lo anterior. **El JCC tiene la esperanza de que este importante asunto para la aspiración de los participantes hacia la vida independiente se atienda de manera efectiva en el 2021 además, el JCC ha contratado los servicios de la Dra. Serena Lowe para asistir a la DSPDI en este esfuerzo.**[50] La Dra. Lowe trabajará con la DSPDI en el desarrollo e implementación de estrategias relacionadas con:

- identificar las oportunidades de fondos federales para que el ELA y sus componentes reciban asistencia técnica, capacitación y apoyo en el desarrollo profesional centrado en la capacidad de los profesionales de apoyo directo y los proveedores de servicios de discapacidad para aplicar las prácticas basadas en la evidencia (es decir, el empleo personalizado y el empleo con apoyo) conocido para apoyar a las personas con ID/DD y otras discapacidades más significativas; buscar, obtener y mantener un empleo integrado competitivo; el diseño de metodologías de pago basadas en iniciativas para incentivar y recompensar las estrategias de prestación de servicios basados en los resultados que apoyan a las personas con ID/DD a obtener y mantener un empleo integrado competitivo;
- colaborar con los patronos para volver a contratar, reclutar, capacitar y contratar a los empleados con discapacidades tras la pandemia de COVID; y

[50] La Dra. Lowe es una experta en relaciones gubernamentales, política pública y defensa global. La Dra. Lowe tiene más de 25 años de experiencia en el desarrollo de políticas públicas que promueven el avance socioeconómico de las personas con discapacidad, y otras poblaciones en riesgo.

- educar e involucrar de manera significativa a los autogestores y a las familias en el diseño y la eventual participación en los programas de capacitación y ubicación de empleo basados en la comunidad que ofrece el ELA.

G. CUESTIONES DE SEGURIDAD Y RESTRICCIÓN

INDICADORES DE CUMPLIMIENTO: 40-52

Informes de incidentes

La práctica de analizar e investigar los incidentes tal como lo exige el JCAP no se evidencia en la plataforma *Therap*.[51] Ante esta falta de cumplimiento, el JCC solicitó a la DSPDI la notificación quincenal de los informes de incidentes de los participantes, con la intención de conocer y garantizar que se está ofreciendo la atención requerida a todos los incidentes que los participantes puedan enfrentar en el programa.

Sin embargo, en los informes suministrados al JCC, la DSPDI no presentó informes del equipo de **control de calidad** sobre el número y tipo de incidentes, estadísticas, informes de investigación y planes correctivos. Además, la gran mayoría de los incidentes reportados en la plataforma *Therap* no cuentan con el **plan de acción correctiva requerido y la información de seguimiento correspondiente.** Aunque la DSPDI cuenta con protocolos para responder a los incidentes, ni los resultados de la investigación ni los planes de acción de prevención han sido facilitados a nuestra oficina, ni están disponibles en la plataforma de *Therap*.

Se desconoce el motivo de la falta de datos. Estas lagunas de información y deficiencias de procedimiento deben ser subsanadas sin demora. Todas las conversaciones que el JCC ha mantenido con el Secretario del Departamento de Salud y su equipo de asesores generan grandes esperanzas de que todas las deficiencias relativas al uso y la presentación de informes en la plataforma *Therap* van a ser atendidos de manera expedita y resueltos con prontitud en el 2021.

Práctica de Restricción - Uso de restricciones físicas y químicas

El JCC reconoce que la práctica del uso de mecanismo de restricción física ha disminuido significativamente y el uso de medicación "según necesidad" (PRN) sigue estando prohibido. Sin embargo, es imperativo investigar la razón detrás de la variedad de medicamentos psiquiátricos

