

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

**UNITED STATES OF AMERICA,**

**Plaintiff,**

**v.**

**COMMONWEALTH OF PUERTO  
RICO, et al.,**

**Defendants.**

**CASE NO. 99-1435 (SCC)**

**MOTION SUBMITTING THE JCC’S SEPTEMBER 2021 SEMI-ANNUAL  
ASSESSMENT REPORT**

**TO THE HONORABLE COURT:**

**COMES NOW** the undersigned as Joint Compliance Coordinator (“JCC”)/Federal Monitor, who respectfully informs the Court as follows:

1. The undersigned hereby submits the JCC’s September 2021 Semi-annual Assessment Report. In compliance with the directives of the Court, the JCC files the aforementioned Report after providing the parties 15 days to review the same and issue their comments and recommendations. (See. Docket No. 2589).

2. The JCC’s Report, the Executive Summary and a Spanish language translation will be available shortly in the JCC’s website for easy access. The same will be available at [www.jccfederalmonitor.com](http://www.jccfederalmonitor.com).

**WHEREFORE**, the JCC respectfully requests that this Honorable Court take notice of the above for all relevant purposes.

**RESPECTFULLY SUBMITTED.**

Civil No. 99-1435 (SCC)

1 In San Juan, Puerto Rico, this 18<sup>th</sup> day of November 2021.

2  
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13 **NOTICE OF ELECTRONIC FILING**

14 **I HEREBY CERTIFY**, that on this date, I electronically filed the foregoing with the  
15 Clerk of the Counseling the CM/ECF system, which will notify copy to the attorneys of record.

16  
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ASSESSMENT REPORT  
UNITED STATES V. PUERTO  
RICO 99-1435  
(SCC)  
SEPTEMBER 2021

Benchmarks and Supplemental Narrative

Joint Compliance Coordinator Team



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

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**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:

- Ms. Emily Lauer (UMass/CDDER, Joint Party-stipulated Expert);
- Dr. Serena Lowe (AnereS Strategies, LLC/Subject matter Expert);
- Dr. Dimaris García, Psy. D. (psychologist and JCC Team Expert);
- Dr. Carmelo Rodríguez, Psy. D. (psychologist and JCC Team Expert)
- Dr. Roberto Blanco, M.D. (Joint Party-stipulated Expert); and
- Dr. María Margarida Juliá (Clinical Neuropsychologist. Joint Party-stipulated Expert).

**Members of the Federal Monitor's Office:**

- Ms. Diana Alcaraz, Esq./CPA (Special Investigator);
- Ms. Tirsá Sosa, MSW (Social Worker and Ex-Director of the Bayamón Daily Center);
- Ms. Jeannie Castillo (Administrative Assistant/ Expert Liason with Participants);
- Mr. Salvador M. Carrión, Esq. (Legal Advisor to the JCC); and
- Mr. Javier González (Executive Director of the Office of the JCC and Monitor in Management).

A handwritten signature in blue ink, appearing to read "Alfredo Castellanos", is written over a horizontal line.

Alfredo Castellanos, Esq.  
Federal Monitor/JCC



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***“[t]he 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 ... It is important to note that the “administrative closure” of this twelve (12) years old case in no way underscores the Constitutional and legal rights of the MRP [now DSPDI] participants as citizens of the United States. To the contrary, 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, Oct. 19, 2011

**I. Introduction**

**A. Methodology and Scope of the Report**

The Federal Monitor’s Office hereby presents its sixth Semi-Annual Assessment Report (“Report”) regarding the Commonwealth of Puerto Rico’s (“Commonwealth”) and the Department of Health’s Division of Services for Adults with Intellectual Disabilities (“DSPDI” for its Spanish acronym) compliance with the party-stipulated benchmarks and the Joint Compliance Action Plan (“JCAP,” Consent Decree).<sup>1</sup>

The Office of the JCC assessed performance, cross-referenced the Benchmarks, and indicated the level of compliance that has been reached as of June 30, 2021.<sup>2</sup> For the first time, the JCC’s Report is providing an in-depth analysis on Benchmarks that represent outcome measures (those that require monitoring and input from clinical experts to determine if services are adequate, meet accepted professional standards, and are being delivered to meet each person’s individualized needs), and, as in the past, providing general compliance assessments for the non-outcome items (those where compliance can be determined often with a simple yes or no answer, or through numerical data).

The aforementioned assessment was prepared relying on specific data furnished by the DSPDI covering the time period between January 1, 2021, to June 30, 2021. Our assessment also includes the opinions and recommendations of the joint party-expert, University of Massachusetts’ Center for Developmental Disabilities Evaluation and Research (“UMass/CDDER”),<sup>3</sup> of subject matter expert Dr. Serena Lowe, as well as the JCC team of experts.<sup>4</sup>

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<sup>1</sup> See Docket No. 1185.

<sup>2</sup> The JCC will make a general assessment, not a weighted statistical analysis. Weighted statistical evaluations may distort, at this particular time, the DSPDI’s progress during the last six months.

<sup>3</sup> See Docket No. 2560.

<sup>4</sup> Pursuant to the directives of the Court at Dockets Nos. 2589 and 3230, the Parties were furnished a copy of the first draft of the present Report for their review and comments. However, the Commonwealth of Puerto Rico did not provide any specific comments for the same but submitted a motion to the Court with their position regarding the same (Docket No. 3544). The JCC discussed the matter with the Commonwealth, and they agreed to follow the Court-established procedure and case precedent as they relate to the Commonwealth’s response for the upcoming



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As the present Report illustrates, the totality of the assessment derived from the Benchmarks shows that the Commonwealth has made important improvements in comparison to the JCC's previous Report.

### **B. Brief Contextual Background**

There have been significant improvements and positive changes in the communications between the Federal Monitor's Office and the DSPDI. In addition, the Commonwealth's legal team has adopted a welcome non-litigious approach as it relates to the Consent Decree.<sup>5</sup> As mentioned in our March 2021 Report, the situation in 2020 was markedly different, markedly worse, where the previous administration typically did not furnish the JCC with the information required to conduct any form of analysis of the clinical areas addressed in the Benchmarks. In addition, the JCC commends the current administration and current DSPDI leadership for their diligent efforts and for providing substantially responsive information in an organized way to the Office of the JCC to facilitate our assessment of the DSPDI's compliance level and to enable us to furnish our corresponding recommendations. Unfortunately, the JCC was not able to do this in the last semi-annual Report.<sup>6</sup>

During this six-month time period, the new administration has been familiarizing itself with general program operations and practices, identifying areas needing a complete overhaul, and developing comprehensive plans to address the deficiencies of the program and the services that are provided to participants. These are positive steps. In assessing compliance activities, the JCC is cognizant of the extraordinary historical circumstances associated with the COVID-19 pandemic, including the recent uptick in community transmission rates, which can make implementing reform measures challenging, especially those related to day programs and employment, among others.

Additionally, the Court approved a significant increase in the current overall DSPDI budget, including an additional \$10,000,000 reserve, which should enable the Commonwealth to implement needed reforms in many essential areas mandated by the JCAP, which would allow the DSPDI to achieve compliance with many benchmark items and, ultimately, achieve sustainable compliance in future.<sup>7</sup> Therefore, the JCC

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JCC semi-annual reports. Notwithstanding the above, the Commonwealth only expressed disagreement with the compliance assessment of very few benchmarks without particularity.

<sup>5</sup> The above change in posture is also evident in that the Commonwealth has not filed any motions this year to challenge any court orders or the JCC's monitoring activities. In addition, the Commonwealth and the JCC have been able to resume the monthly meetings which has been a positive change from last year; during these meetings, the JCC and the Commonwealth can discuss pressing issues to try to resolve them collaboratively, and the meetings provide a vehicle for the JCC and the Commonwealth to exchange important information which is needed for the semi-annual Report. The meetings also enable the JCC to assist the DSPDI by providing technical assistance with regard to our recommendations.

<sup>6</sup> The JCC recently granted the DSPDI's request to furnish additional information that had not been submitted to the JCC within the established deadline. Given the spirit of collaboration that now exists between the DSPDI and the Office of the JCC, granting this request was appropriate.

<sup>7</sup> See Docket No. 3499.



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anticipates seeing further significant progress in the implementation of the needed reforms to address the concerns outlined in the present Report during the next six months.

### **C. JCC Observations Going Forward**

Although there is much work to be done in order for the Commonwealth to achieve full and sustainable compliance as required in the JCAP, the JCC recognizes once again that the Commonwealth is making quantifiable progress towards said objective.

If the action plans that the DSPDI is currently working on with the assistance of joint party-experts and subject matter experts so that outcome items are properly implemented, the Commonwealth should start showing significant progress very soon. The JCC recommends that DSPDI increase its level of engagement with the JCC's joint party-experts and subject matter experts so as to maintain progress until compliance is reached in the Consent Decree. As for the non-outcome items, the JCC is certain that with focused effort, the deficiencies addressed in this Report can be readily addressed such that the Commonwealth should be able to reach compliance with these items during the next few quarters.

There are several priority areas that can have a significant, immediate, and positive impact on the health, safety, and well-being of the participants, if the Commonwealth takes meaningful action in a timely and proper manner. Some of these areas include the following:

#### **i. Opening of New Community Homes**

The opening of new community homes is of paramount importance in order to enable the Commonwealth to transition dozens of participants from private institutional settings to community homes and to permanently eradicate the overcrowding issues that the DSPDI has historically been facing in many of its community homes ("CH"), which cause the participants to reside in almost congregate settings.<sup>8</sup> This has been a recurring issue for years. The JCC expects that with the recent Court-approved budget and the significant recent increase in provider reimbursement rates,<sup>9</sup> the DSPDI can finally invest in expanding residential services and available housing units for many individuals. This will also serve to create new spaces to accommodate individuals throughout the Island who are currently on the DSPDI's expanding waiting list.

The JCC is also looking forward to seeing the DSPDI pilot new approaches to support participants to live in their own homes with appropriate wrap-around supports, and in implementing evidence-based strategies and approaches to assist participants in need of behavioral supports and health management services. Moreover, the JCC looks forward to the DSPDI providing family respite services for those

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<sup>8</sup> With the abrupt closing of the Fundación Modesto Gotay institution, the overcrowding of participants has substantially increased. Overcrowding should be eradicated by no later than June 2022. The undersigned anticipates full collaboration from the DSPDI and expects that any obstacles that have been mentioned to the Office of the JCC regarding the contracting phase of the expansion, have been or will be resolved with the Governor's intervention.

<sup>9</sup> See Docket No. 3499.





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suffering complex traumatic events and for those with a dual diagnosis, as well as providing specialized services to support medication tapering and providing improved models for effectively transitioning individuals from institutional to community-based settings. The above objectives have already been addressed by the Court.<sup>10</sup>

**ii. Timely Payment to Service Providers and Contract Renewals**

There have been significant improvements regarding timely payments to service providers and timely contract renewals with the program due, in great measure, to improvements in the Commonwealth's technological infrastructure. However, the JCC reiterates to the DSPDI and the Health Department that timely provider payments and contract renewals are extremely important matters. Failure to continue with existing practices could ultimately lead to the interruption of essential services to participants, in clear violation of the JCAP and other court orders.<sup>11</sup> The DSPDI should ensure that all problems that have affected timely payments and contractual renewals in the past, are resolved permanently within the context of a system-wide reform<sup>12</sup>. The JCC expects that historical problems with timely payments and renewals will become a relic of the past and expects that the Commonwealth will maintain compliance in this area within the time frame agreed upon by the parties.

**iii. Effective Implementation of Person-Centered Planning Principles**

The implementation of Person-Centered-Planning ("PCP") principles is also one of the most important areas in which the DSPDI can continue to make significant progress. The Commonwealth's initiatives need to include participants' participation and contributions in all matters pertaining to their overall health, safety, and well-being and to support them in reaching the ultimate goal of independent living, optimal self-sufficiency, and full community inclusion according to their needs and preferences<sup>13</sup>. The JCC is aware that the DSPDI has progressed in this regard, but PCP principles have not yet been fully implemented as of the preparation of the present Report. The undersigned recommends ongoing training and skill-building in PCP principles and practices for all staff members working with participants, as it will facilitate needed progress, especially if the training and skills building is executed with the active participation of the JCC's joint party experts. The JCC is optimistic about the DSPDI's recent application to receive technical assistance from the National Center for the Advancement of Person-Centered Practice and Systems (NCAPPS) through the Administration for Community Living and sees this as an opportunity for the DSPDI to accelerate its focus around this pivotal area.

**iv. Effective Implementation of the Mortality Review Committee's Remedial Recommendations**

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<sup>10</sup> *Id.*

<sup>11</sup> See Dockets No. 3339 and 3519.

<sup>12</sup> See Docket No. 3310.

<sup>13</sup> See Docket No. 3510.



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The Mortality Review Committee (“MRC”) has significantly reduced the number of pending mortality reports and has improved the length of time it takes to complete individual reports, more in line with the JCAP mandates. This is good progress. Nonetheless, the MRC has yet to achieve producing said reports within the 30-day timeframe established in the JCAP. The MRC is now generating timely, actionable reports that provide important recommendations for improvement of DSPDI services. Notwithstanding the above, unfortunately, the MRC Chairwoman’s remedial recommendations are still not being implemented promptly or fully by the DSPDI as mandated by the JCAP. The Office of the JCC is confident that the MRC can comply with existing JCAP mandates, and that meaningful progress towards compliance should, in all likelihood, be reflected in the next JCC semi-annual Report. The MRC Chairwoman, Dr. Brugal is a tremendous asset for the DSPDI and for the advancement of eradicating systemic problems that often cause preventable deaths to participants.

**v. Eradication of Polypharmacy Practices**

The JCC also recognizes the recent early efforts that have been initiated by the DSPDI to implement the recommendations set forth in JCC expert Dr. Roberto Blanco’s Polypharmacy Report<sup>14</sup>. However, it is not clear that the efforts to date have resulted in meaningful improvements in the medication profiles of participants. The current levels of polypharmacy, particularly psychotropic polypharmacy, represent substantial risks to the health of participants, and have been cited in mortality reports as a contributing factor in multiple recent deaths of participants. Additionally, multiple high-risk medication combinations are still present in too many participants’ medication regimens. Addressing the above matter at once is of paramount importance to the participants’ health and well-being, and although the undersigned acknowledges that correcting historically detrimental polypharmacy practices could take some time to eradicate in particular cases, it is an issue that should be resolved with full deliberate speed by the DSPDI within the parameters of generally accepted medical practices.

**vi. CEEC Mobile Crisis Team**

The CEEC Mobile Crisis Team is still not functioning according to the mandates of the JCAP, which means that currently, participants are deprived of a specialized unit that should assist them in the event of any emergency, no matter the time of day when the emergency arises and/or where the participant(s) live.<sup>15</sup> The JCC expects this deficiency to be resolved within the next six months, given that, as has been experienced recently, a serious emergency situation can occur at any given moment. The fact that a CEEC Mobile Crisis Team does not exist and/or operates as intended 11 years since the adoption of the JCAP, is simply not acceptable to the Office of the JCC; the undersigned is convinced that the new administration shares the same opinion.

**vii. Management of Chronic Health Conditions**

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<sup>14</sup> See Docket No. 3052.

<sup>15</sup> See JCAP Section III- 5 (C) and (D).



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While it is positive that the DSPDI is consistently maintaining information about people with health risks such as a risk of aspiration pneumonia, additional work is needed to adequately address such critical health risks and to properly manage all chronic health conditions. For example, many of the treatment plans for people with aspiration pneumonia and/or challenges have dietary and positioning plans that do not address participants' pneumonia aspiration condition and related risks. Many participants with seizure disorders do not have access to a neurologist; there are too many individual instances of complex seizure disorders or complicated antiepileptic medicine regimens that are still being managed by primary care physicians, clearly a suboptimal scenario for medical management of seizures.

The present Report will provide a comprehensive assessment as to the Commonwealth's compliance levels in relation to the Benchmarks and the joint party-experts' and at times, subject matter experts', recommended action plans. It is important to emphasize that said recommended action plans were written with the objective of assisting the DSPDI with the creation of a roadmap that if followed, will serve as a guide for the Division to reach compliance and ultimately, sustainable compliance. The JCC is hopeful that the DSPDI will continue in the proper direction to improve the lives of all participants. The Office of the JCC will be available at all times to assist the DSPDI in achieving the above mission and our entire team will double its efforts in all areas identified in the Benchmarks and the JCAP to help the DSPDI reach higher compliance levels in a continuous manner. The ID/DD population in Puerto Rico deserves no less.



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## II. Executive Summary

After concluding the totality of our assessment derived from the Benchmarks, the JCC finds that the Commonwealth has evidenced important improvements in compliance levels in contrast to the JCC's previous semi-annual Report. The JCC highlights that the Commonwealth's current administration has shown significant progress in numerous areas, including a very positive shift in working with the Consent Decree and its effort to collaborate with the JCC and USDOJ.

During this six-month time period, the new administration has been familiarizing itself with general program operations and practices, identifying areas needing a complete overhaul, and developing comprehensive plans to address areas that were patently deficient. In addition to the above, the extraordinary circumstances associated with the COVID-19 pandemic, as well as with recent upticks in community transmission rates, adversely impacted Commonwealth efforts to remediate many areas of the Benchmarks, especially those related to day programs and employment. Therefore, more significant progress in reform implementation is to be expected during the next six-month timeframe, which should be reflected in the undersigned's next report.

**The JCC must commend the Secretary of Health, Hon. Carlos Mellado, and his team for its commitment to finding solutions that are necessary to strengthen the well-being of all participants and individuals with ID/DD that reside in Puerto Rico. The improvements that are reflected in the present Report and the Benchmarks illustrate the positive path that is being followed since the new administration assumed their duties.**

For the present assessment (in contrast with the JCC's previous Reports), the JCC opted to provide an in-depth analysis only for Benchmarks that consist of outcome measures (which require further monitoring and input from clinical experts) and provide only general compliance conclusions regarding those Benchmarks that consist of non-outcome measures (such as preparing and providing updated lists, etc.).

The following sections provide an assessment as to the Commonwealth's compliance with respect to each area of the JCAP and the JCC team and party-experts' recommended action plans.

### **A. Community Placement from Institutions (Benchmarks 4-12)**

The Commonwealth needs to make it a priority in the next six months to develop and implement plans to transition all appropriate participants out of the two remaining private institutions, IPPR and Shalom, and place them in integrated community settings. The Commonwealth needs to ensure that prior to transition, each institutionalized participant is provided with individualized and effective transition planning with a written Individualized Transition Plan ("ITP") based on person-centered planning principles, and to ensure that each transition is performed consistent with each participant's ITP.

The DSPDI has made progress in working to complete ITPs for all participants currently residing in an institution. However, as noted in the JCC Report, there is no space in existing community residences to transition participants out of institutions. In addition, current community residential options are not



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sufficient to meet the needs of participants with complex medical and/or behavioral needs of some participants currently residing in institutions.

It is also important that the DSPDI carry out efforts to move people out of temporary residential services through the Department of Family Affairs or ASSMCA (including institutional-like settings) to improved community-based residential options. For participants whose guardians and family members are resistant to allowing participants to move out of institutions, the undersigned once again strongly recommends that the DSPDI continue to have individual meetings with guardians and family members to hear their concerns and their geographic location needs. DSPDI should ensure that there is a robust exchange of information with the guardians/families about other, possibly new, service options and to properly and effectively explain the JCAP mandates. The DSPDI needs to be more proactive in complying with Sections III-1 (B) and (C) of the JCAP to convince parents and family members of participants residing in institutions of the benefits of integrating participants in community settings. The Office of the JCC has always been willing to assist them in reaching compliance in such important endeavor.

**B. Provider Capacity Expansion in the Community (Benchmarks 13- 16)**

In order to accomplish the transfers from the private institutions and to eliminate overcrowding in existing community residences, the Commonwealth needs to engage with new community providers, find appropriate homes in integrated community settings, and then move participants to those settings.

To help facilitate the transfer and ongoing support of participants with intensive service needs, the JCC also recommends that the Commonwealth create an enhanced or updated rate tier to provide sufficient resources to support new residential service models that would guarantee specialized expertise, such as nursing or skilled behavioral supports in the community, which demand a higher rate of compensation. The current reimbursement study does not include any tiered reimbursement structure to incentivize providers towards offering alternative service models. In addition, minimizing staff turnover rates should be an ever-present objective of the DSPDI. As we have seen during the last year, the loss of key personnel can lead to instability and traumatic events for participants, among other problems and challenges. The new budget grants the DSPDI a tremendous opportunity to create a stable environment for participants.

Furthermore, if the DSPDI does not address the current labor and inflationary challenges that are being confronted nationwide, the same may trigger a precarious situation that could lead to tremendous havoc, including the interruption of services in the program. Failure to address the above situation effective immediately may cause the nullification of the improvements that have been obtained consequent of the Burns study, particularly those that require specialized capacitation and skills. Although the JCC acknowledges that there are no clear solutions as to how to address the current inflationary challenges that lay ahead, the option of staying idle in the midst of such historical economic and labor market transformation should not be an option to the DSPDI, the Department of Health and the Commonwealth of Puerto Rico.



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The JCC is also looking forward to the Commonwealth offering specialized services in community homes which will assist participants with complex behavioral and health needs who require more intensive services, as well as the development and expansion of evidence-based services to provide respite for families and caregivers of those with complex needs, the implementation of new and better approaches to address dual diagnosis challenges, and medication tapering, which are all consistent with the directives of the Court<sup>16</sup>.

**C. Integrated Employment and Day Activities (Benchmarks 17-39)**

The DSPDI continues to identify the majority of its program participants (604 out of 624) to be “unemployable” or “incapable of employment”, when in reality, a vast number of participants are able to engage in some form of work-related activities.

However, the Commonwealth’s current provider models do not offer flexible staffing or the necessary infrastructure to adequately support participants with ID/DD in engaging in competitive integrated employment or other community-based activities. To achieve a sufficient level of competency among the system’s various professionals and provider systems to carry out models that will help the DSPDI better achieve the expectations related to employment and community integration, the DSPDI should engage with one or more entities with demonstrated subject matter expertise and cultural competency to help design, develop, and implement comprehensive training, provider transformation, professional development, and ongoing technical assistance. Maintaining the current assessment and approach towards employment opportunities for participants will not advance the Commonwealth towards compliance with the JCAP.

The DSPDI should implement meaningful reforms to improve its current day and employment support models, since participants need access to more consistent, community-based day programming that aligns with their support and development goals. The above strategies should include bringing in new community-integrated service models, retraining all CTS and ASCERV providers, and changing the employment model for vocational staff away from 30-day contracts.

**D. Safety and Restraint Issues (Benchmarks 40-52)**

The DSPDI should require providers to be trained in behavioral support and crisis intervention. The DSPDI should also recruit behavioral specialists to consult with providers on participants with challenging behavioral conditions, particularly as efforts move forward to lower the sedation levels of participants through reductions in psychotropic medications.

The DSPDI should also do more to monitor critical incidents, ensure listed corrective actions are appropriate, adequate, and implemented, and conduct investigations of omissions of care, improper use of restraints or physical interventions, among others, with the corresponding clearly established corrective actions.

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<sup>16</sup> See Docket No. 3499.



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**E. Health and Mental Healthcare (Benchmarks 53-99)**

The DSPDI should improve the quality of the information it gathers about participants' medical, behavioral, and other service needs, critical incidents, and other information monitoring the DSPDI's activities. In addition, DSPDI should address how it is monitoring and managing the health of participants, including access to regular and preventive care, management of high-risk medical conditions, and treatment of emergent medical issues, and changing medical needs. Substantial work is needed to expeditiously address the high levels of polypharmacy practices that have been observed and documented, particularly psychotropic polypharmacy, high risk medication combinations, and outdated first-generation medications all of which pose real dangers to the health and well-being of a substantial percentage of participants. The JCC understands the challenges that lay ahead in this particular area, but the matter and problem must be addressed immediately.

The DSPDI should also ensure that participants have access to qualified clinicians and should look at alternative models such as building/contracting expertise, including neurologists, since many participants with seizure disorders and/or who are on medications for neurological conditions, are not currently treated by a neurologist.

**F. System-wide Reforms (Benchmarks 100-106)**

As for the System-wide Reforms, the DSPDI has partially completed *the Person-Centered Plans* in the platform; it is using the vocational area platform in Therap's Employment History section; many ITPs for participants in institutions have been documented; there is greater documentation of case notes, interventions and services offered by the Interdisciplinary Teams of the CTS; and there is an increase in documentation of incident reports and "T-logs". The DSPDI still has numerous challenges to overcome in order to achieve full implementation. Nevertheless, it is important to recognize these important efforts and improvements.

The DSPDI should continue providing staff training and coaching on person-centered planning<sup>17</sup> and ensure that services are always planned in a person-centered manner with input from the participants and their chosen supporters, and that the services delivered are always person-centered in practice and not in theory. DSPDI staff needs further training in how to include the participants in the planning process, particularly those with communication difficulties. The provision of technical assistance through the National Center for the Advancement of Person-Centered Planning & Systems (NCAPPS) should help DSPDI design a comprehensive reframing and training initiative to assure person-centered planning is implemented with fidelity in the future.

There has been a significant reduction in the number of pending mortality reports from the Mortality Review Committee ("MRC"), as well as a significant improvement in the time it takes the MRC to

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<sup>17</sup> See Docket No. 3510.



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produce new reports when participants pass away. The MRC is now generating timely, actionable reports that provide important recommendations for improvement of DSPDI services. Notwithstanding the above, the MRC Chairwoman's remedial recommendations are still not being implemented by the DSPDI as mandated by the JCAP and the MRC is still not producing all mortality reports within the 30-day timeframe mandated by the JCAP.

### Conclusion

The JCC recognizes and commends the Commonwealth's efforts to work in a collaborative and effective manner with USDOJ, and the Office of the JCC; this positive posture has started to produce quantifiable progress and consequently, the undersigned expects that the current compliance level will significantly increase once the multiple action plans that are currently being developed by the DSPDI are finally and effectively implemented. The undersigned expects that the above favorable results should be reflected in our ensuing semi-annual reports.

The JCC also recognizes that in addition to the multiple challenges the new administration inherited, the ongoing COVID-19 pandemic has impeded the DSPDI's ability to make progress in key areas of the Benchmarks, especially those regarding employment and daytime activities. As the impact of the pandemic subsides, we expect to see even higher compliance levels.

As mentioned in the previous Report, the JCC looks forward to continuing to work with the DSPDI in the collaborative manner that has prevailed since the new administration assumed its duties in January 2021. The JCC is hopeful that the Commonwealth can achieve significantly higher compliance levels (and ultimately, as previously mentioned, sustainable compliance) if the current efforts continue with full deliberate speed and if the Division further strengthens its collaboration efforts with the JCC, USDOJ, and with the party-experts, such as including the JCC in meetings with family members of institutionalized participants, as well as in the corresponding visits, meetings to discuss important matters related to JCAP mandates, among others. The JCC and our team of experts will increase our efforts to assist the DSPDI in reaching higher overall compliance levels. Compliance will ultimately benefit the entire ID/DD population in the Island<sup>18</sup> by furnishing all participants the opportunity to live meaningful and productive lives to the utmost of every participant's unique talent, capacities, and individual aspirations within each individual's respective community.

### **III. Ratings of Compliance with Specific Provisions of the Agreement**

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<sup>18</sup> Although the DSPDI has passed an important curve and is headed in the right direction, the JCC is compelled to mention that the DSPDI has abandoned the collaborative agreements with the Department of Education and Family Affairs (which were effected through the intervention of the Court and the JCC). Unfortunately, this represents a step back from where we were. The JCC recommends that the Commonwealth reengage with DEFA and re-enter into the prior collaborative agreements immediately. The JCC has brought this to the attention of the Division on a number of occasions and will continue to do so until this is completed.





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**Benchmark 1 – “Translate this benchmark document, as well as any updated versions, into Spanish”**

- The Office of the JCC believes that a translation has been completed and that it is accurate.

**Benchmark 2 – “Disseminate both the English and Spanish versions of these benchmarks to all pertinent personnel”**

- The DSPDI provided a copy of an email communication from the DSPDI Director dated June 28, 2021, as evidence of the delivery of the Spanish translation of the benchmarks to relevant personnel. Going forward, the DSPDI should also provide a list of the classification of the key personnel that should have this document. For example, CTS Directors, CEEC members, and clinical staff.
- The JCC recommends that the DSPDI set forth a process to ensure that said document is furnished to new personnel as needed going forward.

**Benchmark 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”**

- Current List – June 30, 2021
- The Office of the JCC believes the list to be accurate.
- Total Census – 641 participants

Home Classification	No. of Participants	%
Biological Homes	209	33%
Group Homes (Puerto Rico and Florida)	284	44%
Substitute Homes	48	7%
Institutions	98	15%
Independent Living	2	.03%
<b>Total</b>	<b>641</b>	<b>100%</b>

**III.1. Community Placement from Institutions**

**Benchmark 4 – “From the Master List, create a sub-list of all participants who live in an institution (e.g., IP, FMG, Shalom)”**

- Current List – June 30, 2021.



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- The Office of the JCC believes the list to be accurate as it pertains to the DSPDI private institutions of Shalom and *Instituto Psicopedagógico de Puerto Rico* (“IPPR”). Said report shows a total of 83 participants living in private institutions distributed as follows:
  - o Shalom Progressive Institutions (Shalom)- 45
  - o The Psicopedagógico Institute of Puerto Rico (IPPR)- 38. The Office of the JCC noted that Benchmark 3 shows 83 participants living in Shalom and IPPR, while the DSPDI’s report for the current benchmark shows 84. The difference is due to the transfer of Participant #362 from IPPR to Psicopedagógico 2 Community Home, which took place on May 28, 2021.
  
- However, per JCAP standards, there are other institutionalized settings<sup>19</sup> where DSPDI participants reside which are not taken into consideration in this sub-list. Some of these are: Cidra Nursing Home (ASSMCA, participant RLH 1105), Dulce Vida Home in Aibonito (Dept. of Family home, participant CVC 741), Edahir Nursing Home in Moca (Dept. of Family home, participant ANN 346 and ANN 354), Esperanza, Amor y Vida in Bayamón (ASSMCA home, participant IBC 1038), Flores Home in Vega Alta Hope (Dept. of Family home, participant SSM 1113), Juanita III. Martinez Home, Inc. in Arecibo (Dept. of Family nursing home, participant EMF 1063), My New Family (Dept. of Family home, participant JHP 1124), Ramaya Home in Río Grande (ASSMCA home, participant KRP 1121), Ramón Fernández Marina Psychiatric Hospital (ASSMCA, participants ARG 1060, MRA 1093, ELR 1104, AIM 1114, and JHV 1136), and San Gabriel Group Home in Trujillo Alto (ASSMCA home, participant AOD 170). Based on the Participant Master List in Benchmark three, there are a total of 15 participants living institution-like homes for a total of 98 participants as detailed below.
  
- Institutions Census: 98
  
- Distribution of participants by institutions:

Home Classification	No. of Participants as of June 30, 2021	%
IPPR	38	38%
Shalom	45	45%
Other: ASSMCA, Dept. of Family and Psychiatry Hospital	15	8%
<b>Total</b>	<b>98</b>	<b>100%</b>

- As of June 30, 2021, out of the 641 participants receiving services from the DSPDI, 15% are in institutions.

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<sup>19</sup> Overcrowded community homes should also be considered as unacceptable institution-like settings. We have refrained from including them as such in the present Report because the JCC expects that the current unacceptable situation will be resolved by the next two or three semi-annual JCC Reports.



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**Benchmark 5 – “Issue a policy directive that all institutionalized participants can live in the community with adequate supports/services” (JCAP III.1.A)**

- The DSPDI provided a copy of electronic communications dated February 12, 2021, to the management of Shalom and IPPR.
- There is no evidence that policy directives were shared with the other 10 institutions mentioned in Benchmark 4 or with the parents of participants living in institutions. The Office of the JCC recommends that said directives be included on the DSPDI website.

**Benchmark 6 – “Develop a written individualized community transition plan for each participant in an institution using person-centered planning techniques” (JCAP III.1.A, E)**

- The DSPDI reports that 84 participants within the total institutional census of 98 (45 in Shalom + 38 IPPR + 15 Other) have current Individualized Transition Plans (“ITP”)/Phase I).
- The JCC staff reviewed a sample of 12% (10 ITPs) of the 84 ITPs listed by the DSPDI and found the following:
  - o Some of the ITPs have not been uploaded to the Therap Services® platform (“Therap”);
  - o JCC staff could not determine whether the ITPs were consistent with the person-centered plan (PCP). ITPs must be re-reviewed once the DSPDI makes the necessary changes to its person-centered planning process to align with evidence-based practices;
  - o Some of the family members could not be found by the DSPDI thus ITPs were completed without their input; and
  - o Upon further investigation, the JCC found that up to June 30, 2021, a total of 218 ITPs have been recorded in Therap, which includes six of the 15 additional participants living in institutions referred to in Benchmark 4.

Under the current administration, the DSPDI has made good progress trying to complete ITPs for all participants currently residing in an institution; DSPDI simply needs to complete the job for those institutionalized participants outside of IPPR and Shalom.

The DSPDI’s CITE is a subgroup charged with formulating person-centered transition plans and overseeing the implementation of such plans to ensure the successful transitioning of participants from institutions to the community. The CITE should ensure that all ITPs incorporate the participant’s needs and preferences with regard to geographic location and all other aspects that come out of a person-centered planning process. ITPs must be completed with input from the participant and their chosen support team; plans must not be completed solely based on the review and input of DSPDI and institutional staff. The DSPDI should also ensure that participants and their families are aware of the JCAP and the pursuit of community-based living options for participants as a Division priority, including the move away from the use of institutional settings.



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**Benchmark 7 – “For each participant, identify and document in the transition plan the individual and systemic obstacles to community placement from the institution” (JCAP III.1.B)**

- As set out in Benchmark 6, the DSPDI listed 84 ITPs for participants living in institutions. Of the 12% sample reviewed by the Office of the JCC, the following are examples of the obstacles that were identified by the DSPDI in the participant’s ITP:
  - o Participant is used to living in the institution and does not easily adapt to change (based on information provided by family member or guardian);
  - o The DSPDI has not been able to contact family member or guardian. No information was provided as to the steps being taken by the DSPDI to reach/find family member; and
  - o There is no home available that can manage the participant’s health needs. Although the JCC is aware that DSPDI plans to provide more specialized health services, no detailed information has been provided in the ITPs.

The JCC notes that these obstacles can be overcome – participants can and will adapt to the community, lack of active family participation is not a barrier to transition, and specialized services are being developed to address individualized needs.

- There is no evidence of an analysis of the identified barriers or an effective action plan on how to overcome them. Although the list presented has identified the type of homes required by each participant, there is no concrete plan or timetable for when the different home modalities will be opened and the geographical areas in Puerto Rico where they will be located, notwithstanding the fact that the DSPDI’s budget has significantly increased during the last years. DSPDI must take prompt and meaningful steps to identify and overcome barriers to community placement.

**Benchmark 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” (JCAP III.1.C)**

- As set out in Benchmark 6, the DSPDI listed 84 ITPs for participants living in institutions. There are 41 families who are opposed to community placement.
- There were 82 families, equivalent to 97% that refused the initial orientation for the relocation of their relatives to community-based homes. Although the DSPDI has designed a document titled “CERTIFICATION OF VISIT TO FACILITIES OF A COMMUNITY HOME,” there is no concrete analysis, plan, or guide to address the concerns or overcome the objections presented by families or guardians individually.
- As stated in Benchmark 7, there are family members that the DSPDI has not been able to reach. There is no concrete plan on how to find and contact these individuals.



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**Benchmark 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” (JCAP III.1.C)**

- The Commonwealth did not provide a list of meetings with family members/guardians who are opposed to community placement, and did not provide details on the educational process, or whether the Commonwealth offered viable community residential options to them.
- The home models identified by the DSPDI as the types of homes necessary for the community placement of participants living in institutions are not yet available (for example homes with more specialized health services).

**Benchmark 10 – “Take the opposed families/guardians on tours of prospective, successful community residences” (JCAP III.1.C)**

- Of the 41 families opposed to relocation, the families of nine participants were taken on tours during the months of May and June 2021. The community homes visited were (1) Psiopedagógico of PR Group Home I (located in the municipality of Bayamón), (2) Substitute Home Ziomara Flores (located in the municipality of Río Grande), and (3) Substitute Home Héctor Cardona (located in the municipality of Aguas Buenas). This represents a total of 22% of the opposed families/guardians of participants living in institutions per Benchmark 4. However, it was noted that the homes that were toured are not consistent with the ITP and the participants’ individualized needs.

**Benchmark 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” (JCAP III.1.B)**

Under the previous administration, the Commonwealth’s hasty closure of Fundación Modesto Gotay (“FMG”) in August 2020, was alarming and posed a high risk to the transferred participants.<sup>20</sup> Many participants did not have any formal transition plans established or approved, and participants were transported suddenly without notification to their guardians, the JCC, or the Court, without their personal items (including medication, assistive equipment and clothing), and taken to homes where providers knew little about the participants and their support needs. This move was traumatic for participants, and, unfortunately, multiple participants died shortly after their transfer. The Court issued a subsequent order that stated that no participant shall be transferred from any institution without complying with the ITP and other mandates of the JCAP and without the Court’s prior approval after receiving the parties’ respective or joint positions and the JCC’s report and recommendations.<sup>21</sup>

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<sup>20</sup> See Docket No. 3477.

<sup>21</sup> See Docket No. 3263.



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For participants with guardians and family members that are resistant to them moving out of institutions, which appears to be the case for a very substantial number of participants residing in institutions, the DSPDI should continue to have individual meetings (to discuss one participant at a time) to hear the family's concerns, including their geographic location needs, and to ensure that DSPDI fully educates them about the benefits of community living, including new specialized community service options that have just been developed. Discussions with guardians/families likely will not progress until the Commonwealth develops new community options to address their concerns.

Currently, there is no space in existing community residences to transition people out of institutions, and current community residential options do not meet the complex medical and/or behavioral needs of some participants that are currently residing in institutions. The DSPDI has plans to expand its community-based residential capacity and service offerings (see section III.2); it is important that progress is made in these areas to mitigate a major obstacle for de-institutionalization of the remaining DSPDI participants living in institutional settings. Determination of new community home locations should be based primarily on proximal access to community resources, e.g., family and community providers, for each participant residing in the home. Roommate matching should also be based on peer-to-peer rapport.

Among its residential capacity-building initiatives, it is important that the DSPDI include efforts to move people out of temporary residential services through the Department of Family Affairs or ASSMCA (including institutional-like settings of ~23 people per site)<sup>22</sup> to improved community-based residential options. About 15 DSPDI participants currently reside in inappropriate congregate settings. In addition to being suboptimal settings for people with ID/DD to live, the providers of these facilities appear to be unaware of the DSPDI policies and procedures and this presents an increased risk to the participants' welfare. Additionally, although these were designed as temporary placements, participants tend to remain in them longer term in practice. The DSPDI should review its progress in opening new locations this year, identify sources of delays, and implement strategies to avoid these delays and expedite the process of opening new community homes. The Office of the JCC expects that new community homes will be opened by June 30, 2022, following the above recommendations and accepted community placement practices.

**Benchmark 12 – “Monitor all participants placed in the community to ensure they receive all the necessary protections, supports, and services to meet their individualized needs in community settings” (JCAP III.1.E)**

- Compliance with this benchmark is to be determined after a more comprehensive review.

### III.2 Provider Capacity Expansion in the Community

#### General Remarks:

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<sup>22</sup> This based on Office of the JCC visit to Flores home on June 7, 2021.



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Before contracting with providers again, the DSPDI should re-examine their rate structure related to the provision of services for participants with complex conditions. The existing rates do not provide any structure to support new residential service models that would provide specialized expertise such as nursing or skilled behavioral supports in the community. The current Burns & Associates reimbursement study establishes a stronger baseline payment structure to stabilize current residential and CTS providers. The study does not, however, include any tiered reimbursement structure to incentivize providers towards offering alternative models for receiving services (for example, to live in one's own home or apartment with roommates selected by the individual, or to allow someone to work and engage in daily activities in typical community settings).

The DSPDI should review the assumptions in its rate structure prior to issuing the next contracts for FY23 and at least every few years thereafter. Revisiting the rate structure as recommended in this Report is consistent with the "refresh" principle that Burns & Associates supports and recommends.

**Benchmark 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"**

- Current List – June 30, 2021
- The Office of the JCC believes the list to be accurate.
- Total Census – 332 participants

Home Classification	No. of Homes	No. of Participants	%
Group Homes (Puerto Rico and Florida)	44	284	86%
Substitute Homes	20	48	14%
<b>Total</b>	<b>64</b>	<b>332</b>	<b>100%</b>

- Although not identified in the Report, there are two participants living independently.

**Benchmark 14 – "Develop a system wide plan to increase the number of community residential providers to meet participants' individualized needs". (JCAP III.2)**

- Pursuant to filings with the Court pertaining to the Budget for FY22<sup>23</sup> and per discussions in the monthly meetings with the Office of the JCC, the Commonwealth has pledged to:

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<sup>23</sup> See Dockets No. 3697 and 3490.



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- Implement the Burns and Associates, Inc. provider rate study recommendations to increase the rate paid per participant. New rates were implemented in contracts for FY22.
  - Use part of the rollover funds to open at least 12 new community homes within the next calendar year to accommodate the transfer of participants currently residing in institutions and to eliminate the overcrowding in existing community homes. The Office of the JCC anticipates that the Commonwealth will need to open at least an additional eight new homes to accomplish the above objective. The existing DSPDI budget will allow said opening from a fiscal perspective.
- To facilitate compliance with Benchmark 6, the DSPDI created a Community Homes Guideline detailing eight different types of community homes that are or may become available; these are (i) biological home, (ii) home for independent living, (iii) substitute transitional home, (iv) substitute community home (one to three participants), (v) group community home (four to six participants), (vi) Senior Homes (a look from the gerontological perspective), (vii) nursing/health homes and (viii) specialized homes for dual diagnoses and/or mental health similar to Casa Elvira. Although the previous administration prepared a plan, the current administration has yet to issue a concrete plan on the types of homes it will support in its system, the timeline for opening the new homes, locality based on needs, and prospective providers, among others.
  - Homes opened from January 1, 2021, to June 30, 2021:

Name of Home	Date Opened	Type of Home	No. of beds opened
Shalom Adonai (Aguadilla)	03/18/2021	Group	6
Substitute Home Alberto Pérez (Aguadilla)	05/27/2021	Substitute	3
Substitute Home Teresa I. Vazquez (Barranquitas)*	06/30/2021	Substitute	3
<b>Total spaces created</b>			<b>12</b>
Substitute Home Frank R. Santiago (Coamo)	Expected to Open on Sept 2021	Substitute	<b>3</b>

\* Home "opened" on June 30<sup>th</sup>, but as of that date, no participants had been placed in the home.

- Homes closed from January 1, 2021, to June 30, 2021:

Name of Home	Date Closed	Type of Home	No. of beds eliminated
Substitute Home Rubén Alvarado	01/22/2021	Substitute	1
Substitute Home Eric Rios	03/31/2021	Substitute	1





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Casa de Amor (Converted to Substitute Home Idaliz Cintrón)	05/26/2021	Group	3
<b>Total</b>			5

- Comparison of available community homes:

Type of Home	As of 6/30/2021	As of 12/31/2020
Group Homes	44	44
Substitute Homes	20	18
<b>Total</b>	<b>64</b>	<b>62<sup>24</sup></b>

\*Does not include Substitute Home Teresa I. Vazquez, “opened” on June 30, 2021, but not serving any participants.

**Benchmark 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 (JCAP III.2); each participant shall have a private or semi-private bedroom”**

- As set out in Benchmark 13, there are 64 community homes (44 group homes and 20 substitute home). Based on the Office of the JCC’s analysis, there are 15 group homes with more than six participants (13 homes with seven participants; two homes with eight participants) representing 23% overcrowding. It is generally understood that there should be no more than four participants in group homes and no more than one participant in substitute homes in order to meet individualized needs per JCAP criteria. Currently though, the DSPDI is supporting and plans to open group homes with six participants and substitute homes with three participants.
- As of June 30, 2021, the following homes were overcrowded per the Commonwealth’s current criteria:

	Name of Home	Municipality	No. of Participants	Over
1	El Olám II	Aguadilla	7	1
2	Nueva Vida	Corozal	7	1
3	Hacienda Isaí	Manatí	7	1
4	Erikmar	Dorado	7	1
5	Luz Divina Mia I	Coamo	7	1
6	Jehovah Yireh I	Toa Alta	8	2
7	Abimar Inc. I	Vega Alta	7	1

<sup>24</sup> This is only a very slight improvement from 2020, with only a net gain so far of seven beds.