[51] Durante 2017, el ELA entró en un contrato con *Therap Services* para diseñar e implementar un sistema electrónico de registro de incidentes para recopilar de forma rutinaria una información mejor y más oportuna en todo el sistema sobre la salud, la seguridad y el bienestar actual de los participantes a nivel individual. La expectativa era que esta base de datos permitiera al ELA identificar de forma proactiva las crisis o el deterioro de los participantes y a movilizarse más rápidamente para ofrecer los servicios y apoyos necesarios para ayudar a atender las situaciones preocupantes antes de que las mismas empeoren. Además, se esperaba que los datos del sistema electrónico revelaran las tendencias generales y áreas problemáticas concretas, lo que facilitaría y haría más eficaz la reforma de todo el sistema. (Véase la Sección II del JAP, Véase Dkt. 2426, página 5 y la Sección IV-B del JCAP, Véase Dkt. 1185, página 11).

utilizados por los participantes en ausencia de un diagnóstico médico adecuado. Durante el año 2020, el experto certificado por la Corte, el Dr. Roberto Blanco[52] realizó un estudio y emitió la primera fase de su Informe de Polifarmacia, el cual incluye su análisis y las recomendaciones que debe atender la DSPDI sobre este importantísimo asunto.

No obstante lo anterior, el JCC no cuenta con la información adecuada para establecer si dicha reducción es atribuible la orden de cierre de los participantes en sus hogares y a la ausencia de actividades cotidianas, o si es atribuible a un cambio en la práctica de restricciones. El JCC recomienda que la DSPDI trabaje de manera colaborativa con el Dr. Blanco a fin de atender las situaciones detalladas s en su informe y proceda a implementar sus recomendaciones de manera sostenible.

H. CUIDADO DE SALUD Y SALUD MENTAL

INDICADORES DE CUMPLIMIENTO: 53-99

A pesar de que hemos realizado evaluaciones que nos permiten expresarnos en relación con el área de cuidado de salud y salud mental, en este momento el JCC no se ha puesto en condición de realizar algún tipo de evaluación en cuanto al posible impacto que la pandemia del COVID-19 ha tenido en la salud mental de los participantes.

Es importante señalar que, si no fuera por los proveedores de servicios y las organizaciones de padres, el JCC estaría en la oscuridad con respecto a los muchos problemas que los hogares de la comunidad han enfrentado, como las visitas no deseadas del personal de la DSPDI y la falta de medidas preventivas adecuadas, protocolos apropiados, capacitación y otra información actualizada. El JCC está optimista que, para su próximo informe, la total desatención a las órdenes de la Corte y a las solicitudes de información del JCC serán cosa del pasado.

No obstante lo anterior, el JCC reconoce el hecho de que otros programas de ID/DD en otras jurisdicciones tampoco han podido evaluar adecuadamente estas áreas debido a los retos enfrentados por la pandemia del COVID-19. Por ello, el JCC se compromete a realizar una evaluación clínica exhaustiva en cuanto a estas cuestiones en los próximos meses, para lo cual se ha iniciado el proceso de solicitud de la información correspondiente con el fin de complementar el presente Informe.

a. CEEC

[52] El Dr. Blanco es un experto contratado por la Oficina del JCC que ha estado asistiendo en el presente caso durante más de 5 años y está familiarizado con los participantes de la DSPDI y los numerosos problemas que enfrenta el programa. A la fecha, las aportaciones del Dr. Blanco han sido bien recibidas por las partes, la Corte y el JCC a lo largo de los años mencionados. El Dr. Roberto Blanco, M.D. es también profesor asociado de la Facultad de Medicina de la Universidad de Carolina del Norte y director médico del NC START Central.

La intervención y disponibilidad del CEEC para consultas y apoyo no se evidencia con ningún detalle ni precisión. El uso de los servicios de consultoría del CEEC puede inferirse de otros documentos de la DSPDI cuando se menciona al CEEC en los mismos, así como en las notas de los casos en la plataforma *Therap* respecto a su asistencia a las reuniones de teleconferencia y a las consultorías en las áreas de la psicología y enfermería. Sin embargo, tal y como exige la JCAP, el CEEC debería estar desempeñando un papel más activo y con una participación significativamente mayor. Lo anterior simplemente no ha sido así.

Desde septiembre de 2019, la información ofrecida al JCC relativa a los servicios del CEEC ha disminuido y se dispone de poca información para que el JCC pueda analizar los servicios y medir el cumplimiento dentro de este ámbito del JCAP. A pesar de no podemos concluir nuestra evaluación, el JCC está muy preocupado por la aparente falta de recursos humanos y el nivel de experiencia y capacitación del personal existente para poder proporcionar adecuadamente los tipos de servicios que necesitan los participantes. El JCC tiene grandes esperanzas de que la deficiencia mencionada y la necesidad de ser proactivos en todas las áreas de capacitación sean atendidas con celeridad y resueltas efectivamente por la nueva administración.

b. Salud dental

A pesar de la pandemia, el Dr. Juan Molina y la Dra. Jazmín Rosado han seguido ofreciendo servicios dentales a los participantes y a los pacientes encamados. Durante una visita a la Clínica Dental por parte del equipo de la oficina del JCC, se observó que varias áreas requerían atención, algunas de las cuales, al 31 de diciembre de 2020, no estaban aún atendidas. El JCC reconoce y felicita al Dr. Molina, cuyo compromiso de muchos años en servir a la población de ID/DD nunca ha demostrado ser más genuino que durante la pandemia de COVID-19.

c. Nutrición

Durante el primer trimestre de 2020, la nutricionista licenciada de la Oficina del JCC realizó varias visitas a las diferentes facilidades de los CTS, hogares comunitarios e instituciones. En dichas visitas, la nutricionista entrevistó a los cocineros y revisó el menú, la lista de compras de alimentos, los almacenes de alimentos y los registros de temperatura de la cocina. Además, se brindaron recomendaciones para mejorar la preparación de los alimentos de acuerdo con las necesidades de las personas con ID/DD, así como capacitaciones y orientaciones sobre el manejo de la diabetes, y pacientes con trastorno de pica, entre otros. Es imprescindible continuar con los esfuerzos para ofrecer capacitación sobre planes nutricionales, prevención de aspiraciones, disfagia, y capacitación a los empleados de la DSPDI sobre este tema. El JCC prevé que la nueva administración esta comprometida a atender todas las necesidades nutricionales de los participantes de manera consistente con los mandatos del JCC.

d. Comité de Mortalidad y Comorbilidad (MRC)

El JCC considera que se han producido avances significativos en esta área. Los informes de mortalidad suministrados reflejan el ejercicio de la independencia requerida por el presidente del MRC, y sólo están pendientes cuatro informes de mortalidad para 2020 (a excepción de los que están a la espera de los resultados de las autopsias). El MRC también se ha mostrado receptivo a trabajar en colaboración con el experto estipulado por las partes (UMass/CDDER) y se ha acordado reducir los plazos de los informes de mortalidad pendientes a los correspondientes al año 2017 en adelante. Esto permitirá al MRC cumplir con el plazo de 30 días para elaborar los informes de mortalidad. El JCC felicita a la Dra. Yocasta Brugal en sus esfuerzos por resolver los retos que el comité de mortalidad ha enfrentado históricamente y los logros que está alcanzando actualmente.

Mortalidad

De los 26 decesos de participantes ocurridos en 2020, el 54% ocurrieron en una institución, de los cuales el 33% residían en la Institución del Grupo Shalom Facility. Estos datos son extremadamente preocupantes para el JCC.

Al examinar las tasas de mortalidad de la DSPDI antes de la pandemia, los expertos estipulados por las Parte (UMass/CDDER) encontraron que la tasa promedio a lo largo de 2018-2019 es al menos un **40% más alta** que otros programas de servicios que atienden a personas con ID/DD. Esto a pesar de que la población atendida por la DSPDI tiende a tener una menor prevalencia de necesidades de salud graves en comparación con la mayoría de las poblaciones de ID/DD atendidas en los Estados Unidos. Además, aunque la tasa de mortalidad en la población general de Puerto Rico tiende a ser más alta (alrededor de un 6% que la de los Estados Unidos en general), este hecho no explica el alza en las tasas de mortalidad observadas en la población de participantes de la DSPDI.