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8	Mekaddesh I	Moca	7	1
9	Dulce Amanecer II	Corozal	7	1
10	Kairo	Vega Baja	7	1
11	Pacto de Amor	Aguadilla	7	1
12	Janick	Morovis	7	1
13	Nueva Esperanza	Aguadilla	7	1
14	Abimar II	Vega Alta	7	1
15	Rayo de Luz	Vega Baja	8	2
<b>Total Community Homes with Overcrowding: 15</b>				<b>17</b>

- Too many of the 65 DSPDI-contracted community homes are overcrowded institution-like settings with more than six participants per group home. As of June 2021, 13 group homes have seven residents, and two group homes currently have eight participants. There are no longer any substitute homes serving more than three participants. The DSPDI also reported that all participants living in overcrowded settings (group homes with more than six residents) have had phase 1 of the ITPs completed, and they reported outreach to families. Similar to the ITPs completed for participants residing in institutions, it is essential that these plans come out of a person-centered planning process that includes participation from the participant and their chosen supporters (family, guardians, friends, etc.).
- All efforts should be made to ensure that participants coming out of institutions are not placed in overcrowded homes or in other institution-like settings, e.g., long-term care facilities administered by other state agencies, i.e., ASSMCA. If placements do not take place due to inadequate or inconveniently located living options, then institutionalized participants are placed on a waiting list until a placement match has been made. The time spent on the waiting list is undetermined, but proper placement should be finalized in a short period of time.
- Based on the number of participants living in institutions (83 participants) and institution-like settings (15 participants), the number in overcrowded homes (17 participants), and the participants on the waitlist (26 participants), it is evident that opening 12 new homes will not be sufficient to address the unmet needs of the participants of the DSPDI. Hence, the undersigned recommends that at least 20 new community homes should be opened by the end of the current fiscal year.

**Opening of New Homes:**

The DSPDI has reported that contracts are underway to open 12 new group homes in FY22, with a likely bed total of 72. As referenced in Benchmark 14, the DSPDI reported that in 2021, as of June 2021; three new homes were opened, two homes were closed, one group home was changed to a substitute home, and one additional home is scheduled to open. As a result of all this, there was a very modest net gain of seven community beds. In addition, the DSPDI reported that IPPR plans to open seven new community homes. DSPDI should carefully monitor the IPPR transition planning, the settings of the new



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IPPR homes, and the services delivered to these homes, to ensure that they do not replicate institutional-like environments either physically and/or in practice, characterized by a low level of active engagement of participants, universal locking of access to personal possessions, lack of privacy, etc., which is currently experienced by IPPR residents.

The Commonwealth provided no written plans or policies on which participants within existing overcrowded DSPDI-contracted community homes were going to be selected to reside in these newly established homes, or how these placement decisions would be ultimately made. The Commonwealth's information on the 12 new homes did not indicate whether these homes were intended for participants currently living in overcrowded community homes, in institutions, or for individuals who have been determined as being eligible for DSPDI services but are currently on the 'waiting list'.

While there has been some progress in this area, it is important for the DSPDI to fast-track the opening of new, high-quality community-based residential service settings that address the needs of the participants. Between people living in institutions, in over-crowded group homes, in temporary residential services through ASSMCA (as referenced elsewhere in this report), and those on the existing waitlist, there are multiple groups of participants with time-sensitive needs to move to a proper community living unit. It is important that the DSPDI have an effective process now to meet the need to urgently move these participants to the community, and align their person-centered service needs with what the living units will provide (services, clinical supports, location, etc.).

This individualized tailoring process is important to ensure a good and appropriate fit for participants who move. The DSPDI should consider issuing an RFP to contract with an organization with expertise in (a) effectively transitioning individuals with ID/DD into their own homes in the community; and (b) providing residential supports and community-based supports to help individuals with complex conditions in need of intensive services and supports to live, work and thrive in the community. The contract could help facilitate a pilot of a segment of individuals who are, for example, on the waitlist for community services or individuals in overcrowded homes to transition into individualized supported living services, as part of a 3–5-year demonstration. A successful demonstration could then help to create a more permanent supported living service model for DSPDI to embed into its service offerings in the future.

**Benchmark 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” (JCAP III.2)**

Compliance with this benchmark is to be determined after a more comprehensive review and as reforms are implemented.

In monthly meetings with the Office of the JCC and in other talks, the DSPDI discussed its intention to create or enhance specialized medical or behavioral services in community homes. This is an important development in meeting the needs of participants with complex conditions who cannot be served well



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given the current limited array of community settings within the DSPDI service system. It will be critically important that the direct support staff working in community settings with these participants receive specialized training in supporting people with complex medical and behavioral needs, respectively. Currently, for example, there is no evidence of the use of a crisis management and behavioral supports curriculum for staff supporting people with complex behavioral needs; this training and the associated use of safe strategies for positive behavioral supports is critical to the success of this new service model. Community-based services for people with complex needs should include regular assessment and care from nurses and other professionals in alignment with each individual's care needs.

The DSPDI provided an Evaluation Tool for the Monitoring of Group Homes. No details were provided on how this tool is administered or utilized for quality purposes. The DSPDI should ensure that the staff has clear guidance on the frequency with which the tool should be used, whether the evaluations are to be performed unannounced, how they will apply to the different proposed home modalities, and how the results should be communicated and used. Staff should have a clear understanding of how to respond to issues identified during the evaluation, whether this is through verbal or written feedback, a corrective action plan process, etc. Findings from the evaluations and subsequent follow-up should be documented electronically, and the DSPDI should follow-up with group homes to ensure any identified issues are properly addressed.

The DSPDI provided an Assistive Technology Request Chart. The DSPDI should modify this chart so that it also includes fields reflective of request dates and completion request dates. This will help track the time it takes to fulfill more complex/more expensive requests versus simpler ones such as requesting a digital 'smart' alarm clock.

During JCC consultant Dr. Serena Lowe's 2021 onsite visit to several group/community homes, several concerns were noted. First, most individuals appeared to have non-COVID-19 restrictions in terms of where they spent their time (i.e., not being allowed to be in their bedroom during the day), when and what they could eat, what they could do, and where they could go. There were no structured activities for anyone that was not employed in competitive integrated employment ("CIE") or participating in a CTS day program. There were no locks on bathrooms or bedrooms, and thus no privacy allowed to the individual participants. Ironically, however, there were locks on cupboards, closets, and refrigerators, restricting participants' access to food, clothing, and other household items. They were not allowed to have visitors, and when families came to visit, they could only meet in the common living area.

While the homes typically had 1-2 vehicles to transport people, there were no planned activities other than weekly shopping trips and outings less than once per month (even prior to COVID-19). The Commonwealth should strive to provide community services in settings that are integrated in and support full access to the greater community; are selected by the individual from among setting options; ensure individual rights of privacy, dignity and respect, and freedom from coercion and restraint; optimize autonomy and independence in making life choices; and facilitate choice regarding services and who provides them. Each participant should have privacy in their unit including lockable doors, choice of roommates and freedom to furnish or decorate the unit; control of his/her own schedule



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including access to food at any time; the ability to have visitors at any time; in a setting that is physically accessible. All of this is consistent with JCAP criteria.

### III.3 Integrated Employment and Day Activities

#### General Remarks:

The COVID-19 pandemic process has prompted changes in the labor market, generating new opportunities, as well as challenges. This requires a reevaluation of the services required by the population served in their employment evaluation, search, job placement or retention process, within the context of aspiring towards a more independent life.

Reintegration of participants into competitive integrated is one of the most significant challenges we face in the COVID era. Participants have endured a long period of more than 12 months without a job routine due to the COVID-19 pandemic. Challenges to obtaining or retaining employment include: maintaining skills, completion of essential tasks, implementing basic protection measures like requiring participants to use masks correctly, and solidifying ongoing family supports or other necessary resources.

Although the variability in the changed labor market has produced an increase in the availability of employment opportunities, the number of hours sought with pay increases throughout many sectors, the Commonwealth has made no concrete or significant progress to take advantage of these positive labor trends to identify new employment opportunities for participants, or to increase the number of hours employees are working, or to seek an increase in their hourly pay. It seems that more participants can work and that the small number of participants who are working are chronically underemployed.

These new labor trends could provide an opportunity to identify new employers and to negotiate better conditions of employment or payment. The DSPDI should view these factors and their management as a current and positive opportunity to address unemployment and under-employment concerns. When the strengths, resources, priorities, abilities, interests, functional capacity, and the informed selection of the participant allow it, a participant can obtain a competitive job and maybe even work at multiple jobs, thereby, increasing the possibility of achieving a more independent life. The current labor environment also presents a favorable opportunity to evaluate participants in real work scenarios, thereby, increasing the likelihood of them obtaining work in those settings.

#### Structural Challenges within the DSPDI that Limit Access to Employment Options for Participants:

It is disappointing that the DSPDI continues to identify the vast majority of its program participants (604 out of 624) to be "unemployable." Perhaps the most distressing finding is that the Commonwealth has designated a significant percentage of individual participants as "incapable of employment." It appears the system is designed to provide access and exposure to vocational skills building and potential employment opportunities only to a limited number of participants with the highest acuity, and even



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then, in very restricted situations (often in a segregated environment or in positions making below the minimum wage). The daily centers lack the knowledge or expertise in how to best support participants through evidence-based practices (i.e., discovery, customized employment, integrated work-based learning experiences, or individualized supported employment), and lack the experience in how to build strong relationships with local businesses in an effort to identify and develop jobs for participants.

Creating access for participants to pre-employment training services, work-based learning experiences, Discovery,<sup>25</sup> customized employment supports, individualized supported employment services, and support for self-employment, small business development or entrepreneurship are identified as areas critical to assuring that all participants are given adequate exposure and support to pursue and engage in competitive, integrated employment. Working together with other agencies, as the JCC has previously recommended, can increase the availability and opportunities for work-based learning experiences, employment, and the maximization of economic resources.

Said referrals require a follow-up of the observations made and close communication aimed at strengthening areas where improvement is needed and working together with the professionals and the respective areas that provide the services. A disproportion exists between available human resources and the participant at the day centers (CTS). By way of example, Ponce CTS has 4 job trainers and a job promoter, while Vega Baja CTS has only 2 job trainers and no promoter. Also, official, and adapted vehicles are essential for the effective delivery of employment services to participants, yet transportation issues are rife within DSPDI, thereby, impeding participant employee options. The current budget allows DSPDI to rectify its transportation issues.

In administrative terms, significant changes stand out, such as the integration and presence in the process of new human resources and the approval of the Manual of Standards and Procedures of the Vocational Rehabilitation Counseling Services Area ("ASCERV") in force from March 2021 to March 2023. Said manual sets general and specific objectives, description of services and human resources, norms, and procedures, as well as evaluation instruments. In addition, scientifically validated instruments have been acquired that allow to adequately complement the evaluation process. As a result, greater activity and integration of the procedures documented through Therap by the ASCERV team is observed in the area designated for said process. However, integration, evaluation and recording by all professional areas must still be reinforced from an integral perspective of the participant. Despite having inserted the PCP<sup>26</sup> into Therap, there is still opportunity to strengthen support between professional areas in search of the participant's objectives and not independent of the area they represent. In terms of training, professional training is still necessary for all.

We set out below some challenges, as well as potential alternatives, to better enable participants to lead a more independent life, do some work, and/or finding a job, consistent with JCAP criteria:

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<sup>25</sup> Discovery is the foundation of Customized Employment.

See <https://www.nationaldisabilityinstitute.org/employment/discovery-and-customized-employment/>

<sup>26</sup> The JCC recommends periodic seminars and/or workshops in order to ensure that PCP principles are always implemented and followed.



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- Availability of job coaches and job trainers consistent with the need for services: It is imperative that investments are made to hire and retain additional job coaches and trainers, including transitioning to a more stable contractual arrangement with these professionals, as opposed to the current 30-day contractual relationship which causes an environment of excessive and/or magnified instability, uncertainty, and fear.
- Provider transformation & professional development: Investments must be strategically made to provide vocational rehabilitation counselors, job developers, job coaches, and other professionals within the system with training and ongoing support, mentoring and coaching to assure they possess the competencies and autonomy to apply evidence-based strategies and services to support participants in pursuing, accessing, and sustaining competitive integrated employment. Additionally, a technical assistance center should be established, comprised of experienced subject matter experts who can provide ongoing support to providers and direct support professionals in the implementation of tested and validated models for supporting individuals with ID/DD in the generic workforce and typical community.
- Reevaluate assessments of unemployability among participants: As the Commonwealth expands the capacity and competency of its system to provide services utilizing evidence-based practices to support individuals in CIE, we suggest re-evaluating the findings of any assessment that led to a determination that a current participant is unemployable. This is consistent with JCAP criteria. Also, the Commonwealth should embed lessons learned from this reevaluation process into remedial strategies as part of the system's ongoing person-centered planning process reforms and enhancements. In addition, the DSPDI should investigate employment coalitions that support employment of people with disabilities and explore the Ticket-to-Work program.
- Increase opportunities for job advancement, increased hours of employment, and increased wages: Existing employment contracts should be reevaluated and re-assessed and possibly renegotiated to assure career advancement, increased hours, and increased wages or benefits to improve the individual's overall employment experience.
- Tasks not compatible due to current health conditions: We recommend performing new occupational tailoring to ensure current employment compatibility or to consider a change to an employment goal that is compatible with their current conditions.
- Transportation: Help identify alternative transportation strategies and potential funding to support participants' access to employment and other community-based activities.
- Family support: The Commonwealth should include or strengthen counseling services and better integrate the social work professional to support the participant's family. This is imperative to enable participants to lead a more independent life. DSPDI should consider reaching out to and partnering with Puerto Rico's Council on Developmental Disabilities and APIADI (Spanish



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acronym for the Association for the Inclusion of Adults with Intellectual Disability) to facilitate this.

The JCC recommends that the DSPDI work with the subject matter experts to develop and implement an *Employment First* systems change policy framework, and to enter into a technical assistance contract with an entity with experience in (a) providing customized and individualized employment services to individuals with I/DD; and (b) providing job development, coaching, and retention services using evidence-based practices.

The DSPDI should explore ways to improve the day and employment supports model. As the public health crisis allows, participants need access to more consistent (5-days/week) models, individualized community-based day programming based on the goals and support needs articulated in each individual's person-centered plan. The DSPDI should consider new models, such as provider-based day services, site-less day services, and more services that truly build vocational skill and potential in participants. The 'reopening' of day services provides an opportunity to reshape the prior insufficient, outdated, and isolating day service model of prior administrations. Additionally, as progress is made in de-institutionalization efforts, it is critical that these sites are not used to provide day programming or other services to participants living in the community.

**Benchmark 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”**

- Current List – June 30, 2021.
- The list furnished by the DSPDI is based on employment prior to the pandemic. It shows that, out of the 641 participants served by the DSPDI, 20 participants (3% of the total population served), had employment before the pandemic. However, as of June 2021, of those 20 participants “potentially employed”:
  - o Three participants are now actually working<sup>27</sup> (less than 1% of the 641)
  - o 17 participants are currently not working. 11 participants are expected to go back to work in the coming months or are continuing to negotiate employment contracts with the new company in charge of maintenance services for the DSPDI. This model, referred to as a “state-use model”, does not necessarily result in the intended outcome of competitive, integrated employment, often paying individuals below the minimum wage and segregating them from non-disabled workers. The remaining six participants continue in evaluation and/or negotiation with family members on the conditions for

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<sup>27</sup> The list furnished by the DSPDI represented that four participants are working, but upon further investigation by the Office of JCC, we discovered that as of June 30, 2021, participant AOR 972 was not working.





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their return to work. No concrete evidence was obtained about their status with their employer or employment agreements.

- This level of potential employment is substantially below Benchmark 29's target rate of 25%.
- Total Number of Participants working:

	Employed Participants	%
06/30/2021	3	Less than 1%
12/31/2020 (JCC March 2020 Report)	20*	3%
06/30/2019 (JCC Sept 2019 Report)	19	3%

"Potentially employed" is defined for purposes of this Report as participants that were previously employed, but since March 2020, were excused from work by their employers due to the pandemic.

- With regard to the hours worked and hourly wages, based on the list provided:

Hourly Wage	No. of Participants (Potentially Employed and Employed)	Comment regarding working hours
\$8.25/hour	2	One is currently working (16 hours a week with increase potential), and the other one is not currently working due to the pandemic (potential work of 12 hours).
\$5.00/hour	2	Hourly wage is below the current federal minimum. Although their weekly hours are 25, this is not consistent with the cost of living at the time. Neither participant is currently working due to the pandemic.
\$7.25/hour	16	16 participants have potential work at an hourly wage of \$7.25; only one is currently working for 20 hours a week.

- o For the three working participants:
  - CRA 411 is working for \$7.25 an hour and his weekly hours were reduced from 30 to six;
  - EB 425 is working for \$8.25 an hour, and weekly hours were increased from four hours to 16 hours a week; and
  - JEO 718 is working for \$7.25, 20 hours a week with potential for increase.



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- There is no evidence of our participants working 40 hours per week at the minimum wage or over. This presents an obstacle for those participants who possess the knowledge and skills for a totally independent life.

**Benchmark 18 – “For those working in the community, develop individualized action steps to ensure no one working in the community is underemployed” (JCAP III.3.A)**

The DSPDI still has a lot of work to do to address the needs of the participants who were working before the beginning of the COVID-19 pandemic. This was a missed opportunity by the DSPDI given the emphasis that the Office of the JCC has placed on participant employment, particularly after visiting the ID/DD programs in Seattle. Nevertheless, the Office of the JCC will work with the DSPDI to assist it in overcoming present challenges.

- The DSPDI issued an action plan for each of the 20 potentially employed participants (listed in the report for Benchmark 17). Each plan is broken down into three phases generally consisting of the following:
  - o Phase 1 – A counselor in Vocational Rehabilitation will conduct a home visit to interview and evaluate the participant and provide individual counseling and guidance. Out of the 20 potentially employed, 12 participants (representing 60%) are ‘partially’ in Phase 1;
  - o Phase 2 – A job promoter will visit each workplace to determine the necessary transition steps (such as development of skills) for the participant to return to work and will evaluate the number of hours available for the participant. Out of the 20 potentially employed, four participants (representing 25%) are ‘partially’ in Phase 2; and
  - o Phase 3 – The participant is reincorporated into the workplace. For participants already working, a job coach will continue to monitor and provide support. None of the 17 formerly employed participants are in Phase 3 of the action plan yet. As referenced, only three participants (representing 20%) are in Phase 3 (working participants).<sup>28</sup>
- The following needs have been identified:
  - o CTS Aguadilla: two participants require extensive and persistent support once they begin the intensive phase in their employment;
  - o CTS Bayamón: one participant requires limited to extensive support in the intensive phase;
  - o CTS Vega Baja: there is a need to recruit an employment trainer in the CTS of Vega Baja for participant LV; and

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<sup>28</sup> Although participant AOR 972 was identified as working in the report furnished by the DSPDI as employed, she was excluded since it was found that as of June 30, 2021, she had not been reincorporated into the workplace.



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- For 20% of the participants, there is no evidence of whether the potential for additional tasks have been explored or whether the participant has other interests.

Dr. Lowe met with two of the participants that have been in the same job (janitorial services) for over a decade, making subminimum wages and working an average 12 hours/week. Based on her visit and in-depth interviews/discussions with these participants, Dr. Lowe is confident that both individuals could be working at least 30 hours/week and in positions with more engaging work. Dr. Lowe also believes these individuals should be receiving a market wage reflecting what their non-disabled peers are making for similar work, and no less than the federal minimum wage.

**Benchmark 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)” (JCAP III.3.A, B)**

As of the last report provided by the DSPDI, 20 participants had been employed pre-pandemic; only three are currently working. All three are underemployed. All of these participants were categorized as ‘underemployed’ in the last report in March 2021, as well. Pre-pandemic, all but two of these participants were all reported to be making minimum wage; the remaining two were paid \$5/hour. Those participants employed prior to the pandemic were working between 6-20 hours. The majority was listed as desiring an increase in hours per week worked.

As referenced above, each of these participants has a documented action plan that is set in three phases. The report provides a status of each phase that the participant is currently in. Over 50% of these participants continue to be in Phase 1, which predominantly consists of a home visit by a rehab counselor to conduct interviews and screening. Other than the three who are working, no one is in Phase 3, which is when someone is working. It’s difficult to determine from the Commonwealth’s process and reporting the extent to which the 17 participants are under-employed. It appears that some have re-training needs and others have personal complications affecting their ability to work. Other additions to the ‘underemployed’ status report that would be helpful in evaluating the progress related to the action plan implementation include phase completion deadlines/timeframes and phase completion dates.

**Benchmark 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”**

- Current List – June 30, 2021.
- The Office of the JCC believes the list to be accurate.
- The DSPDI furnished a table that combined Benchmarks 20, 21, 24 and 25. The report lists a total of 640 participants (difference to Master List of 641 in Benchmark 3 is due to report not including participant MCC 151 who passed away in July 2, 2021). As it pertains to this



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benchmark, the furnished report identified 77 participants not working in the community but able to work (including the three working participants and 17 potentially employed participants indicated in Benchmark 17) the date of the most recent DSPDI assessment, date and author. However, it was noted by the Office of the JCC that the ID/DD level for some of the participants is not up to date. For example:

- Participant #505 ID/DD level listed in the report is “No ID/DD”. According to Dr. Margarida Julia’s report dated November 7, 2019, participant was diagnosed with an ID/DD level of “Mild”.
- Total Number of Participants working:

	July 2019 (JCC Report Sept. 2019)	December 2020 (JCC Report March 2021)	June 30, 2021 (JCC Report Sept 2021)
Employed Participants	19	4	3
Participants able to work but not working	9	22	74
Participants in Vocational Workshops (BM 25)	56	58	---
Self-Employed (BM 28)	16	15	---
Referrals to Voc. Rehabilitation Adm.	7	---	14
Participants classified as “unable to work” (BM 24)	514	490	510

--- Information not provided. In addition, there were 53 participants for which no assessment information was provided.

**Benchmark 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” (JCAP III.3.C)**

- During the height of community spread of COVID 19 in 2021, the DSPDI paused doing vocational assessments. The DSPDI reports that they have restarted employment evaluations for non-employed participants. According to data provided in June 2021, 58 participants had been re-evaluated for vocational potential. All but one of these participants was deemed not eligible for employment. The JCC is of the opinion that there is much room for improvement in this regard, thus it will redouble its efforts to assist the DSPDI in improving the same. In order to accomplish said goal, immediate effective attention and action plans of what the DSPDI and participants are actually able to accomplish as it relates to employment must be adopted as soon as possible.
- The DSPDI furnished a table that combined Benchmarks 20, 21, 24 and 25. As it pertains to this benchmark the report furnished shows that 58 of the 640 participants (9%) listed were re-assessed during April and June 2021. However, information as to the scientifically validated tools/tests used for evaluation was not provided.