I. REFORMA AMPLIA DEL SISTEMA

INDICADORES DE CUMPLIMIENTO: 100-106

La DSPDI no ha logrado la implantación total de la plataforma *Therap Services*. El JCC ha constatado que actualmente la DSPDI sólo utiliza el 50% de la capacidad de la plataforma. Para el JCC es de suma importancia que la DSPDI logre el pleno funcionamiento de la plataforma, lo que sin duda ayudará al DSPDI a adelantar el cumplimiento con el JCAP. Esperamos colaborar con la nueva administración en alcanzar este importantísimo objetivo.

Por último, a pesar de que el programa de respiro estaba en sus etapas incipientes, su implementación se retrasó debido a la pandemia de COVID-19. La implementación de dicho plan es importante para alcanzar el pleno cumplimiento en esta área del JCAP, tal y como se ha hecho con la Línea de Crisis. A pesar de que dicho programa no se ha implementado adecuadamente,

el JCC permanecerá vigilante (a medida que las cosas vuelvan a una cierta forma de normalidad), sobre cómo finalmente el programa de respiro opera y atiende a los participantes del programa.

J. CONCLUSIÓN

En resumen, el JCC está consciente de los numerosos retos que la humanidad, los Estados Unidos, Puerto Rico y el mundo han enfrentado durante el año 2020 y el impacto que estos tuvieron en la implementación adecuada de varios indicadores de cumplimiento y las acciones correctivas sugeridas por el JCC que se incluyeron en el Informe de septiembre de 2019. No obstante, el JCC tiene grandes expectativas (basadas en numerosas videoconferencias, conversaciones telefónicas, cartas del Secretario, Órdenes Administrativas y reuniones) de que tenemos ante nosotros un equipo con una visión y un compromiso que el suscribiente no ha presenciado en todos los años de trabajo en el presente caso. No obstante lo anterior, el JCC nunca renunciará a su obligación de mantener informada a la Corte Federal sobre cualquier asunto que pueda poner en riesgo la salud, seguridad y el bienestar de algún participante y de proporcionar a la nueva administración una mano amiga para ayudarles a superar los retos que heredaron de la administración anterior. Si surge algún asunto que entre en conflicto con las directrices de la Corte o con la divulgación de documentos, nuestro próximo informe mostrará si nuestro optimismo está fundamentado y confirmado.

En cuanto a la falta de información clínica relacionada con el área de cuidado de salud y salud mental del presente Informe, el JCC reconoce el hecho de que programas de ID/DD en otras jurisdicciones del continente tampoco han podido evaluar adecuadamente estas áreas debido a los muchos retos enfrentados durante el año 2020 en relación con la pandemia de COVID-19. Sin embargo, debido a la importancia de la misma en beneficio de las partes, los cuidadores y los interesados, el JCC se compromete a elaborar una evaluación clínica a ser completa en los próximos meses. El JCC ya ha solicitado la información y documentación correspondientes con el objetivo de complementar el presente Informe con la ayuda de su equipo de expertos, en particular de la UMass/CDDER.

En la medida que el ELA avanza, es la esperanza del JCC que la nueva administración priorice sus obligaciones bajo el Decreto de Consentimiento, y utilice la oportunidad y los fondos disponibles para provocar una transformación duradera y comprensiva del sistema que mejore significativamente las oportunidades de los puertorriqueños con ID/DD para sobresalir en todos los aspectos de la vida comunitaria, así como establecer un nuevo marco visionario para el futuro del compromiso del ELA con esta importante población. Tales esfuerzos requerirán un liderazgo audaz, valiente y dedicado, y esta población no merece menos de sus líderes gubernamentales. El JCC se compromete firmemente a apoyar al ELA de cualquier manera posible si demuestra un compromiso legítimo y genuino con la reforma.