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**Benchmark 22 – “Develop individualized, concrete action steps with timeframes to maximize their community employment” (JCAP III.3.C)**

- The DSPDI furnished a table that combined Benchmarks 22, 23, 26 and 27.
- A report detailing the actions plans for 53 participants (8% of the population) was presented by the DSPDI. Each of the 53 participants has a three-phase action plan that was prepared during March 2021 and June 2021. 51 of the 53 participants (94%) are listed as “partially phase 1” implementation. No deadlines or timeframes were set forth in the plan.
- The action plan is as follows:
  - o Phase 1 - Assessment, determination of employment and work potential and individualized planning. Rehabilitation Counselor will conduct interview, screening, evaluations and DCF-ET;
  - o Phase 2 - ASCRV services will be coordinated based on DCF-ET results; and
  - o Phase 3 - Reassessment and determination of services according to the results of the second phase.
- See Benchmark 27.

At a planning level, the JCC team of experts opines based on the information that was furnished, that the person-centered planning process currently does not reflect evidence-based practices based on exposure of the individual to options in the most integrated setting(s), supported-decision making, or a comprehensive process involving a diverse support team. Additionally, the current process combines functional assessment and level of need/eligibility determinations into person-centered planning instead of seeing these as three distinct components that should inform but not drive one another. Additionally, the current planning process does not expend a great deal of time talking to participants about the value of employment, entrepreneurship, or their career interests. In fact, the vast majority of individual participants are automatically deemed unemployable due to previous assessments using tools that lack a presumption of employability. Instead of presuming that all or the majority of individual participants can work and engage in CIE, the process incorrectly presumes that the vast majority of participants cannot work, even though they have never been given an opportunity to pursue work or vocational experience. Incorrect presumptions will only affect and/or impede the real job opportunities and self-employment opportunities that participants have, hence the continued assessment of non-compliance.

Further, at a systems and provider level, the current provider models do not yield flexible staffing or infrastructure to support participants with ID/DD in optimally engaging in competitive integrated employment or other community-based activities. Professionals engaged at various levels of supporting



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participants with ID/DD lack knowledge or experience in utilizing evidence-based strategies and practices to support people to pursue, attain or secure CIE; live at an optimal level of independence in typical homes, neighborhoods, and communities; and engage in meaningful interactions, relationships, and activities in the broader community with both disabled and non-disabled peers.

To achieve a sufficient level of competency among the system's various professionals and provider systems to carry out models that will help DSPDI better achieve the expectations related to employment and community integration. The JCC team of experts deems it imperative that the DSPDI utilize some of its funding set aside for implementation of the agreement to contract one or more entities with demonstrated subject matter expertise and cultural competency to help design, develop, and implement comprehensive training, provider transformation, professional development, and ongoing technical assistance. Once the above is properly implemented, the DSPDI can expect the results that they aspire to achieve. The JCC is certain that the above goal will be accomplished.

**Benchmark 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)” (JCAP III.3.D)**

- The DSPDI furnished a table that combined Benchmarks 22, 23, 26 and 27. See Benchmark 27

**Benchmark 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”**

- The DSPDI furnished a table that combined Benchmarks 20, 21, 24 and 25. As it pertains to this benchmark, the furnished list includes all 640 participants (the difference to the Participant Master List at Benchmark 3 is due to participant 151, who passed away on July 2, 2021, not being included).
- The list indicates that of the 640 participants served by the DSPDI, 621 are not employed (97%) of which 510 have been classified as not able to work in the community.

**Benchmark 25 – “Professionally assess or re-assess for community employment all of these other participants who are not currently working in the community” (JCAP III.3.C)**

- The DSPDI furnished a table that combined Benchmarks 20, 21, 24 and 25. According to said list, 587 participants have been evaluated between 2015 and 2021 and 58 have been re-evaluated during June 2021.



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**Benchmark 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” (JCAP III.3.A)**

- The DSPDI furnished a table that combined Benchmarks 22, 23, 26 and 27.
- See Benchmark 22.

**Benchmark 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)” (JCAP III.3.D)**

- The DSPDI furnished a table that combined Benchmarks 22, 23, 26 and 27. The report does not specify which participants have been professionally assessed and deemed employable versus those that may have been possibly assessed and deemed not able to work. There are a total of 53 participants that are in this list that could fall under either category. Each of these participants has a documented action plan that is set in three phases. Roughly 90% of these plans were made in June 2021, and the remainder (5 participants) in March 2021. The report provides a status of each phase the participant is currently in. All but two participants continue to be ‘partially in Phase 1’, including those five participants that had their action plans made in March. Only two of these 53 participants are categorized as “Partially Phase 1-2”.

**Benchmark 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”**

The information provided by the DSPDI for this indicator outlines the processes for determining potential participants interested in self-employment (those that are deemed not able to engage in sustainable employment, but participate in production workshops), as well as the processes for the daily evaluations conducted during self-employment production workshops. The information provided by the DSPDI does not list the participants who engage in self-employment activities, nor are these participants identified as underemployed.

Significant work is needed in this area to support participants in exploring and developing viable pathways to self-employment. In addition, it should not only be an option for participants that are deemed unable to engage in sustainable employment. Given the pandemic and related restrictions to participant outings, job developers may want to consider engaging participants in virtual market options, e.g., Facebook market, eBay, Etsy, etc., where participants can sell their products at any time and are not restricted to quarterly in-person sales events, which the job developers currently coordinate. The Office of the JCC opines that the existing paradigm must be modified with celerity within a proper timeframe.



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The Workforce Innovation & Opportunity Act defines self-employment as a gainfully occupied individual who works for himself or herself as opposed to a salaried or commissioned worker who is the employee of another. Additionally, Section 134(c)(3)(D)(vii) of the Workforce Innovation and Opportunity Act (WIOA) cites “entrepreneurial training” (also known as self-employment training) as an allowable training service for adults and dislocated workers. It is recommended that DSPDI apply these federal statutory parameters around what constitutes a self-employment placement within its current service delivery model. Additionally, the Commonwealth should utilize resources available on how to successfully develop self-employment strategies for individuals with disabilities that are available through the U.S. Department of Labor's Office of Disability Employment Policy.

**Benchmark 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)”**

Per the US Department of Labor, the working age range is 16 to 64 years. Per DSPDI’s ASCERV, the working age range for DSPDI’s participants is 20 to 40 years with either a mild or moderate ID/DD diagnosis. The latter criterion reinforces the fact that DSPDI’s ASCERV automatically deems participants with a severe or profound ID/DD diagnosis as unemployable and excludes them from the employability screening process. While some of these participants may not be able to work for valid reasons, they should not be categorically excluded. According to the chart provided by the DSPDI for this benchmark, 20% of the DSPDI’s ‘working age’ participants are employed. However, the percentage of working age participants, disregarding their reported level of ID/DD, is in fact 1.0% (3 working participants/300 working age population). Given this information, there continues to be a significant gap in this benchmark and the need for employee screenings for all ID/DD participants regardless of their ID/DD diagnosis.

Acknowledging the challenges of identifying and pursuing competitive integrated employment opportunities for ID/DD participants during the COVID epidemic, structural problems inherent in the DSPDI service-delivery model persist that systemically discourage employment. Individuals currently living with family members commonly lack any access to services that would support their independent engagement in community life or in pursuing, seeking, securing, and sustaining CIE.

Even for participants in CTS programming, accessing services to meaningfully support employment is minimal or obsolete. During interviews with vocational rehabilitation counselors and executive leadership of the Centers, it became clear that evidence-based practices related to discovery, career development, customized employment, or integrated day activities are not part of the current CTS model. In fact, in most cases, participants are presumed to be incapable of engaging successfully in integrated work or other community integration activities.





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The strategies offered are based more on supporting the existing business model of CTS, which are predicated on a centralized structure in which the participants are all co-located in a congregate setting and staff are cross-trained and able to support large groups of individuals simultaneously by requiring them to participate in planned, pre-organized group activities throughout their day. These congregate, facility-based models are insufficient as a sole option of service and do not offer opportunities to receive supports in the most integrated setting. The JCC is certain that with the assistance of CDDER and Dr. Lowe, the DSPDI can accomplish the necessary transformation related to employment as explained in this Report in an effective and successful manner. The JCC is committed to assisting the DSPDI with the above extremely important mission and goal.

When these systemic challenges and substantive programmatic reforms are made, in conjunction with investments in systems-change, the Commonwealth will be able to achieve compliance levels as it pertains to this benchmark. It is important to emphasize that, there are lessons from COVID related to staff restructuring that could be used to inform future systems change and provider transformation efforts. During COVID, rehabilitation counselors and other members of the individual's support team have come and visited participants individually in their own home. Thus, there could be some opportunity to use those visits as a way to do some focused, responsible exposure to community-based experiences or to begin to initiate Discovery and other career planning exploratory activities in an effort to think creatively about how to support an individual in their community without requiring them to attend the CTS full-time. The undersigned is certain that the DSPDI, with the assistance of CDDER and Dr. Lowe can accomplish the above objective in a reasonable period of time within the parameters of a proper timetable.

**Benchmark 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” (JCAP III.3.E)**

- The DSPDI furnished a table listing 569 participants as deemed not able to work in the community (89% of the 641-population served by the DSPDI per Benchmark 3). Although recommendations, referrals, and results/status of evaluations were included, the furnished report does not include a plan for participant engagement in community activities.

**Benchmark 31 – “Implement the plans” (JCAP III.3.E)**

- Of the 569 participants deemed not being able to work in the community, 546 (95.96%) participants that receive day services across the seven CTS and CTS-like sites have a completed Personal Focus Worksheet (PCP), 234 (41.12%) have an annual ASCERV report, and 516 (90.69%) have a non-potential employment certificate. The charts fail to indicate specific plans regarding community activity engagement, and whether the Personal Focus Worksheet (PCP) plans have been implemented, and, if so, what the participant's respective progress is with respect to their plan.



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**Benchmark 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”**

- There was no information furnished by DSPDI regarding this benchmark. CTS day programming has yet to resume since the global pandemic was declared in March of 2020<sup>29</sup>.

**Benchmark 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” (JCAP III.3.F)**

- The DSPDI included a list of participants that did not attend the CTS for the period of January to June 2021. The list includes 81 participants (12% of the 641), gender, and reason for not attending the CTS. Some of the reasons for not attending date back to 2018 and others refer to documents included in paper file (no further reason is included in the list).

**Benchmark 34 – “Develop individualized plans for these participants to maximize meaningful, functional community activities that foster their growth and independence (JCAP III.3.F); ensure that participants engage in such community activities at least two times per month”**

- There was no information furnished by DSPDI regarding this benchmark.

**Benchmark 35 – “Implement the plans” (JCAP III.3.F)**

- There was no information furnished by DSPDI regarding this benchmark.

**Benchmark 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”. (JCAP III.3.G)**

- See Benchmark 37.

**Benchmark 37 – “Implement the plan” (JCAP III.3.G)**

- No individualized or system wide plan for all the DSPDI participants to engage in meaningful community activities was provided. However, the DSPDI did provide a list of all non-labor, ‘community’ activities carried out (total of 4,999 activities) from January through June 2021. Of all the DSPDI participants, 61.62% (395) are engaged in at least one of those activities and 22.94% (1147) of these activities were documented as being conducted virtually. The range of activities per participant was one to 82. Most of the service areas responsible for coordinating

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<sup>29</sup> Although the above is correct, the DSPDI did not take the opportunity to deliver the services to participants through a combination of visits and videoconferences.



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these community engagement activities include Recreational Therapy (1,880 activities), Occupational Therapy (1,675 activities), Psychologist (457 activities), Job Coaching (349 activities), Job Developer (191 activities), Social Work (151 activities), Vocational Rehabilitation Counselor (115 activities), Speech Pathology (88 activities), and Health and Security (64 activities).

This benchmark was impacted greatly by pandemic-related participant outing restrictions in the community. Looking forward, the JCC (and our team of experts and party-experts) is convinced that this is an area that the DSPDI can enhance, including more expanded and innovative service options, and meaningful, engaging programming for a full five days per week if desired by participants.

**Benchmark 38 – “Ensure that staffing, transportation, other resources are adequate and reliable to meet individualized needs for integrated day activities in the community (JCAP III.3.H); ensure that buses have ramps and other needed accessibility supports”**

Per the information provided by the DSPDI, in June of 2020, the DSPDI acquired 19 additional vehicles (16 passenger vans, two cargo vans, and one SUV) to be used across all CTSs, including the Central Level office. Evidently, these 19 vehicles were excluded from the CTS vehicle inventory reports provided by the DSPDI as there is a footnote under each report stating ‘the DSPDI made a request to procure 19 vehicles for Central Level and all CTSs. Order number attached: 2040440178’.

Regardless, the following statistics are based on the information provided. The DSPDI has a total of 47 vehicles of which only 31 are maybe operational (25.8% of these have ramps) and the remainders are undergoing vehicle maintenance. Some of these vehicles have been in the shop for over a year. The range of operational vans per CTS is one to six vans and in no condition for safe operation; Central Level and the Ponce CTS have the most, while the Rio Grande CTS has the least. Additionally, the DSPDI has a total of 29 drivers across all CTSs and Central Level that are categorized as regular or transitory drivers.

It is recommended that the DSPDI carefully evaluate its fleet maintenance, the resource allocation per CTS in combination with transportation needs of the centers, and the alignment with the type of vehicles available compared to the transportation needs. Based on this evaluation, the DSPDI must develop and implement strategies to ensure adequate, safe transportation to support optimal programming for participants. It is also recommended that they assess the feasibility of repair of some of these vehicles or whether they need to be replaced. The JCC, as previously expressed to the DSPDI, has significant concerns with the state of all vehicles that have been visually inspected and deems the same as a risk to the safety of the participants and DSPDI contractors and/or employees.

**Benchmark 39 – “Ensure there are sufficient job coaches and job trainers to meet individualized needs in the community” (JCAP III.3.I)**

The DSPDI provided information for this benchmark. In this data, the DSPDI has classified their ASCERV staff as either a job coach or job trainer. Historically, the DSPDI has only used the terms job coach or job developer. It is unclear whether ‘job trainer’ is the same as the previously used ‘job developer’, or



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whether the job trainers are tasked with providing vocational training to participants rather than developing jobs. If the 'job trainer' is providing vocational training, it will be important to clarify whether job coaches are then responsible for developing jobs, or whether this responsibility is currently met by any staff. If the job trainers are charged with developing jobs, the ratio of job trainers to job coaches is the inverse of other models. In the DSPDI, there are currently many more job trainers than job coaches. This deficiency in resources must be remedied if compliance is to be accomplished and thereafter, sustainable compliance levels, are to be achieved.

There appears to be a relatively low number of job trainers and job coaches relative to the number of participants who are working or those who have potential to work. There are existing Job Coach and Job Trainer vacancies in the Bayamon and Vega Baja CTSs (which have the highest percentage of participants), which will hinder employment progress in these CTS areas unless filled.

Our Office recommends that job coaches and job developers have access to professional development opportunities and exposure to innovative models in other systems to help advance the range and creativity of employment opportunities supported for participants. There is no fiscal impediment to achieve the above goal. The above serious concern must be resolved, and fortunately for the DSPDI, the budget that the undersigned has obtained will allow the Division to remedy the situation by retaining the services of ID/DD skilled job trainers and coaches. The same should be reflected in our next reports.

The DSPDI should consider using a different employment model for individuals hired to support ASCERV services. The current 30-day contracts create an unstable employment situation and run the risk of losing staff that have been trained given that instability. Alternatively, the DSPDI should consider the use of significantly longer contracts or official employment as is the case in most jurisdictions in the mainland.

#### III.4 Safety and Restraint Issues

##### General Remarks:

In this area the objective is to guarantee the safety, well-being, and protection of all participants, especially those who are vulnerable, at high risk. Part of this process is the review of incidents, reporting, investigating, and establishment of protocols. Also, when serious incidents occur, the same should be investigated promptly, but preferably never over 21 days after the incident occurred.

The DSPDI should require providers to be trained in behavioral supports and crisis intervention,<sup>30</sup> preferably by an existing and approved curriculum and facilitate access to these resources. Providers do not currently have the training they need to adequately and safely support participants with mental and/or behavioral health needs as evidenced by recent crisis events and the evidence of the use of

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<sup>30</sup> This matter will be further addressed in our next Report.



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multiple unapproved restraints by providers in the last year (mechanical in substitute home, physical at IPPR).

In addition to the clinical psychologists available through the DSPDI, the Division should try to recruit some behavioral specialists (which the JCC deems imperative) to consult with providers on participants with the most challenging behavioral conditions, particularly as efforts move forward to lower the sedation levels of participants through reductions in psychotropic medications.

The DSPDI should continue to enhance the use of Therap by providers. The DSPDI can do significantly more to monitor critical incidents, ensure that listed corrective actions are appropriate and adequate, and conduct investigations of omissions of care, improper use of restraints or physical interventions, etc. If the DSPDI does not already have a policy guiding the investigation of allegations of physical and sexual abuse and the omission of care, it is recommended that one be developed. If the DSPDI does have such a policy, it should review its adequacy, and the consistency of its implementation. This aligns with the JCC's recommendation in the report on the closure of Fundación Modesto Gotay Institution ("FMG") to proper surveillance plans and incident monitoring to identify and mitigate issues with service provision quickly, among other recommendations regarding the subject matter

**Benchmark 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)**

- A report was furnished by the DSPDI identifying 20 high-risk participants. However, based on a review by the Office of the JCC, this list is incomplete. For example, participant INR 156 is not identified on this list. In addition, no evidence of assessment and analysis was provided.
- The new administration of DSPDI has created the "*Participant Health, Safety and Well-being Protocol*", approved on March 10, 2021. This protocol has the objective of implementing a comprehensive quality assurance program to track, analyze and guarantee health (physical and mental), safety, well-being, and adequate medical attention. However, the protocol does not include the name of the collaborators or references necessary to validate that protocol was prepared in accordance to scientific evidence and no evidence of implementation was provided.

**Benchmark 41 – "Implement measures to ensure participant safety and welfare based on this analysis" (JCAP III.4.A)**

- The DSPDI presented a report with data on the incidents corresponding exclusively for the period of June 2021 by the new "Incident Committee" of DSPDI. Report information are illustrated in the following tables:

**Incident Committee Report corresponding to June 2021 (Table A)**

JUNE Incidents (IRs) Month:	Number of incidents *
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<b>IRs by Home</b>	23
<b>IRs by CTS</b>	2
<b>IRs by Institution</b>	6
<b>Total</b>	<b>31</b>
<b>IRs by participant**</b>	<b>31</b>
<b>IRs classified as "High"</b>	<b>16</b>

\* The Incident Committee only reports 31 total incidents for June 2021, 16 out of 31 classified as "High". Three of the incidents reported are identified as incidents of "aggressor participants". Investigation reports and corrective plans were not provided.

- An Analysis on Incident Patterns (Table B) report from January 2021 to June 2021 (Benchmark 49) was also submitted by the DSPDI. Below is a table detailing information in report (Column 1) versus all the Incidents Reports (IRs) by Therap- Services Platform (Column 2).

<b>INCIDENTS</b>	<b>Column 1 Number of Incidents classified as "High" in Incident Analysis Report (Benchmark 49)</b>	<b>Column 2 Number of IRs (Low, Medium and high) in Therap-Services Platform.</b>
<b>January</b>	5	108
<b>February</b>	25	109
<b>March</b>	20	158
<b>April</b>	16	168
<b>May</b>	28	149
<b>June</b>	3	164
<b>Total of IRs</b>	<b>97</b>	<b>856</b>

- Remarks:
  - According to Therap, there were 856 incidents in total. The DSPDI report only specified in the report those incidents classified as high, omitting the low and medium incidents.
  - The Incident Committee reported in Table A listed 16 incidents rated "high" in June and the Incident Analysis Report in Table B listed three incidents rated "high". The number of incidents reported by the DSPDI for the month of June did not coincide in their reports.
- Observations:
  - The DSPDI is limiting reporting to incidents classified as "high". All incidents, regardless of their classification, require analysis and support in order to identify



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trends and patterns. Low and medium incidents were not given the required attention, evaluation, or the remedial action they merit which can lead to another incident of a greater scale in the short and/or long term. Further, the Commonwealth is to investigate the serious incidents: "The Commonwealth will revise its incident reporting and investigation protocols to ensure the standardized, complete and in-depth investigation of ALL serious incidents involving MRP Participants so as to improve participant's safety and welfare." (JCAP.III.6.B);

- Taking all incidents into account allows us to analyze and identify trends and patterns;
- Is important to know what type of attention and use is being given to incidents classified as Low and Medium; and
- There is no consistency in the number of incidents reported as previously stated (June 2021) throughout the various documents submitted by the DSPDI.

The DSPDI has categorized 20 participants as high-risk. The in-depth incident report submitted was reflective of June 2021; there were a total 16 incidents and the group homes with the highest rates of incidents (4) were the Shalom institutions and Mekaddesh II Community Home. There were no formalized measures or report reflective of the implementation status of any measures included in the information provided.

**Benchmark 42 – Using data from Therap combined with first-hand accounts, analyze peer-to-peer interactions that create risk of harm (See JCAP III.4.A.1)**

As part of the reporting and analysis of incidents, the DSPDI furnished a table of "Peer to Peer Interaction Analysis" in which 97 incidents of participants were reported from January to June 2021, classified as "high" level. It should be noted that this table has the terms and the language established in the JCAP, however, the report lacks essential information for an analysis in order to reach a conclusion and furnish recommendations as to the incidents. For instance, name of the hospital, purpose of visit, specific treatment, evaluation, result of the intervention, follow up and corrective preventive actions.

**Peer to Peer Interaction Analysis table by DSPDI (Examples):**

Home	Participant	Control No.	Date of IR	Level	Corrective Actions	Incident
Rayos de Amor, Inc. (P. 923)	OMG	1107	2/02/21	High	Participant treated in emergency room and discharged with treatment	Hospital
Shalom Adonai (P. 923)	MRG	27	2/05/2021	High	Participant evaluated in emergency room	Hospital



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Hogar Modesto Gotay I. (P. 925)	MSF	632	03/05/2021	High	First aid by the home staff. Medical evaluation at the Federico Trina Hospital in Carolina. Encouragement to improve supervision.	Hospital
Shalom Adonai (P. 925)	SMTC	647	03/18/2021	High	Intervention in the areas of psychology and social work.	Grip (“Agarre”)
Casa Elvira (P. 926)	EA	1032	04/26/2021	High	Non-violent crisis management techniques	Altercation
Psicopedagógico III. (P.927)	SME	240	04/27/2021	High	Held his hands and legs in place for several minutes.	Conduct
Nueva Esperanza (P. 928)	ALL	313	05/01/2021	High	He was taken to the hospital for treatment.	
CTS Aguadilla Biological Home (P. 931)	CMR	1123	05/15/2021	High	Psychiatric evaluation at Metropolitano Hospital in Cabo Rojo.	Assault
Nueva Esperanza (P. 936)	EEF	1072	06/20/21	High	Protective techniques and activation of additional personnel.	Restraint Related to Behavior

**Peer to Peer Interaction Analysis Table Observations:**

The JCAP requires an action to eliminate the cause of a non-conformity and prevent recurrence. When reviewing the information in the column titled “Corrective Actions” it was found that there is some information, but there is essential information missing that can help with the analysis to further understand the root cause of the incident and the measures that need to be taken to prevent future recurrences. (See Section III, 4-A (2) of the JCAP).

As in this case, the vast majority of the reported incidents in the Therap platform do not have the required corrective plan and the corresponding follow-up.

In accordance with the JCAP, the incident reports should analyze patterns and trends; identify the causes that triggered the incident and develop and implement remedies for prevention in the future. There must always be an objective goal that can be measured. The Office of the JCC is aware that the DSPDI has protocols and provides attention to the incidents, but the follow up and the prevention action plans are still unknown to our Office.

**Benchmark 43 – “Implement effective measures to address peer-to-peer risk factors to prevent harm” (JCAP III.4.A.1)**

- The DSPDI provided a list of high-level peer-to-peer incidents (97 incidents) recorded from January through June 2021. A total of 50 participants were involved





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in these incidents and 18 of these participants had anywhere from two to nine incidents on record (one participant had nine incidents). Nearly 50% (23/50) of these incidents were categorized as aggression, altercation, or assault. However, there were no formalized measures or report reflective of the implementation status of any measures included in the information provided.

No information was provided on peer-to-peer interactions that were not considered to be high level.

**Benchmark 44 – “Using data from Therap combined with first-hand accounts, identify vulnerable participants at risk of harm” (III.4.A.2)**

- The DSPDI presented a table titled “Vulnerable participants at Risk of Harm” in which eight participants are identified as vulnerable. It should be noted that these eight participants were the victims in the incidents from March to May 2021 and seven of these eight participants are living in institutions. This table does not include January, February, and June 2021.

**Benchmark 45 – “Implement effective measures to minimize/ eliminate their risk factors” (JCAP III.4.A.2)**

- The DSPDI has categorized eight participants as vulnerable. 75% of these participants reside in IPPR and none of these eight individuals were involved in any of the 97 high-level peer-to-peer incidents. There were no formalized measures or report reflective of the implementation status of any measures included in the information provided.

**Benchmark 46 – “Using data from Therap combined with first-hand accounts, identify aggressor participants” (JCAP III.4.A.3)**

- The DSPDI provided a table classified as “Identify Aggressor participants in which 13 participants report incidents from April to June 2021. The following should be highlighted of this matter:
  - o This list only takes into account 13 participants with incidents of “assault on others” from April to June 2021;
  - o This table does not include January, February or March 2021;
  - o This table does not track participants identified in past years by the DSPDI;
  - o The DSPDI only includes participants with “incidents of aggression towards others”, even so, this table does not include the participants: MFW 167, CMR 1123 and RLH 1105, who the Incident committee reported as aggressors in his report (P. 922); and
  - o Measures to implement effective measures to minimize/eliminate aggressor risk triggers are unknown.

- **Recommendations:**



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- Aggressor Participants: Do not use aggressive participants as exclusive criteria just for attacking others, the DSPDI should not be limited to incidents of “assaulting others” to identify aggressor participants. The commonwealth should take into consideration participants with a history of assault, Self-injury, destruction of property, disruptive behavior and verbally aggressive among others;
- Vulnerable Participants: Vulnerable participants can be people with compromised physical and mental health, use of polypharmacy, history of trauma and / or victim abuse, and not only limited to being the victims of aggression by other to classify “vulnerable”. Accordingly, they should also consider participants who were transferred from Modesto Gotay institution last year;
- It is important to define aggressive and vulnerable participants; and
- Present consistency in the time that the report covers from January to June since they only report a few months and omit others.

**Benchmark 47 – “Implement effective measures to minimize/eliminate aggressor risk triggers” (JCAP III.4.A.3)**

- Although the DSPDI provided a list of 13 participants identified as aggressors, when reviewing the data, we found there were nine distinct aggressors, some of whom had two incidents. Of these nine aggressors, four were included in the high-level peer-to-peer incident report and were found to be involved in a total of 12 incidents (one participant had seven high-level peer-to-peer incidents recorded). There were no formalized measures or report reflective of the implementation status of any measures included in the information provided.

**Benchmark 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” (JCAP III.4.B)**

- The DSPDI has informed the Office of the JCC that it has incidents documented in the Therap Services platform. According to the JCAP, the serious incident reports should be investigated within forty-five (45) days to prevent serious incidents in future. However, the JCC recommends that said incidents should strive to complete such investigations within 21 days.
- The Office of the JCC recognizes that the new DSPDI leadership is receptive and establishing a structure to address incidents (protocols, education, etc.). However, the outcome of the prevention and action plans remains unknown.



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**Benchmark 49 – “Informed by data from Therap, develop a system wide plan to analyze incident patterns and trends to prevent incidents in the future” (JCAP III.4.B)**

- See Benchmark 48.

**Benchmark 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” (JCAP III.4.B)**

- An analysis and/or investigation of the incidents established per the JCAP were not identified in the information provided by the DSPDI. There is no information or evidence of the development of preventive plans, monitoring of incidents and/or recommendations, as the undersigned has previously mentioned and reiterated. The DSPDI should be proactive in identifying patterns to develop and offer adequate and appropriate interventions in response to these findings. See the example below of incident report in Therap for participant CMR 1123. Note that incident information was extended to September 2021 to show a pattern.

**Table: Incidents reported for CMR 1123:**

Date of Incident	Number and Type of Incidents	Psychiatric Hospitalizations
September 9, 2021	Altercation & Assault	Hospital Metropolitano (Utuado)
August 10, 2021	Assault	Hospital Metropolitano (Utuado)
July 17, 2021	Assault	Hospital Metropolitano, Cabo Rojo
June 22, 2021	Assault	Hospital Metropolitano (Utuado)
May 15, 2021	Assault	Hospital Metropolitano, Cabo Rojo
April 15, 2021	Assault	Hospital Metropolitano, Cabo Rojo
<b>Total:</b>	<b>6</b>	<b>6</b>

**- Findings:**

- o A participant who lives in a biological home has been aggressive towards his father. Said incidents have continued for a period of six months, as can be seen above. Due to these incidents, CMR is admitted in a psychiatric hospital on a monthly basis;
- o The DSPDI evaluated the participant and determined that he should be placed in a community home. However, six months have passed since said determination and the participant is still on the DSPDI wait list;
- o The behavioral plan implemented by the Aguadilla CTS team is not showing results. The participant continues displaying aggressive behavior;



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- CMR is in medical/psychiatric and hospital treatment without behavioral changes. There is no evidence of interventions and / or evaluation by the CEEC team; and
- There is no evidence of analysis and investigation of CMR incidents.

A monthly analysis of various incident classifications per participant and by community home was provided by the DSPDI. However, the information provided did not include any system wide plans nor remedial measures or report reflective of the implementation status of any measures included in the information provided.

**Benchmark 51 – "Implement effective measures to minimize/eliminate use of all restraints on participants" (III.4.C).**

- Of the list of 97 high-level peer-to-peer incidents recorded from January through June 2021, only one had 'Restraint Related to Behavior' listed as the type of incident. There were no formalized measures or report reflective of the implementation status of any measures included in the information provided. There were at least two incidents of restraint that occurred during the year for participants that were not documented as such. Ten years after the adoption of the JCAP and 21 years into the case it is time to eradicate at once incidents of restraint. The JCC is confident that the current administration can accomplish the above with minimal effort.

**Benchmark 52 – "Prohibit use of standing PRN or "stat" orders for chemical restraints on participants" (JCAP III.4.C).**

The Office of the JCC recognizes that the practice of physical restraints mechanism has been virtually eliminated, and the use of "as needed" (PRN) medication is still prohibited. However, it would be constructive to know why the use of the variety of psychiatric medications that participants use in the absence of a medical diagnosis. The analysis of Dr. Blanco's Report offers findings on psychiatric medication and yields data that must be addressed by the DSPDI. In addressing the problem of polypharmacy, it warrants to be noted that the Commonwealth hired a Pharmaceutical Consultant and Mortality, Morbidity & Polypharmacy Committee who is in charge of the "Special Polypharmacy Project" to attend this matter. This is a positive step in the analysis and identification of psychopharmacological information but an implementation in the change in medication in the participants has not yet been seen.

**Physical Restraint:**

We identified cases of physical restraint in reports, tables and the Therap platform where the restraint was presented as a corrective measure by use of different "techniques". The following table presents examples of physical restraint in the documents submitted by the DSPDI:

Reports of DSPDI	Example of Physical Restraint
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<b>Table: "Peer to Peer Interaction Analysis by DSPDI (Benchmark 42).</b>	"Management techniques in non-violent crises", "Held in a correct way holding his hands and his legs for several minutes" and "protective techniques."
<b>Report: "Identify Aggressor participants" (Benchmark 46).</b>	The report presents different techniques applied to four participants as a corrective action in the event of an incident, for example: "Technique of handling in non-violent crises."
<b>The Incident Committee Report</b>	The report presents one incident of "Restraint Related to Behavior" to participant.
<b>Therap Services Platform</b>	In the area of "General Event Report" of Therap-Services; two incidents in homes were reported as "Restraint Related to Behavior." (June 2021) Example: 1. Participant MES 250 "His hands and legs are held until he calms down." No corrective action was reported. 2. Participant AMR 729 – as corrective action reported: "orientation, therapeutic grip and consultation with psychologist."

- **Recommendations:**

- Evaluate personnel who has training for the proper use and intervention of non-violent techniques. How will the implementation be evaluated and how will the DSPDI ensure that it is done in a safe manner? What credentials does the person who offered the training has? (present evidence);
- Use alternatives non-pharmacological treatments, such as functional and behavioral analysis, behavior support plans, planning for challenging behaviors, positive and negative reinforcement interventions, educational programming, and communication supports used adequately; and
- Evaluate the prevalence risk factors and psychosocial implications of challenging behaviors. Determine what are the environmental factors maintaining the participant's challenging behavior.

### III.5 Health Care and Mental Health Care

#### General Remarks:

As previously mentioned throughout the present Report, the COVID-19 pandemic continues to impact the health services to the ID/DD population. The Specialized Clinicians need to adapt to the changing environments in which they deliver care through community services. During this time, the DSPDI



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continued offering mental and physical services in remote modality and on-site visits from interdisciplinary teams from CTS (Nurses, social workers, psychologists, among others). The effectiveness of the same will be evaluated and addressed in the JCC's March 2022 Report.

During January 2021, the DSPDI began the vaccination process against COVID-19 for the participants and we commend, as previously informed to the Court, the Department of Health's initiative in the vaccination drive. By June 9, 2021, 97% of the participants (618 participants) had been fully vaccinated. There are 23 participants that are not vaccinated, most of them residing in biological homes. The Office of the JCC continues to monitor the implementation of the DSPDI's "*Covid-19 Action Plan and Protocol*", of March 20, 2020.<sup>31</sup> At the present, the implementation of the "Strategic Plan for the opening of the habilitative services and the labor reintegration of the participants" is in Phase 2.

**Dental Health:**

Despite the pandemic, Dr. Molina, and Dr. Rosado, as well as the 4th year dental students from the UPR Medical Sciences Campus, continued offering dental services to participants and bedridden patients. From January 2021 to June 2021, 115 participants have been attended at the DSPDI Dental Clinic. As of May 27, 2021, they restarted dental maintenance appointments and established a strategic plan to prioritize patients who had not received their routine cleanings for the longest time. Currently, the dental team is working hard to bring more than 400 patients up to date.

Recently, Dr. Molina acquired a portable dental machine for low radiation digital radiography. This has allowed Dr. Molina to see more clearly possible pathologies that help make effective dental treatment decisions. In addition, as the machine is portable, it can be transported to homes and center to provide service in places distant from the Bayamón clinic. In addition, Dr. Molina continues to be in communication with Mr. Don Boyle, expert designer for more than 30 years of protective equipment for special patients, with the aim of improving the design of his equipment and the development of more advanced equipment aimed for patients that are uncooperative and/or bedridden and portable equipment.

Dr. Molina, through the collaborative agreement between the DSPDI and the School of Dental Medicine of the UPR Medical Sciences Campus, continues to motivate and train the next generation of dentists in Puerto Rico with his non-pharmacological management techniques and with the hope that in a few years access to dental services for the population with ID/DD will cease to be a problem.

According to the furnished report, the DSPDI is working on a plan to improve the physical plant of the basement in Bayamón and the acquisition of dental equipment. All these initiatives are in the process of awaiting the services in the Aguadilla CTS facilities and the optimization of the dental clinic facilities at the central level. We commend Dr. Molina once again for his passion and unwavering commitment to service the ID/DD population in Puerto Rico.

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<sup>31</sup> See Docket. 2767.



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**Overall Polypharmacy:**

Polypharmacy, across all medications taken regularly, is divided into different levels. Five or more medicines is considered mild polypharmacy; seven or more medicines is considered moderate polypharmacy; and 10 or more medications is considered severe polypharmacy. Overall, 65.7% of participants experienced some level of polypharmacy.

<b>Absolute Med Count (OTC or Rx Only)</b>			
Total Absolute Meds/ID	# of IDs	Absolute Polypharmacy Level	% of Census
5 to 6	143	Mild	22.63%
7 to 9	186	Moderate	29.43%
10+	94	Severe	14.87%
<b>Total</b>	<b>423</b>		<b>65.7%</b>

*Excludes OTC vitamins and dietary supplements*

**Benchmark 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” (JCAP III.5.B)**

- The DSPDI furnished a list for the period of June 2021 detailing the participants by name and contact information of the primary care physician and specialty.
- The Office of the JCC believes the list to be complete and accurate.

**Benchmark 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” (JCAP III.5.A)**

- The DSPDI furnished a table that combined Benchmarks 54, 55, 56, 57 and 58 including a list of nursing referrals and list of participants with significant changes in health. No further information was submitted by DSPDI.

**Benchmark 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”**

The DSPDI should continue to work on the quality of the information regarding participants’ medical, behavioral, and other service needs, as well as critical incidents, and other information about the DSPDI’s activities. While recent efforts aimed at improving recorded medical diagnoses are promising, further work on information quality is needed as gaps hinder the ability to inform quality assurance on an individual- and- systemic basis.



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In addition, the Division should continue to look at how they are monitoring and managing the health of participants, including access to regular and preventive care, management of high-risk medical conditions, treatment of emergent medical issues and changing medical needs. The DSPDI should also ensure that they consider a range of risk factors, including medical support needs, when defining who they consider to be vulnerable service recipients.

Related to this benchmark, information was provided by the DSPDI on 19 participants. In reviewing the events related to these changes in conditions, some recommendations emerge:

- It is essential that participants who are presenting changes in behavior are first assessed for medical conditions, rather than initially treating these psychiatric changes. Training for staff surrounding behaviors should teach all staff – direct support staff through to clinicians – to consider behavior as communication and to first work together to rule out medical conditions. For example, a participant exhibited both neurological and behavioral symptoms and was initially sent to a psychiatric hospital. However, the participant had a serious neurological condition and physical condition and was later placed in the ICU after symptoms progressed.
- After a participant is discharged from the hospital following surgery, staff should be trained on how to manage the wound, care for the participant and to make sure that they follow the medical orders and recommendations of the doctor who attended the participant. For the time being, regular nursing care should be provided to effectively address the above problem area. An example of the above can be observed and verified when two participants returned home after fall-related operations and subsequently developed ulcers around their incision points. A third participant had a fall-related fracture and later developed a pressure ulcer that required medical treatment. The above complications could have been avoided with trained and enabled staff. The JCC is concerned that the above human resource deficiencies, if not properly addressed by competent personnel can lead to more serious medical and health complications that could lead to preventable illness or death. The above is simply preventable with reasonable efforts by the DSPDI, and the JCC, once again, reiterates its commitment to doubling its efforts to assist the DSPDI in effectively addressing the present matter.
- Moreover, multiple participants had very serious falls resulting in fractures in their lower extremities, particularly in their leg bones.<sup>32</sup> It is recommended that the DSPDI ensure that risks associated with falls are identified and mitigated for all participants, and that direct support staff have specialized training pertaining to falls, physical injuries, and particularly, repeated falls. After any fall, it is important that IDT teams review the environment and events to try to understand what caused the person's fall and mitigate that risk going forward. It is quintessential for the DSPDI to review whether participants with risk factors (i.e. most of the adult population with ID/DD) have received bone density screenings regularly to identify potential osteoporosis risk and additional risks related to said condition.

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<sup>32</sup> Falls can lead to more significant and serious health conditions often because of underlying health conditions.





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**Benchmark 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 (JCAP III.5.B); participant information may be located in the home, CTS, CEEC, Central Office, and/or elsewhere”**

- The DSPDI furnished a table that combined Benchmarks 54,55, 56, 57 and 58 including a list of nursing referrals and list of participants with significant changes in health. In addition, a copy of a letter dated June 21, 2021, from the DSPDI Director addressed to the DSPDI Clinical Directors, nursing personnel and social workers was furnished. Said letter establishes that, for medical visits, the before mentioned professions should provide the person accompanying the participant with a copy of the referral, and printed copies of Therap’s health passport and consultation form. No further information was submitted by the DSPDI.

**Benchmark 57 – “Maintain effective communication with community clinicians to determine if they provide informed and comprehensive individualized evaluations and treatment that meet individualized participant needs” (JCAP III.5.B)**

- The DSPDI furnished a table that combined Benchmarks 54,55, 56, 57 and 58 including a list of nursing referrals and list of participants with significant changes in health. No further information was submitted by the DSPDI.

**Benchmark 58 – “Ensure participants receive necessary health care in a timely manner to meet their individualized needs in the community” (JCAP III.5.G)**

The DSPDI furnished a table that combined Benchmarks 54,55, 56, 57 and 58 including a list of nursing referrals and list of participants with significant changes in health. No further information was submitted by the DSPDI.

It is disappointing to note that no information was provided for this very important benchmark by the DSPDI. The JCC and all experts involved in our monitoring duties expect that by the next few Reports the above deficiency will once again dissipate. The Office of the JCC will be available at all times to assist the DSPDI in said objective.

The DSPDI must continue to consider how they will ensure participants have access to qualified clinicians, particularly given the challenges in the current medical system in Puerto Rico. Moreover, the Division may need to look at alternative models such as building/contracting expertise in addition to the generic medical system in the Island, and if necessary, establish relationships with Mainland clinicians, even if it is combined with short visits on a temporary basis and through the use of videoconferences supplemented by local medical services. This includes neurologists, as many people with seizure disorders and/or who are on medications for neurological conditions are not currently seen by a neurologist. The above predicament should be remedied at once.



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**Benchmark 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 (JCAP III.5.H); priority at-risk condition criteria are set forth in JCAP III.5.H”**

- The DSPDI provided a list of 20 high-risk participants. These identified participants share a common diagnosis: “Intermittent explosive disorder”. Even though no other diagnoses were identified, no further information was provided that would allow the Office of the JCC to know the reasons for the classification criteria for high-risk participants. The following table illustrates the number of high-risk participants between the years 2018 – 2021:

- High-Risk Participants:

Year	Physical Condition	Behavioral	Aspiration Risk	Diagnose with Epilepsy (Benchmark 74)	Risk of Bowel Obstructions
2021	---	20*	90 (BM 75)	256 (BM 70)	171
2020	---	23	132	251	---
2019	359	16	101	250	---
2018	410	90	138	252	---

(---) The participants with physical conditions were included in the “High Risk and Longitudinal Report of Medications Report” but the total number corresponding to this category was not provided.

\* Number of High-Risk Participants

- Like previous years, 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. As previously emphasized in the previous JCC Report, we recognized the value and usefulness of the information compiled in the above-mentioned report. However, this “High Risk and Longitudinal Report of Medications” presented by the DSPDI does not present a summary of the analysis of the information compiled through time, so it does not comply with what is expected in a longitudinal evaluation and with the creation of proper action plans moving forward. It is important to present an analysis of the findings presented in said report. For example: the DSPDI and the CEEC should enumerate the total number of participants who have had changes in their medication (adding or discontinuing prescriptions as well as dosages changes) and provide the number of participants that are under polypharmacy. Said practice will significantly assist in overcoming the above extremely serious problem.

The JCC is compelled to highlight that this is the first time that a JCC Report includes a clinical evaluation of this nature. Thus, the reason why we contracted the services of UMass/CDDER.



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- **Recommendations:**

- The objective of the JCAP in this area 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; and
- The DSPDI should provide evidence of an action plan to implement effective measures to minimize/ eliminate their risk factors of the participant from the High-Risk Participants List (JCAP III.4.A.2) The Pharmaceutical Consultant of the DSPDI could contribute her knowledge and analysis on the longitudinal Report medications. The JCC trusts that the above can be accomplished with reasonable effort in a short timeframe.

**Benchmark 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 (JCAP III.5.I)**

- For this benchmark the DSPDI referenced consolidated list of priority, at-risk participants containing each participant’s conditions, risk classification, comments regarding medical evaluations, follow up-efforts with physicians and medication (list furnished for Benchmark 59 to 65). However, as it pertains to this benchmark, no information was provided by the DSPDI.

**Benchmark 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” (JCAP III.5.I)**

- The DSPDI did produce a list of participants with a diagnosis of epilepsy and information about their most recent seizure. However, there was no additional information about how the DSPDI is monitoring these conditions, nor any additional information about tracking these other conditions.

**Benchmark 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”**

- The DSPDI provided a list of members of seven local teams that have been formed to produce crisis response that includes nurses. No information was furnished about how these teams are functioning. It is our understanding that the DSPDI has added more nurses to their staff and has reorganized nursing services into its own Department within the Division. However, there was



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no specific information about these changes in terms of the number of nursing staff hired, whether the nurses are operating in a traveling program, nor documentation of nursing contacts with participants. No information was provided for this benchmark by the DSPDI.

**Benchmark 63 – “Using data from Therap and other sources, regularly compile and analyze incident, outcome, intervention, treatment information for each priority at-risk person” (JCAP III.5.J)**

- No analysis was provided by the DSPDI to evaluate compliance with this benchmark.

**Benchmark 64 – “Regularly share this information with community clinicians” (JCAP III.5.J)**

- No information was provided by the DSPDI to evaluate compliance with this benchmark.

**Benchmark 65 – “Maintain effective communication with community clinicians to determine if they utilize this information to implement measures to meet individualized participant needs” (JCAP III.5.J)**

- No information was provided for this benchmark by the DSPDI.

### Neurological Care

**Benchmark 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)” (JCAP III.5.K)**

- Current List – June 30, 2021. The DSPDI identified 256 participants with a diagnosis of epilepsy and presented evidence of a collaborative agreement with the “Sociedad Puertorriqueña de Epilepsia”, which expires on June 30, 2022. The DSPDI did not present evidence of implementation of the agreement and its outcome.
- The Office of the JCC believes the list to be accurate.

**Benchmark 67 – “Ensure that neurologists provide participants with a seizure disorder with comprehensive neurology evaluations as needed, at least annually” (JCAP III.5.K)**

- No evidence was provided to support annual comprehensive neurology evaluations. See Benchmark 70.

**Benchmark 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” (JCAP III.5.K.1)**



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- Reference was made by the DSPDI to a master list of participants with epilepsy (See Benchmark 66). However, the list provided does not provide sufficient information to identify participants with 10+ seizures in the past year or with no seizures in the past two years.

**Benchmark 69 – “Ensure that neurologists provide effective care for those having 10+ seizures per year” (JCAP III.5.K.1)**

- CDDER was unable to assess this benchmark in the current report. Information for neurological evaluations was provided in largely illegible hand-written notes in Spanish.

**Benchmark 70 – “Ensure that neurologists provide effective care for those who have not had a seizure in the past two years” (JCAP III.5.K.1)**

Of the 641 participants served by the DSPDI in June 2021, 256 (40%) were reported by the DSPDI to have a diagnosis of epilepsy. Of these participants, 46 (18%) were reported to have had a seizure in the last two years; recent seizure history was not known for one newly served participant. 210 (82%) participants diagnosed with epilepsy did not have a seizure in the last two years. Of people with epilepsy without a seizure in the past two years, 192 (91%) were receiving one more antiseizure medication; 36 of whom did not have a neurologist, and at least 55 had not seen their neurologist in over a year (in some cases in many, many years (ex. since 2011, 2013, 2016, 2017, etc.). For the people who are on antiseizure medication who have not had a seizure in many years, the DSPDI should ensure that said participants have access to and see a neurologist to review their continued need for antiseizure medication.

Regarding efficacy of care, CDDER is unable to fully assess this benchmark in the current Report. Information for neurological evaluations was provided in largely illegible hand-written notes in Spanish. However, some gaps in care were observed from the information provided by the DSPDI. For example, one participant had a seizure in the past year that was severe enough to require hospitalization but was reported by the DSPDI not to have a neurologist under a field for recent care. Another participant was on six simultaneous anticonvulsant medications and had not seen their neurologist in over a year; the last reported contact with the physician was the receipt of a phone order to continue the medications. Multiple participants with epilepsy had not reportedly seen a neurologist for many years (ex. since 2016, 2017 or 2019), and the anticonvulsant medications for a substantial portion of participants were prescribed and managed by primary care physicians.

While 40% of participants (256 people) were reported by the DSPDI to have epilepsy, 63% (or 399 people) were currently prescribed anticonvulsant medications. The number of people on anticonvulsants is more than 50% higher than the number of people with a diagnosed seizure disorder. Because many of these medications have cross-therapeutic uses, such as for mental health and/or neurological conditions, CDDER was not able to assess the accuracy of the list of people with epilepsy. Given the large number of participants on anticonvulsant medications without an epilepsy diagnosis, the DSPDI should review the accuracy of this information to ensure the diagnoses are aligned with the



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reason for the use of these medications. The above review would be extremely beneficial to the DSPDI and the well-being of participants.

**Benchmark 71 – “Ensure that neurologists weigh the benefits of medication use and adequately document the rationale for anticonvulsant medication” (III.5.K.2)**

- See Benchmark 70.

**Benchmark 72 – “Ensure the use of intra-class polypharmacy is minimized and fully justified” (JCAP III.5.K.2)**

- See Benchmark 99.

**Benchmark 73 – “Formalize a relationship with the Epilepsy Foundation of Puerto Rico and use the relationship to improve neurological care and outcomes for participants” (JCAP II.5.K.3)**

- Collaborative Agreement with the Epilepsy Foundation of Puerto Rico expires on June 30, 2021 (2020-DS0595). A new collaborative agreement (2022-DS0268) has been formalized for FY22 which expires on June 30, 2022, and, as expressed by the DSPDI, this agreement provides for faster and more specialized neurological services. However, no evidence of implementation has been furnished by the DSPDI.

### Aspiration Risk

**Benchmark 74 – “From the Master List, create a sub-list of those participants at risk of aspiration and/or aspiration pneumonia”**

- The DSPDI provided a report for the period of January 1 to June 30, 2021, listing 90 participants who are at risk of aspiration.
- The Office of the JCC believes the list to be accurate.

**Benchmark 75 – “Implement individualized plans to eliminate unsafe mealtime practices, per JCAP criteria, to minimize risk of aspiration/pneumonia”. (JCAP III.5.L)**

The DSPDI provided a table of people with identified aspiration risk. 90 participants were listed in this table. About 90% of the people on this list have some recommendations listed on their treatment plans related to their diets. However, a substantial portion of the recommendations do not appear to be directly related to mitigating aspiration risk; instead, they specify calorie targets and/or meal frequency, or address low sugar or low-fat needs for other conditions, or list only that the diet should be bland or free of irritants. Only two people of the 90 had diet orders that made specifications about any needs to thicken liquids. For people who are tube fed, it was not always clear from the order listed whether they



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were permitted to have any food or drink by mouth. There was no information provided about the implementation of these plans or their effectiveness.

The majority of the evaluations appeared to be completed by a nutritionist, a few were completed by primary care physicians. Of the 90 participants listed, seven were indicated to have been evaluated by a speech/language pathologist or a gastroenterologist. About 20% of the participants have not been evaluated or need to be re-evaluated.

It is positive that nutritional evaluations have been involved for these participants, as they frequently have weight management or other dietary needs due to comorbid chronic conditions that warrant dietary considerations. However, these nutritional assessments frequently appear focused on these other needs, and often appear to omit factors that would be relevant to aspiration risk. The Office of the JCC strongly advises the DSPDI to seek more involvement of a dietician and/or speech/language pathologist in evaluating these participants and providing input into both their nutritional and positioning plans.

**Benchmark 76 – “Implement individualized plans to keep non-ambulatory individuals in proper alignment to minimize risk of aspiration/pneumonia” (JCAP III.5.L)**

The DSPDI provided a table of participants with identified aspiration risk, and on this table included a column related to an indication as to whether the person was bedridden or not, and the recommendation and treatment plan for bedridden participants, which was labeled to be responsive to this benchmark.

Most of the treatment plans for people who were listed to be bedridden and had an identified aspiration risk were for changing of position every two hours. There was no information provided about the implementation of these plans or their effectiveness. While it is important to understand and mitigate the risk of skin issues for people who are non-ambulatory, these plans do not address aspiration risk. For example, the plans did not include any instructions related to alignments such as height of bed elevation or post-meal positioning, which would be expected when considering strategies to minimize aspiration risk.

Treatment plans for non-ambulatory participants with identified aspiration risks do not include any strategies to mitigate their aspiration risk. Moving forward, it would be beneficial for the DSPDI to seek more involvement of dieticians and/or speech/language pathologists in evaluating these participants and providing input into both their nutritional and positioning plans. Training for staff should also be given when aspiration-specific strategies are introduced.

**CEEC**

**Benchmark 77 – “Ensure CEEC regularly evaluates all participants (JCAP III.5.C); compile list of ongoing evaluations”**



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- The following information in the table corresponding to CEEC Report Evaluations from January to June 2021:

Type de Evaluations	Evaluations completed
Re-evaluations: Updating of information and completion of the ITP.	<b>90 participants</b> All 90 re-evaluations were carried out on participants from Institutions (Shalom and IPPR).
Psychological re-evaluation: Emotional state Level of functioning	<b>1 participant</b>
New Admission Assessments (ENI): Confirmation of diagnoses and level of functioning	<b>48 persons</b> - Note: they report 69 evaluations of new admission; however, 17 of these evaluations were canceled by family members, and four persons did not attend. For a total of 48 evaluations. These, evaluations are identified as coming from the community (no further information was provided) and Court referrals.
<b>Total:</b>	<b>139 Evaluations reported by the CEEC</b>

- The focus of the evaluations has been directed to participants from institutions and the community. The DSPDI has a census of 641 participants and only 91 re-evaluations, 550 participants remain pending to be evaluated by the CEEC; which means that only 14% of the participants have been re-evaluated.

**Benchmark 78 – “Ensure CEEC regularly reviews the adequacy and appropriateness of individualized community health care and mental health care (JCAP III.5.C); compile list of ongoing reviews”**

- Although the Office of the JCC saw evidence that the CEEC has been supporting and offering its services, no further information was provided by the DSPDI to verify if regular reviews were conducted by the CEEC.

**Benchmark 79 – “Ensure CEEC promptly raises red flags and actively advocates on behalf of individuals when community services do not meet their individualized needs (JCAP III.5.C); compile list of ongoing instances of contacting community clinicians to raise red flags/advocate for participants, summarizing result of contact”**





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- Although the Office of the JCC saw evidence that the CEEC has been supporting and offering its services, no list was provided of ongoing instances of contacting community clinicians to raise red flags/advocate for participants, summarizing results of contact.

**Benchmark 80 – “Ensure CEEC informs community clinicians of recent adverse health or mental health outcomes that may implicate treatment (JCAP III.5.E); compile list of ongoing instances where CEEC informed community clinicians, summarizing result of contact”**

- The DSPDI referenced a list of participant hospitalizations and visits to the emergency room. However, no information was provided as to the CEEC informing community clinicians of recent adverse health and mental health outcomes that may implicate treatment or summary of results. See Benchmark 81.

**Benchmark 81 – “Develop and implement effective system wide plan for CEEC to promptly communicate concerns to community clinicians that improve outcomes (JCAP III.5.E); compile list of improved outcomes after CEEC intervention”**

The Office of the JCC recommends that the DSPDI appoint a medical doctor as lead or co-lead of the CEEC, in alignment with the JCAP.

After the changes in CEEC membership and recent trainings, the CEEC should formulate a specific action plan as to how they will meet the requirements set out by the JCAP including metrics they will monitor to achieve those activities. CEEC members should receive additional ongoing professional development in areas relevant to clinical needs of adults with ID/DD, in quality documentation/progress notes, person-centered planning, trauma-informed services, etc. to ensure they are highly skilled in identifying and addressing the needs of participants.

No information on CEEC interventions or associated outcomes was provided by the DSPDI.

**Benchmark 82 – “Implement a system wide protocol to alert licensing, ombudsman agencies of community clinician improprieties (JCAP III.5.F); compile list of alerts”**

- No evidence was provided regarding a system-wide protocol for these alerts or a list of alerts.

**Benchmark 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”**

The CEEC is described in the JCAP as a specialized mobile clinical evaluation unit and has the responsibility of re-evaluating and reviewing if participants are receiving the adequate care with respect to physical and mental health. Furthermore, it is expected that, as a team of experts, they provide



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support on crisis interventions, emergencies, and in the transition process of participants. Since the year 2017 to the present, the CEEC description was changed to a “specialized clinic in evaluation and consulting,” comprised of a multidisciplinary team, medical director, psychiatrist, nutritionist, occupational therapist, community nurse, social worker, and a clinical coordinator in the field of psychology.

- Currently, the CEEC continues to assume a role of consultants. However, the CEEC consultants’ availability and support is not evident in the documents submitted by the DSPDI. The use of CEEC consulting services is indirectly evident in documents in which they are mentioned, as well as case notes of Therap, attendance to conference call meetings, and consults in the fields of psychology and nursing. Nevertheless, as mentioned in accordance with the JCAP, the CEEC should be carrying out a more active role with greater participation in order to become an effective mobile crisis team.

At the present:

- o The Mobile Crisis Team is now divided by the Consultation and Support Staff (CEEC) and the first responders are the Interdisciplinary Teams of the seven CTS. Changes in consultation and support staff have occurred, but the handling and mobile crisis team is not evidenced. Multiple incidents have occurred (for example, with Participant INR 156 and CMR 1123) and the CEEC team did not respond to said emergency crisis.
- For the first time the CEEC team has a Thanatologist and an Epidemiologist.

**Benchmark 84 – “Ensure CEEC mobile crisis team is comprised of multi-disciplinary group of DD professionals (JCAP III.5.D)”**

- See Benchmark 85.

**Benchmark 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”**

Gaps in crisis response have recently been observed, including during a serious crisis situation in the summer of 2021, in which the Federal Monitor and members of the JCC team had to intervene<sup>33</sup>. It is recommended that the DSPDI investigate the failure of the IDT to respond to this incident to fully gather facts, and subsequently, that the DSPDI considers using a Root Cause Analysis to identify the systemic

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<sup>33</sup> The DSPDI staff did not respond to the physical location during the incident, and there was a substantial delay (to the following day) in assessing the welfare of the participant after the incident including addressing physical wound care. Over four days after the incident, no members of the CEEC had visited or called the service location in regards to the incident. Said incident occurred proximate to the June 30<sup>th</sup> deadline covered in this Report.



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weaknesses that contributed to the events so that preventive strategies can be identified and implemented.

In July, the JCC made a series of initial recommendations after a crisis situation including that mobile crisis teams should be active. The JCC also recommended the mobile crisis teams have a dedicated office space, and that the teams include personnel that can attend people with mental health disorders, including members of the CEEC, as mandated by the JCAP. The personnel in charge of the participant's clinical services in the referenced crisis situation (who are from the Vega Baja CTS) were only able to provide services in a remote manner.

The DSPDI has recently reorganized the CEEC and has organized seven teams of CEEC and CTS teams to respond to crisis situations. It will be important for the DSPDI to develop and implement a localized response structure, and assess the adequacy of this structure to ensure that mobile crisis teams can respond quickly (**e.g. on site within one hour**) balanced with other current responsibilities at the respective CTS and/or CEEC teams.

No information was provided from the DSPDI regarding instances where mobile crisis teams have intervened recently, or the results of such interventions.

## **Mortality Review**

### **General Remarks:**

Pursuant to the JCAP, the Mortality and Comorbidity Committee composed of eight professionals from the DSPDI, holds monthly meetings to discuss mortality reports. The chairperson of the Mortality Review Committee (MRC) is Dr. Yocasta Brugal. In 2020, 26 deaths were reported. According to the Mortality and morbidity report, the highest death of participants was 46% in institutions, followed by group homes by 31% and 11% in biological homes

The JCC expressed the importance of establishing regulations and a protocol to conduct a "root cause analysis" (Benchmark 89 & 90, JCAP III.5.N.5). The Office of JCC is currently awaiting information as to how the DSPDI will implement the recommendations set forth in the mortality reports. 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 appropriately (JCAP N. 7.) The DSPDI should present "actionable plans" to have clear and measurable strategies and begin to specify who will be in charge of identifying who will oversee the implementation of the remedial action plan. The above is of quintessential importance to ensure the necessary system-wide reforms and to comply with JCAP mandates.

**Benchmark 86 – "Create and maintain a mortality review committee comprised of well-respected health care and quality review personnel, headed by an independent chairperson" (JCAP III.5.N)**



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- As certified by the DSPDI on June 14, 2021, the MRC members are Dr. Yocasta Brugal (Chairwoman), Ms. Suzanne Roig (DSPDI director), Ms. Lisandra Cartagena (Committee Coordinator), Ms. Karla Gonzalez (Clinical and Habilitative Area Supervisor), Ms. Quiudinashka Ramos (Nursing Coordinator), Ms. Mayra Santana (Nutritionist), Dr. Carolina Carmona (DSPDI physician) and Dr. Ivonne Rosario (DSPDI Pharmacist and Polypharmacy). An updated list of deceased participants as of June 30, 2021, was also included.
- Mortality Rate:

Year	Death	Population	Mortality Rate (per 1000)
06/30/2021 (mid-year)	13	641	
2020	26	635	40.9%
2019	15	635	23.6%

**Benchmark 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 (JCAP III.5.N.2, 4); compile list of MRC meetings and death reviews”**

- Minutes for the period of January to June 2021 were included as evidence that the MRC meets on a monthly basis (except for the month of February 2021). See Benchmark 91.

**Benchmark 88 – “Ensure MRC has access to all pertinent people, information related to the course of care leading up to the death” (JCAP III.5.N.3)**

- As certified by the DSPDI on June 14, 2021, the MRC has access to all personnel and records. See Benchmark 91.

**Benchmark 89 – “Ensure MRC performs a root-cause analysis to identify any preventable causes of illness and death” (JCAP III.5.N.5)**

- See Benchmark 91.

**Benchmark 90 – “Ensure MRC issues a final report on each death promptly, per JCAP criteria, with root-cause analysis and recommendations to address outstanding issues” (JCAP III.5.N.5)**

- See Benchmark 91.

**Benchmark 91 – “Monitor to ensure prompt and effective implementation of all MRC recommendations and continue to monitor until full implementation (JCAP III.5.N.7); compile tracking table of recommendations and implementation status”**



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The quality of the mortality reports completed by the independent MRC have continued to evolve to increase their discussion of systemic issues and corresponding recommended actions. The MRC reports issued in 2021 have clear, actionable recommendations, and very directly point to areas of concern and areas of action that the DSPDI should implement for systemic improvement. These reports represent a very informative and important source of information from which the DSPDI can identify and direct targeted systemic improvement in services.

It is of the utmost importance that the DSPDI ensure that they have a process for implementing the specific recommendations for systemic improvement included in mortality reports and for tracking and reporting on the progress of said work. The recommendations included in the MRC reports to date hit squarely upon issues with the health of the participant population identified in other areas of this Report as confirmed by numerous different sources of information.

The DSPDI reported verbally in September 2021, that they are working with the Chairwoman of the MRC on recommendations made by the committee. The above is every encouraging, and it is important that they are receptive to the recommendations of the MRC. However, no written evidence of the above efforts was provided.

It is very important that the DSPDI work to implement the MRC recommendations without delay, particularly given the similarity between deaths in key areas. About half of the deaths continue to be in adults of younger ages, and there are contributing factors that suggest that many deaths were preventable, particularly those that include toxic effects of overmedication by psychotropic medications and those with missed diagnoses and/or missed opportunities to intervene. These factors represent the majority of the deaths that have been reviewed in 2021 to date (9).

The deaths during 2021 include ones that have contributing factors of sedative (and other psychotropic) toxicity, starvation/malnutrition, aspiration pneumonia, and missed medical diagnoses.

After reviewing the MRC recommendations made in 2021, we find that the MRC continues to identify diagnoses missed by the DSPDI, including constipation, ulcerations, and dysphagia. There were multiple, substantial gaps in taking vital signs that were important opportunities to identify decline earlier, delays in care and medical interventions, and lapses in providing choking resuscitation and CPR administration. Reflective of the risks of over-medication with psychotropics discussed in other benchmarks, there were deaths related to both toxic over-sedation, as well as a choking death with suspected contributing factors from high doses of psychotropic medications. These contributing factors represent very serious issues with the quality of care for the recently deceased participants, and the areas of systemic improvement identified by the MRC, including staff training, proactively addressing overmedication, and the management of constipation and aspiration should be priority targets for the DSPDI strategies in alignment with other evidence presented in this report.

**Benchmark 92 – “Monitor to ensure MRC process is effective to avoid preventable illnesses, deaths for similarly situated individuals” (JCAP III.5.N)**



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- It has not been possible to assess this benchmark over the last year, as it is unknown which of the MRC recommendations the DSPDI has implemented, and their corresponding level of effectiveness. It is clear that multiple issues observed by the MRC persist across participants, including the effects of high levels of polypharmacy, side effects of medications, delays in medical care, and gaps in management of chronic conditions.

## Mental Health

### General Remarks:

Significant work is needed to address the very high levels of overmedication, including over-sedation of participants. Efforts to date have only been for a small subset of participants and have only reached out to physicians to ask to set up a call to discuss the patient's case. There is no evidence that any recommendations for medications have been communicated with prescribers to date, even for the group that the DSPDI has identified as being among the highest risk given their current medication profile. As this continues to be a contributing factor to deaths, it is critical that more progress is made in this area and that direct work with prescribing physicians is initiated at a much faster pace.

The DSPDI should also consider implementing strategies to prevent high risk inter- and intra-class polypharmacy, particularly for psychotropic medications.

### Medication:

Adults with ID/DD are prescribed high levels of medication with polypharmacy. One of the most significant findings in the area of mental health was the polypharmacy report by Dr. Blanco in August 2020. As established by the JCAP, it is important to minimize the use of intra-class polypharmacy. For the management of polypharmacy, the DSPDI has named a Pharmaceutical Consultant and Mortality, Morbidity & Polypharmacy Committee who is in charge of the "Special Polypharmacy Project".

The DSPDI has taken action as to the findings and recommendations of Dr. Blanco. Recognizing the problem of polypharmacy is the first step to begin the process of change required. The JCC is hopeful that the Polypharmacy Project will be the beginning of many other efforts to help participants to have adequate and safe pharmacological treatment for their health and mental health. At present, there is still no change in the medications of the DSPDI participants and they continue to be exposed to the risks that polypharmacy imposes on their health and quality of life.

- Recommendations:
  - o Identify additional strategies to address challenges in dialogue with community physicians;
  - o Frequent consultation meetings with Dr. Blanco;



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- Develop and implement a strategic plan for the evaluation and prevention of polypharmacy in participants with objective of establishing effective and safe measures to minimize polypharmacy, duplicity medication and adverse events; and
- Provide education to DSPDI staff on polypharmacy identification.

**Dual Diagnosis:**

It is important to understand the coexistence and prevalence of psychiatric disorders and intellectual disabilities. Participants with dual diagnoses should have a psychological/psychiatric plan and be provided comprehensive interventions for their well-being. People with ID/DD are vulnerable because of their limited cognitive abilities.

From January 2021 to June 2021, the DSPDI reported participants with psychiatric hospitalizations and 17 of these mental hospitalizations were under Law 408. The list of participants with psychiatric diagnoses was not provided by DSPDI.

- Recommendations:
  - At present, the Commonwealth should create a crisis respite home or homes in integrated community settings as an alternative to forced contact with a psychiatric hospital; this community option will be less stressful and more therapeutic for an individual with a dual diagnosis in crisis than an institutional setting. and
  - Provide training workshops to educate employees that serve participants with dual diagnoses.

**Benchmark 93 – “From the Master List, create a sub-list of all participants with mental illness, specifying their mental illness diagnosis/es” (JCAP III.5.G)**

- The DSPDI furnished a list that combined Benchmarks 93, 94 and 95 including participants diagnosis, mental health care professional, date of last evaluation, date of follow up evaluation and recommendation. It is evident that the DSPDI is working to maintain an updated list, however, said list does not seem to be complete in terms of what participants are being treated for as found in Therap and paper records.

**Benchmark 94 – “Ensure participants receive necessary mental health care in a timely manner to meet their individualized needs in the community” (JCAP III.5.G)**

- No information was provided for this benchmark by the DSPDI.

**Benchmark 95 – “Ensure that all mental illness diagnoses are consistent with DSM criteria and justified in the record” (JCAP III.5.M)**



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- It was found that not all participants have updated DSM diagnoses recorded in Therap or across all reports/data.

**Benchmark 96 – “Ensure that no participant receives psychotropic medication in the absence of a clinically justifiable diagnosis of mental illness” (JCAP III.5.M)**

The information provided from May 2021 by the DSPDI included a list of participant’s medical diagnoses and their current medications. In many cases, there were no medical diagnoses listed that would support the use of one or more medications currently prescribed to the participants.

For example, a participant was listed to have a diagnosis of “other epilepsy” and was on anticonvulsants but was also prescribed numerous other psychoactive medications (Haldol, Benadryl, Ativan, trazodone, Cogentin) including antipsychotics and antianxiety medications and two other medications (folic acid, estralozam) without corresponding diagnoses or justification.

Since February 2021, the DSPDI has made efforts to update diagnostic information of participants. Home visits were conducted by nurses to gather improved information, and 251 records (approximately 40% of the DSPDI population) have been evaluated and their diagnoses and medications have been updated. The DSPDI has also analyzed the medications prescribed for 25 participants to assess the concordance between the drugs used by the participant and the diagnoses documented in their file. These efforts are an early start in moving toward improvement in this area, particularly in the quality of the information in the participant’s file. The DSPDI has reported having five nurses on the Polypharmacy Committee who have reviewed 294 individual files for matches between participants’ diagnoses and their prescribed medication. The DSPDI reported plans to update another 120 records in this manner by the end of December 2021.

In June 2021, the DSPDI sent a letter to people accompanying participants to medical appointments (clinical coordinators, nurses, social workers) to request the prescriber of any new prescription to include the diagnosis corresponding to each prescribed drugs using the codes of the International System of Classification of Diseases (ICD-10) going forward.

Additional work is needed, particularly to identify people who are taking medications for which there is no associated diagnosis and to work with prescribing clinicians to ensure that the medications are clinically justifiable, and in most cases, are not just used to control behavior.

**Benchmark 97 – “Ensure that type, dosage of psychotropic medication are appropriate and needed for each participant, per JCAP criteria” (JCAP III.5.M)**

Based on data from March 2021 for 632 participants served by the DSPDI at the time, the following tables profile their medication use at the time.

**Psychotropic Medication Use by Class:**





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Psychotropic Type	No. Participants	% of DSPDI Population
Antipsychotic	443	70.09%
Antidepressant	345	54.59%
Anti-anxiety	383	60.60%
Mood Stabilizer	17	2.69%
Anticonvulsant	399	63.13%
Stimulant	3	0.47%
<b>Total Participants on one or more psychotropic</b>	<b>555</b>	<b>87.82%</b>

The use of psychotropic medications in the population served by the DSPDI is very high, with the vast majority (over 87%) receiving one more psychotropic medication daily. In particular, the rate of use of antipsychotic medications is extremely high and does not correspond to the frequency of psychoses-related diagnoses in participants. The use of anti-anxiety medications, anticonvulsants and antidepressants is also quite high. Further work to ensure participants are on medications for clinically justifiable reasons, optimize medication regimens and deprescribe unnecessary medications is an important area of continued work for the DSPDI. Coupled with this, should be enhancements to individualized supports to ensure participants remain stable during deprescribing, and active engagement of participants in their lives (particularly as they become less sedated from medications).

**Interclass Psychotropic Polypharmacy:**

# of concurrent Psychotropics*	No. Participants	% of DSPDI Population
1	50	7.91%
2	101	15.98%
3	141	22.31%
4	145	22.94%
5	72	11.39%
6	38	6.01%
7	5	0.79%
8	3	0.47%
<b>Total</b>	<b>555</b>	<b>87.82%</b>

*\*Includes antipsychotics, antidepressants, anxiolytics, mood stabilizers, anticonvulsants, and stimulants.*

Applying the same methods used in Dr. Blanco's 2020 report, polypharmacy (simultaneous use of two or more daily psychotropic medications) can occur at different levels. As previously mentioned, three or four medications are considered mild polypharmacy, five or six medications are considered moderate



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polypharmacy, and seven or more medications are considered severe polypharmacy. Given these parameters, we have identified 286 (45.25%), 110 (17.41%), and eight (1.27%) participants that fall respectively under mild, moderate, and severe levels of psychotropic polypharmacy. In comparison with Dr. Blanco's 2020 report, the level of psychotropic polypharmacy is lower across all levels.<sup>34</sup>

The use of psychotropic medications that introduce effects such as sedation and respiratory depression, which increase with the use of multiple psychotropic medications, present a risk of death. These effects can contribute to numerous other serious health risks such as aspiration pneumonia, falls, constipation and intestinal obstruction.

**High Risk Medication Combinations:**

The use of certain medications in combination can introduce additional risks. For example, the use of a benzodiazepine and barbiturate at the same time can increase a person's risk of adverse respiratory depression. In the 2021 medication profiles, 33 participants were on at least one barbiturate and one benzodiazepine at the same time, a reduction of six people from Dr. Blanco's 2020 analysis. Among participants on both barbiturates and benzodiazepines, 84.85% (28/33) of these participants have a diagnosis of either severe (19 participants) or moderate ID/DD (9 participants). Of these 28 participants, 57.14% (16 participants) reside in group homes, 25% in biological homes, and the remainder lives across all other resident settings. Furthermore, the majority of these 28 participants receive day services from either CTs located in Vega Baja (7), Ponce (6), and Aguadilla (5).

First generation antihistamines have central-nervous system effects and are also psychoactive medications. They have cross-therapeutic use as sleeping pills or treatment of anxiety due to their antidopaminergic effects. These medications also contribute to intestinal drying and present constipation risks. The two most frequently observed in medication prescribed to the DSPDI participants, Diphenhydramine (Benadryl) and Hydroxyzine (Vistaril), both have psychoactive effects including sedation and act as an anxiolytic. Diphenhydramine (Benadryl) has major drug interactions with anxiolytics, sedatives, and hypnotics, and must be used cautiously in patients with a history of depression and other psychiatric disorders. In addition, this medication exhibits substantial anticholinergic effects, and is not recommended for use in people with gastrointestinal obstructive disorders, among other conditions. Hydroxyzine (Vistaril) may be used to treat anxiety, but it is important to note that whether used for allergies or anxiety, it is not recommended for long-term use; its use is recommended to be limited to no longer than four months because it has not been shown to be effective in the long-term and some research evidence suggests that long-term use, particularly in older adults, could be linked to dementia.<sup>35</sup> The table below reviews how these two psychoactive

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<sup>34</sup> Dr. Blanco reported 472 of 632 patients (74.68%) had mild psychotropic polypharmacy, 253 of the 632 patients (40.03%) had moderate psychotropic polypharmacy and 51 of the 632 patients (8.07%) had severe psychotropic polypharmacy.

<sup>35</sup> U.S. Food and Drug Administration. Vistaril (hydroxyzine pamoate). Pfizer Labs. 2014. [https://www.accessdata.fda.gov/drugsatfda\\_docs/label/2014/011459s048,011795s025lbl.pdf](https://www.accessdata.fda.gov/drugsatfda_docs/label/2014/011459s048,011795s025lbl.pdf)  
Cai X, Campbell N, Khan B, Callahan C, Boustani M. Long-term anticholinergic use and the aging brain. *Alzheimers Dement.* 2013;9(4):377-385. doi:10.1016/j.jalz.2012.02.005



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antihistamines are prescribed for participants with other prescription medications in combinations that are considered to be either high risk or contraindicated.

	In combination with:	No. Participants	% of DSPDI Population
Diphenhydramine (Benadryl, Banophen)	Anxiolytics	74	11.71%
	Antidepressants	67	10.60%
	Anticholinergics	19	3.01%
Hydroxyzine (Vistaril)	Anxiolytics	34	5.38%
	Antidepressants	34	5.38%
	Antipsychotic	44	6.96%
	Anticholinergics	13	2.06%

A total of 100 participants (15.82% of DSPDI census) regularly take Diphenhydramine and the frequency descriptions indicate that this drug is administered daily for this entire subset. Among these people, 14.40 % of the DSPDI census (91 participants) take some type of Diphenhydramine daily and at least one other anxiolytic, antidepressant, or anticholinergic.

A total of 55 participants (8.70% of DSPDI census) are on Hydroxyzine and the frequency descriptions indicate that this drug is administered daily for this entire subset. Nearly 8% of the DSPDI census (50 participants) take Hydroxyzine (Vistaril) daily and at least one other anxiolytic, antidepressant, antipsychotic, or anticholinergic.

Among participants taking Diphenhydramine and Hydroxyzine, nearly none of them have a diagnosis listed that indicates that these medications may be used allergy relief or other clinical indications for antihistamines. It is unclear if they are being used for their antihistamine effects, or their psychoactive effects.

Per the Federal Drug Association (FDA), the use of the antipsychotic Thorazine in combination with anticholinergic drugs can be fatal. In data provided by the DSPDI, 65 participants were prescribed Chlorpromazine (Thorazine) daily, and 19 participants (3% of the DSPDI population) and at least one anticholinergic daily. It is strongly recommended that the DSPDI review these medication combinations as a priority for high-risk polypharmacy if these individuals have not already been included in the subset prioritized to date.

**DSPDI Polypharmacy Committee:**

As part of the DSPDI's Polypharmacy committee, the Division has conducted work in 2021 to update the records of participants inclusive of their prescribers and related contact information.



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There is an initial group of 31 participants (identified in Phase 1 of the Action Plan, representing 5% of the DSPDI population) for whom the committee conducted individualized medication profile reviews. In July 2021, the DSPDI sent certified letters to 22 general practitioners and psychiatrists requesting a discussion of the participant they were treating. The DSPDI reported expecting to send 30 additional prescriber-targeted letters during July, August, and September of 2021. The DSPDI reported plans to have consultations with neurologists and psychiatrists as needed for complex cases and wanting to discuss with the prescribers ways to decrease or eliminate psychotropic medications that may not be necessary, as well as alternative treatment options for first generation psychotropics.

The DSPDI has reported conducting individual medical profile reviews for 25 of these participants by the DSPDI's Polypharmacy committee; it is unclear whether the results of these reviews and any corresponding recommendations have been shared yet with prescribers. The letters sent to prescribers did not contain any specific, individualized recommendations, but were rather to provide the background/context for the medication reviews and to attempt to open a line of communication with the prescribers to discuss each participant in this initial group. The DSPDI has not provided information on the efficacy of these letters, including how prescribers are responding, the rate of uptake to the request for individualized discussions, and whether there have been any changes to participant's medication profiles as a result.

The DSPDI reported the expectation that similar letters requesting a discussion will be sent to all participants' physicians on or before December 2021. However, there is misalignment with other information provided suggesting they plan to send 30-40 letters per quarter to prescribers. They also report plans to conduct 60 medication evaluations for the upcoming two quarters, adding a total of 120 evaluations by the end of 2021. There appears to be the potential for some misalignment in strategies if the letters requesting discussions with prescribers will go out by December 2021, but less than 25% will have had these individual medication profile reviews conducted by that time.

It is unclear how the DSPDI will prioritize the individual medication profile reviews/discussions for the remaining 95% of participants. It is recommended that the patterns of risky and suboptimal medication patterns observed in this Report be considered for some of the next prioritization.

**Recommendations for Polypharmacy committee:**

- It will be important for this committee to evaluate their work and success in safely de-prescribing medications in their first group of individuals under review. This evaluation should include whether there is a need for specialized clinical resources or a clinical environment for this titration down of medications, and whether community prescribers were receptive to the DSPDI's advice and had what they needed to safely heed the recommendations. Lessons learned should be considered for the approach with the next group of participants by the committee.



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- As there are substantially more participants with intraclass polypharmacy and other suboptimal prescription medication plans, the DSPDI should work to come up with a plan to identify the group of participants at the next-highest level of risk related to their medication profiles.
- The DSPDI is also working to, through their office in charge of health plans, identify participants who are on Medicare and Advantage plans because of their eligibility for the Medication Therapy Management (MTM) service offered by Part D plans as required by Centers for Medicare and Medicaid Services (CMS). It is recommended that the DSPDI consider meeting with the MTM services to ensure that they understand the management needs of people with ID/DD prior to expanding the use of this service greatly.

See discussion for Benchmarks 98, 99. It appears that this benchmark is largely unmet for many participants.

**Benchmark 98 – “Minimize use of typical/first generation psychotropic medication” (JCAP III.5.M)**

First generation antipsychotics are associated with a higher risk of adverse side effects, particularly when used in the long term. These side effects can include neurological effects related to loss of muscle tone, tremors, and other involuntary movements, as well as increased risk of cardiovascular conditions, weight gain and metabolic syndromes.

The following table lists first generation antipsychotics observed in the lists of medications prescribed to participants in 2021. One hundred ten (110) participants were prescribed these medications in 2021, representing 17% of participants served. The use of these medications is recommended for consideration as part of the reduction and optimization of medications.

<b>First generation Antipsychotics</b>	<b>No. Participants</b>	<b>% of DSPDI Population</b>
Haloperidol Decanoate (Haldol)	29	4.59%
Chlorpromazine (Thorazine)	65	10.28%
Fluphenazine (Prolixin)	12	1.90%
Perphenazine (Trilafon)	4	0.63%
<b>Total</b>	<b>110</b>	<b>17.41%</b>

In about half of people on Thorazine, the dosages used are those indicated for people in acute schizophrenic or manic states (according to the NIH’s database of drug information). A substantial portion of these participants is not in institutional settings, nor do these levels of medication appear to be for short-term use as suggested by prescribing guidelines. For example, a 29-year-old male living in a



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group home received 400 mg four times a day and 600 mg at bedtime, resulting in a daily dose of 1800 mg/day (maximum dose is 2000 mg/day). Multiple other participants were on substantial doses (e.g. 600 mg/day) in combination with other psychoactive medications.

These health-related risks related to the use of first-generation psychotropics increase with older age, and with long-term use. Specifically, the FDA warns that elderly patients with dementia-related psychosis treated with antipsychotic drugs are at an increased risk of death. There are currently 15 participants over the age of 65 taking one or more antipsychotics. For example, the oldest participant (82 y/o) on antipsychotic medications was taking two different antipsychotic medications. In addition, the person on the most simultaneous antipsychotics was over 66 years old. It is recommended that the DSPDI review the use of these medications particularly in older adults as the risk of serious, adverse health effects is even greater for adults in this age group.

In the data provided by the DSPDI, multiple participants were prescribed first generation antipsychotics were also prescribed anti-Parkinson's medications without any diagnosis of Parkinson's disease. These medications are also used to treat neurological effects such as tardive dyskinesia that can be caused by long-term use of first-generation antipsychotic drugs and their use in people treated these antipsychotics may be for neurological side effect management.

The DSPDI reported that they planned to discuss the use of antipsychotic drugs with equal or greater effectiveness and with a better profile of adverse effects. We will review, comment, and make any necessary recommendations in the next JCC semi-annual Report as to the progress that the DSPDI reaches in relation to the above plan.

**Benchmark 99 – “Minimize use of intra-class psychotropic medication polypharmacy” (JCAP III.5.M)**

**Intraclass Psychotropic Polypharmacy:**

There is a high amount of intra-class polypharmacy for psychotropic medications in the population of participants served by the DSPDI. Within the psychotropic medication classes below, we have also presented information about intraclass polypharmacy within subgroups that carry heightened risk of adverse health effects related to utilization of multiple of these medications, including atypical antipsychotics and benzodiazepines. Individual participants with polypharmacy within these subgroups are recommended for prioritization of medication review and work with prescribers to find pathways to more optimal medication use. Intraclass polypharmacy was highest for anticonvulsants. It appears that prescribers are attempting to use a low level of multiple anticonvulsants to treat participants, which is at times used to try to minimize adverse side effects. However, there is not a strong evidence base for the therapeutic effectiveness of this practice, and it is not considered best practice. For participants with higher levels of intraclass polypharmacy in anticonvulsants and other psychotropic medications that are being prescribed/managed by a primary care physician, it is recommended that the DSPDI ensure and facilitate access to specialist consults (neurology, psychiatry as appropriate) to ensure the use of optimal medication combinations to treat the participant's conditions.



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Psychotropic Type	No. Concurrent Meds within class	No. Participants	% of DSPDI Population
Antipsychotic (all)	1	413	65.35%
	2	29	4.59%
	3	1	0.16%
<i>Atypical Antipsychotics</i> <sup>36</sup>	1	345	54.59%
	2	9	1.42%
Antidepressant	1	258	40.82%
	2	79	12.50%
	3	8	1.27%
Anti-anxiety	1	369	58.39%
	2	14	2.22%
<i>Benzodiazepine</i>	1	274	43.35%
	2	127	20.09%
	3	8	1.27%
Anticonvulsant	1	264	41.77%
	2	105	16.61%
	3	24	3.80%
	4	5	0.79%
	5	1	0.16%
Mood Stabilizer	1	17	2.69%
Stimulant	1	3	0.47%
<b>Total</b>			

CDDER did not have sufficient information to review the justification of the intra-class polypharmacy. The DSPDI should review and apply the guidance from Dr. Blanco's 2020 report on deprescribing and optimizing medication utilization in this area.

### III.6 System wide Reforms

#### General Remarks:

<sup>36</sup> While the majority of benzodiazepines prescribed to participants were antianxiety medications, some are classified as sedatives, which is why these intraclass figures differ from those of antianxiety medications.



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Since the year 2016 to the present, the DSPDI has started to implement the Therap platform to respond to the JCAP mandates. The DSPDI submitted the last “Therap Services Implementation Plan”, in August 24, 2020.

Therap had 974 active users by August 2020 and had only one coach to provide training and support on how to use the platform.

According to the DSPDI, on February 16, 2021:

- Number of houses documenting in the Therap Services platform: 40 homes;
- Number of houses that do not have yet an account in Therap: 24 homes;
- Number of houses pending documentation on the platform by CTS:
  - o CTS Bayamón: 11
  - o CTS Vega Baja: 4
  - o CTS Río Grande: 3
  - o CTS Aguadilla: 3
  - o CTS Ponce: 2
  - o CTS Cayey: 1
- Number of homes pending to be created on the platform: 1; and
- Number of Institutions documenting in Therap platform: 2 (Partial documentation).

In the past months, the Office of the JCC recognized that the DSPDI has started using the documentation in the following areas:

- The DSPDI had been partially completing the Person-Centered Plan in Therap (called the Person Focus Worksheet or PFW). At the present, the protocol of the Person-Centered Plan has not been approved.
- The DSPDI is also starting to use the platform in Therap for Individual Plan Employment History section.
- “Individual Transitional Plan” (ITP) for participants in institutions had been documented in Therap. ITPs for ongoing transfers are also being prepared in Therap.
- Greater use in the documentation of case notes, interventions and services offered by the Interdisciplinary Teams of the CTS. Unfortunately, the content of the information is superfluous; not providing details or essential information that allows a full understanding of what is stated in the note. There is no uniformity in the writing of documentation.
  - o Increase documentation of incident reports and “T-logs”.
  - o In most cases, participants have updated information in their “Individual Home Page” profile.

This platform has still numerous challenges to overcome in order to achieve full implementation, but it is important to recognize these efforts.





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**Benchmark 100 – “Implement a comprehensive quality assurance program to track, analyze, and ensure participant safety, welfare, health care, mental health care issues and outcomes” (JCAP III.6.A)**

- The DSPDI has approved a Participant Health, Safety and Well-being Protocol however, there is no information or evidence of implementation at this time. See Benchmark 40.

**Benchmark 101 – “Implement prompt and effective measures to address patterns and trends that adversely impact participant safety, welfare, health, and mental health” (JCAP III.6.A)**

- See Benchmark 100.

**Benchmark 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”**

- As of June 30, 2021, all service mediators serve no more than 24 participants. However, it has been identified that the CTS of Aguadilla will be in need of new service mediators due to the opening of new homes. The Office of the JCC will continue to monitor the growth of service mediators and report about the same in the next JCC Report.

**Benchmark 103 – “Work with family members of participants on a plan to address quality issues that impact participants”.**

- During the current public health crisis, families and service providers have increased responsibility for supporting participants given the closure of day programs as well as public health rules limiting certain activities. It is important that the DSPDI ensures that these families and providers have access to adequate respite services to ensure that participants are well supported, and that families and providers are supported to address their own needs and continue being able to support the participant.

**Benchmark 104 – “Create and maintain toll-free crisis hotline, staffed 24/7 by qualified professionals that can effectively help to resolve issues” (JCAP III.6.B)**

- A crisis line call log registry was presented for the period of January to June 2021, detailing the date, time, participant, home, name of the person calling, reason for consult, recommendation followed and the name of the professional answering the line. For the period covered, Dr. Carmona was on call and 40 calls were registered. Given the amount of incidents occurring and recorded, this number seems low. In addition, there is no evidence of a plan or schedule for staffing the hotline 24/7.
- Upon interviews held by the Office of the JCC to providers and guardians, it was found that it is not commonly known that the DSPDI has a crisis line answered by professionals 24/7.



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**Benchmark 105 – “Create and maintain a system wide email system to facilitate prompt communication to all pertinent individuals, per JCAP criteria to resolve outstanding issues” (JCAP III.6.C)**

- Certification dated June 30, 2021, signed by the Director of the DSPDI certifying the following:
  - o All Therap users have access to the SCOMM tool, which facilitate the sharing of sensitive and confidential information.
  - o All DSPDI personnel has a personal email with the Health Department Outlook platform with access to Microsoft Teams. However, the Office of the JCC found that not all personnel is currently using said platform.

**Benchmark 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”**

- A list of social workers assigned to biological homes and the Social Worker Protocols was provided by the DSPDI.
- The DSPDI also submitted the Respite Service Protocol, which is not signed as approved and includes references older than 5 years. According to the protocol, there respite is offered in three modalities: (1) CTS extended hours, (2) temporary stay in community home, and (3) one to one service. It was noted that the proposed Respite Service Protocol is not tempered to our current reality. For example: The COVID-19 pandemic and earthquakes. These topics and their management should be part of the protocol and the trainings considered as preparation for the personnel that offers or will offer the service in any of its modalities.
- During the period of January to June 2021, only one participant from the IPPR was reported as participating in the respite program for a period of 2 weeks.
- As of June 30, 2021, the following homes are part of the respite program:

	<b>Name of Home</b>	<b>Municipality</b>	<b>No. of Participants</b>	<b>No. of Beds Available for Respite</b>
1	Agape Mitchell I	Morovis	6	1
2	Luz Divina Mia II	Coamo	6	1
3	Centro Ayuda Comunitaria Porta de Sol	Aguadilla	6	1
4	Camino de Luz	Coamo	6	1
<b>Total no. of beds available for respite</b>				<b>4</b>

**Additional Recommendations from CDDER:**



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- The DSPDI should continue to provide training on person-centered planning to the staff involved with developing and implementing participant's service plans. While recent training efforts have been a good start, it is important that the Division supports delivering services in a person-centered manner. However, there is more information needed here to ensure that services are fully planned in a patient-centered manner, and that the services delivered are person-centered in practice. Staff needs further training and coaching in how to include the participants in the planning process, particularly those with communication difficulties. The DSPDI should also continue to work on the PCP self-assessment developed by federal partners to assist with developing a strategy for improvement in this area.

#### **IV. Conclusion**

In conclusion, the JCC recognizes that the Commonwealth's efforts to work in a collaborative and effective manner with USDOJ, the JCC and the party-experts have started to show some progress and expects that the current compliance level will significantly increase once the multiple action plans that are currently being developed by the DSPDI are finally and effectively implemented.

The JCC also recognizes that in addition to the multiple challenges the new administration inherited, the ongoing COVID-19 pandemic has prevented the DSPDI from making progress in key areas of the Benchmarks, especially those regarding employment and daytime activities, which should also start showing higher compliance levels once the current situation subsides.

As mentioned in the previous Report, 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. The JCC is hopeful that the Commonwealth can achieve significantly higher compliance levels if the current efforts are maintained and if they strengthen their collaboration efforts with the JCC, USDOJ and especially, with the party-experts for the benefit of the entire ID/DD population in the Island.



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**EXHIBIT A: BENCHMARK LEVEL OF COMPLIANCE**

No. BM	Benchmark	JCC September 2021 Report
1	Translate this benchmark document, as well as any updated versions, into Spanish	<b>In Compliance</b>
2	Disseminate both the English and Spanish versions of these benchmarks to all pertinent personnel	<b>In Compliance</b>
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	<b>In Compliance</b>
<b>III.1 Community Placement From Institutions</b>		
4	From the Master List, create a sub-list of all participants who live in an institution (e.g., Instituto Psicopedagógico, Modesto Gotay, Centro Shalom)	<b>Substantial Compliance working towards In Compliance</b>
5	Issue a policy directive that all institutionalized participants can live in the community with adequate supports/services OR for each institutionalized participant, conduct and document an individual evaluation on his/her appropriateness for community placement regardless of community capacity (JCAP III.1.A) (all cites below are to JCAP)	<b>Substantial Compliance working towards In Compliance</b>
6	Develop a written individualized community transition plan for each participant in an institution using person-centered planning techniques (III.1.A, E)	<b>Partial Compliance working towards Substantial Compliance</b>
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)	<b>Partial Compliance working towards Substantial Compliance</b>
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)	<b>Partial Compliance working towards Substantial Compliance</b>
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)	<b>Partial Compliance working towards Substantial Compliance</b>
10	Take the opposed families/guardians on tours of prospective, successful community residences (III.1.C)	<b>Partial Compliance working towards Substantial Compliance</b>



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No. BM	Benchmark	JCC September 2021 Report
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)	<b>Working towards Substantial Compliance</b>
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)	<b>Working towards Substantial Compliance</b>
<b>III.2 Provider Capacity Expansion in the Community</b>		
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	<b>In Compliance</b>
14	Develop a systemwide plan to increase the number of community residential providers to meet participants' individualized needs (III.2)	<b>Partial Compliance working towards Substantial Compliance</b>
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.	<b>No Compliance working towards Partial Compliance</b>
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)	<b>No Compliance working towards Partial Compliance</b>
<b>III.3 Integrated Employment and Day Activities</b>		
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	<b>Substantial Compliance working towards In Compliance</b>
18	For those working in the community, develop individualized action steps to ensure no one working in the community is underemployed (III.3.A)	<b>Partial Compliance working towards Substantial Compliance</b>
19	Implement the action steps to ensure that no one working in the community is underemployed (III.3.A, B) This is in addition to original benchmarks: (with the understanding that the Commonwealth cannot guarantee optimal employment, but nonetheless will continue its efforts to avoid underemployment) (III.3.A,B)	<b>No Compliance working towards Partial Compliance</b>



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No. BM	Benchmark	JCC September 2021 Report
20	From the Master List, create a sub-list of those who are currently not working in the community, but have been professionally assessed or identified in the past as able to work in the community; designate on this sub-list the date/author(s) of the most recent assessment	<b>In Compliance</b>
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)	<b>Partial Compliance working towards Substantial Compliance</b>
22	Develop individualized, concrete action steps with timeframes to maximize their community employment (III.3.C)	<b>Partial Compliance working towards Substantial Compliance</b>
23	Implement the action steps to ensure that: everyone who is able to work is working in the community; and everyone working in the community is not underemployed (III.3.D) THIS IS IN ADDITION TO ORIGINAL BENCHMARK : (with the understanding that the Commonwealth cannot guarantee optimal employment, but nonetheless will continue its efforts to avoid underemployment) (III.3.D)	<b>No Compliance working towards Partial Compliance</b>
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	<b>In Compliance</b>
25	Professionally assess or re-assess for community employment all participants who are currently not working in the community but have been professionally assessed or identified in the past as able to work in the community (III.3.C)	<b>Partial Compliance working towards Substantial Compliance</b>
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)	<b>Partial Compliance working towards Substantial Compliance</b>
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)	<b>No Compliance working towards Partial Compliance</b>



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No. BM	Benchmark	JCC September 2021 Report
28	Develop and implement a program to promote self-employment for appropriate participants, specifying the number of times per trimester each participant is to be engaged in community self-employment activities; examples of self-employment may include, but not be limited to, work at fairs and urban markets selling arts and crafts participants create.	<b>No Compliance</b>
29	Systemwide, ensure that at least 25 percent of all participants of working age are employed in the community, on a full-time or part-time basis based on individualized needs, at minimum wage or above, at a location where the employee interacts with individuals without disabilities and has access to the same opportunities for benefits and advancement provided to workers without disabilities. (With the understanding that the Commonwealth cannot guarantee employment, but nonetheless will continue its efforts to find paid employment and avoid underemployment)	<b>Working towards Substantial Compliance</b>
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)	<b>Partial Compliance working towards Substantial Compliance</b>
31	Implement the plans (III.3.E)	<b>No Compliance</b>
32	For those participants who are not working in the community but attend a day program at a CTS, ensure that these participants attend the day program at least four days per week; ensure that staffing, transportation, and other resources are adequate to meet individualized needs; ensure that buses have ramps and other needed accessibility supports	<b>Partial Compliance working towards Substantial Compliance</b>
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)	<b>Substantial Compliance working towards In Compliance</b>
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	<b>Partial Compliance working towards Substantial Compliance</b>
35	Implement the plans (III.3.F)	<b>No Compliance</b>
36	Develop a systemwide plan for all participants to maximize non- work activities in the community that are meaningful, functional, and foster growth and independence to meet individualized needs (III.3.G)	<b>Partial Compliance working towards Substantial Compliance</b>



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No. BM	Benchmark	JCC September 2021 Report
37	Implement the plan (III.3.G)	<b>No Compliance</b>
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	<b>Partial Compliance working towards Substantial Compliance</b>
39	Ensure there are sufficient job coaches and job trainers to meet individualized needs in the community (III.3.I)	<b>Partial Compliance working towards Substantial Compliance</b>
<b>III.4 Safety and Restraint Issues</b>		
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)	<b>Partial Compliance working towards Substantial Compliance</b>
41	Implement measures to ensure participant safety and welfare based on this analysis (III.4.A)	<b>No Compliance</b>
42	Using data from Therap combined with first-hand accounts, analyze peer-to-peer interactions that create risk of harm (III.4.A.1)	<b>Partial Compliance working towards Substantial Compliance</b>
43	Implement effective measures to address peer-to-peer risk factors to prevent harm (III.4.A.1)	<b>No Compliance</b>
44	Using data from Therap combined with first-hand accounts, identify vulnerable participants at risk of harm (III.4.A.2)	<b>Partial Compliance working towards Substantial Compliance</b>
45	Implement effective measures to minimize/ eliminate their risk factors (III.4.A.2)	<b>No Compliance</b>
46	Using data from Therap combined with first-hand accounts, identify aggressor participants (III.4.A.3)	<b>Partial Compliance working towards Substantial Compliance</b>
47	Implement effective measures to minimize/eliminate aggressor risk triggers (III.4.A.3)	<b>No Compliance</b>
48	Informed by data from Therap, develop a systemwide plan to ensure that serious incidents, per JCAP criteria, are reported promptly and investigated within 45 days, all to prevent serious incidents in the future (III.4.B)	<b>Partial Compliance working towards Substantial Compliance</b>
49	Informed by data from Therap, develop a systemwide plan to analyze incident patterns and trends to prevent incidents in the future (III.4.B)	<b>Partial Compliance working towards Substantial Compliance</b>





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No. BM	Benchmark	JCC September 2021 Report
50	Implement these systemwide plans and implement remedial measures to address any individual and/or systemic issues that arise from the investigations and incident analysis to ensure participant safety and welfare and minimize/eliminate abuse and neglect (III.4.B)	<b>No Compliance</b>
51	Implement effective measures to minimize/eliminate use of all restraints on participants (III.4.C)	<b>No Compliance</b>
52	Prohibit use of standing PRN or "stat" orders for chemical restraints on participants (III.4.C)	<b>No Compliance</b>
<b>III.5 Health Care and Mental Health Care</b>		
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)	<b>In Compliance</b>
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)	<b>No Compliance</b>
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	<b>No Compliance</b>
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	<b>Partial Compliance working towards Substantial Compliance</b>
57	Maintain effective communication with community clinicians to determine if they provide informed and comprehensive individualized evaluations and treatment that meet individualized participant needs (III.5.B); However, the original benchmark reads as follows: Monitor community clinicians to ensure they provide informed and comprehensive individualized evaluations and treatment that meet individualized participant needs (III.5.B)	<b>No Compliance</b>
58	Ensure participants receive necessary health care in a timely manner to meet their individualized needs in the community (III.5.G)	<b>Working towards Substantial Compliance</b>
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	<b>Partial Compliance working towards Substantial Compliance</b>



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<b>60</b>	Through Therap and other means, implement a systemwide plan to work with community clinicians to promptly and proactively develop and implement tailored and intensive protections, supports, services for priority at-risk participants to meet their individualized needs (III.5.I): <b>NOTE</b> , original benchmark did not mention THERAP.	<b>No Compliance</b>
<b>No. BM</b>	<b>Benchmark</b>	<b>JCC September 2021 Report</b>
<b>61</b>	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)	<b>Partial Compliance working towards Substantial Compliance</b>
<b>62</b>	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	<b>Partial Compliance working towards Substantial Compliance</b>
<b>63</b>	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)	<b>Working towards Substantial Compliance</b>
<b>64</b>	Regularly share this information with community clinicians (III.5.J)	<b>Working towards Substantial Compliance</b>
<b>65</b>	Maintain effective communication with community clinicians to determine how they utilize this information to implement measures to meet individualized participant needs (III.5.J)	<b>Working towards Substantial Compliance</b>
<b>Neurological</b>		
<b>66</b>	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)	<b>Partial Compliance working towards Substantial Compliance</b>
<b>67</b>	Ensure that neurologists provide participants with a seizure disorder with comprehensive neurology evaluations as needed, at least annually (III.5.K)	<b>Partial Compliance working towards Substantial Compliance</b>
<b>68</b>	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)	<b>No Compliance</b>
<b>69</b>	Ensure that neurologists provide effective care for those having 10+ seizures per year (III.5.K.1)	<b>No Compliance</b>



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<b>70</b>	Ensure that neurologists provide effective care for those who have not had a seizure in the past two years (III.5.K.1)	<b>Working towards Substantial Compliance</b>
<b>No. BM</b>	<b>Benchmark</b>	<b>JCC September 2021 Report</b>
<b>71</b>	Ensure that neurologists weigh the benefits of medication use and adequately document the rationale for anticonvulsant medication (III.5.K.2)	<b>Partial Compliance working towards Substantial Compliance</b>
<b>72</b>	Ensure the use of intra-class polypharmacy is minimized and fully justified (III.5.K.2)	<b>No Compliance</b>
<b>73</b>	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)	<b>In Compliance</b>
<b>Aspiration Risks</b>		
<b>74</b>	From the Master List, create a sub-list of those participants at risk of aspiration and/or aspiration pneumonia	<b>In Compliance</b>
<b>75</b>	Implement individualized plans to eliminate unsafe mealtime practices, per JCAP criteria, to minimize risk of aspiration/pneumonia (III.5.L)	<b>Working towards Substantial Compliance</b>
<b>76</b>	Implement individualized plans to keep non-ambulatory individuals in proper alignment to minimize risk of aspiration/pneumonia (III.5.L)	<b>Working towards Substantial Compliance</b>
<b>CEEC</b>		
<b>77</b>	Ensure CEEC regularly evaluates all participants (III.5.C); compile list of ongoing evaluations	<b>Partial Compliance working towards Substantial Compliance</b>
<b>78</b>	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	<b>No Compliance</b>
<b>79</b>	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	<b>No Compliance</b>
<b>80</b>	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	<b>No Compliance</b>



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<b>81</b>	Develop and implement effective systemwide plan for CEEC to promptly communicate concerns to community clinicians that improve outcomes (III.5.E); compile list of improved outcomes after CEEC intervention	<b>No Compliance</b>
<b>No. BM</b>	<b>Benchmark</b>	<b>JCC September 2021 Report</b>
<b>82</b>	Implement a systemwide protocol to alert licensing, ombudsman agencies of community clinician improprieties (III.5.F); compile list of alerts	<b>No Compliance</b>
<b>83</b>	Ensure CEEC serves as a mobile crisis team, providing prompt, effective, flexible, individualized, mobile, expert support, services, and advice at community sites during emergencies, crises, transitions 24/7 to meet individualized needs (III.5.C); compile list of mobile crisis team visits/interventions, summarizing result	<b>No Compliance</b>
<b>84</b>	Ensure CEEC mobile crisis team is comprised of multi- disciplinary group of DD professionals (III.5.D)	<b>No Compliance</b>
<b>85</b>	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	<b>No Compliance</b>
<b>Mortality Review</b>		
<b>86</b>	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)	<b>In Compliance</b>
<b>87</b>	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	<b>In Compliance</b>
<b>88</b>	Ensure MRC has access to all pertinent people, information related to the course of care leading up to the death (III.5.N.3)	<b>In Compliance</b>
<b>89</b>	Ensure MRC performs a root-cause analysis to identify any preventable causes of illness and death (III.5.N.5)	<b>Substantial Compliance working towards In Compliance</b>
<b>90</b>	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)	<b>Substantial Compliance working towards In Compliance</b>



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<b>91</b>	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	<b>No Compliance</b>
<b>92</b>	Monitor to ensure MRC process is effective to avoid preventable illnesses, deaths for similarly situated individuals (III.5.N)	<b>No Compliance</b>
<b>No. BM</b>	<b>Benchmark</b>	<b>JCC September 2021 Report</b>
<b>Mental Health / Salud Mental</b>		
<b>93</b>	From the Master List, create a sub-list of all participants with mental illness, specifying their mental illness diagnosis/es (III.5.G)	<b>Partial Compliance working towards Substantial Compliance</b>
<b>94</b>	Ensure participants receive necessary mental health care in a timely manner to meet their individualized needs in the community (III.5.G)	<b>No Compliance</b>
<b>95</b>	Ensure that all mental illness diagnoses are consistent with DSM criteria and justified in the record (III.5.M)	<b>Partial Compliance working towards Substantial Compliance</b>
<b>96</b>	Ensure that no participant receives psychotropic medication in the absence of a clinically justifiable diagnosis of mental illness (III.5.M)	<b>No Compliance</b>
<b>97</b>	Ensure that type, dosage of psychotropic medication are appropriate and needed for each participant, per JCAP criteria (III.5.M)	<b>No Compliance</b>
<b>98</b>	Minimize use of typical/first generation psychotropic medication (III.5.M)	<b>No Compliance</b>
<b>99</b>	Minimize use of intra-class psychotropic medication polypharmacy (III.5.M)	<b>No Compliance</b>
<b>III.6 Systemwide Reforms</b>		
<b>100</b>	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)	<b>Partial Compliance working towards Substantial Compliance</b>
<b>101</b>	Implement prompt and effective measures to address patterns and trends that adversely impact participant safety, welfare, health, and mental health (III.6.A)	<b>Working towards Substantial Compliance</b>
<b>102</b>	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	<b>Partial Compliance working towards Substantial Compliance</b>
<b>103</b>	Work with family members of participants on a plan to address quality issues that impact participants	<b>No Compliance</b>



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<b>104</b>	Create and maintain toll-free crisis hotline, staffed 24/7 by qualified professionals that can effectively help to resolve issues (III.6.B)	<b>Substantial Compliance working towards In Compliance</b>
<b>105</b>	Create and maintain a systemwide email system to facilitate prompt communication to all pertinent individuals, per JCAP criteria to resolve outstanding issues (III.6.C)	<b>Partial Compliance working towards Substantial Compliance</b>
<b>106</b>	Develop a family support program consistent with the criteria in the CBSP (V) that includes service mediators for participants living at home, as well as a subsidy and respite program; participation in the program will be voluntary with prior authorization in private homes	<b>Partial Compliance working towards Substantial Compliance</b>



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**EXHIBIT B: MISSING/PENDING INFORMATION**

<u>No. BM</u>	<u>Benchmark</u>	<u>Comment in JCC Report</u>
<b>III.3 Integrated Employment and Day Activities</b>		
31	Implement the plans (III.3.E)	DSPDI furnished "List of Documentation in Individualized Plans or Vocational Plans and Status of Migration to Personal Focus Worksheet in THERAP", reference in Benchmark 30. The charts fail to indicate specific plans regarding community activity engagement, and whether the Personal Focus Worksheet (PCP) plans have been implemented, and, if so, what the participant's respective progress is with respect to their 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	DSPDI furnished "List with all activities performed during the pandemic", referenced in Benchmark 36. There was no information furnished by DSPDI regarding this benchmark. CTS day programming has yet to resume since the global pandemic was declared in March of 2020.
33	From the Master List, create a sub-list of those who <b>do not work or participate in formal day program activities at a CTS</b> and assess why they do not and remain at home (III.3.F)	The DSPDI included a list of participants that did not assist the CTS for the period of January to June 2021. The list includes 81 participants (12% of the 641), gender, and reason for not attending the CTS. Some of the reasons for not attending date back to 2018 and others make reference to documents included in paper file (no further reason is included in the 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	DSPDI furnished "List with all activities performed during the pandemic", referenced in Benchmark 36. There was no information furnished by DSPDI regarding this benchmark.
35	Implement the plans (III.3.F)	DSPDI furnished "List with all activities performed during the pandemic", referenced in Benchmark 36. There was no information furnished by DSPDI regarding this benchmark.
<b>III.4 Safety and Restraint Issues</b>		



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41	Implement measures to ensure participant safety and welfare based on this analysis (III.4.A)	DSPDI furnished a report issued by the Incident Committee. The DSPDI report only included those incidents classified as high, omitting the low and medium incidents. There were no formalized measures or report reflective of the implementation status of any measures included in the information provided.
42	Using data from Therap combined with first-hand accounts, analyze peer-to-peer interactions that create risk of harm (III.4.A.1)	DSPDI furnished report of peer-to-peer interactions and incidents. It should be noted that this table has the terms and the language established in the JCAP, however, the report lacks essential information for an analysis in order to reach a conclusion of the incidents.
43	Implement effective measures to address peer-to-peer risk factors to prevent harm (III.4.A.1)	DSPDI furnished a report issued by the Incident Committee, referenced in Benchmark 41. There were no formalized measures or report reflective of the implementation status of any measures included in the information provided. No information was provided on peer-to-peer interactions that were not considered to be high level.
44	Using data from Therap combined with first-hand accounts, identify vulnerable participants at risk of harm (III.4.A.2)	The DSPDI furnished a list of vulnerable participants, pursuant to Therap data. Table does not include January, February and June 2021.
45	Implement effective measures to minimize/eliminate their risk factors (III.4.A.2)	DSPDI furnished a report issued by the Incident Committee, referenced in Benchmark 41. There were no formalized measures or report reflective of the implementation status of any measures included in the information provided.
46	Using data from Therap combined with first-hand accounts, identify aggressor participants (III.4.A.3)	The DSPDI furnished a list of aggressor participants, pursuant to Therap data. Table does not include January, February or March 2021, nor does it track participants identified as aggressor in past years. The DSPDI only includes participants with "incidents of aggression towards others". Further, table does not include the participants: MFW 167, CMR 1123 and RLH 1105 that the Incident Committee reported as aggressors. In addition, measures to implement effective measures to minimize/eliminate aggressor risk triggers are unknown.
47	Implement effective measures to minimize/eliminate aggressor risk triggers (III.4.A.3)	DSPDI furnished a report issued by the Incident Committee, referenced in Benchmark 41. There were no formalized measures or report reflective of the implementation status of any measures included in the information provided.





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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)	DSPDI furnished a report issued by the Incident Committee, referenced in Benchmark 41. The Office of the JCC recognize that the new DSPDI leadership is receptive and establishing a structure to address incidents (protocols, education, etc.). However, the outcome of the prevention and action plans remains unknown.
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)	DSPDI furnished a report with statistics and analysis of incidents, pursuant to Therap data and Report issued by the Incident Committee referenced in Benchmark 41. However, no plan was provided for the analysis of incident patterns and trend to prevent future incidents.
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)	A monthly analysis of various incident classifications per participant and by community home was provided. However, the information provided did not include any neither system wide plans nor remedial measures or report reflective of the implementation status of any measures included in the information provided.
51	Implement effective measures to minimize/eliminate use of all restraints on participants (III.4.C)	DSPDI furnished a report issued by the Incident Committee, referenced in Benchmark 41. There were no formalized measures or report reflective of the implementation status of any measures included in the information provided. However, there were at least two incidents of restraint that occurred during the year for participants that were not documented as such.
<b>III.5 Health Care and Mental Health Care</b>		
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	The DSPDI furnished a table that combined Benchmarks 54, 55, 56, 57 and 58 including a list of nursing referrals and list of participants with significant changes in health. Other than a letter issued by the Director requiring delivery to physicians of pertinent medical information from Therap, no more information was submitted by DSPDI.
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)	The DSPDI furnished a table that combined Benchmarks 54, 55, 56, 57 and 58 including a list of nursing referrals and list of participants with significant changes in health. Other than letter issued by the Director requiring delivery to physicians of pertinent medical information from Therap, no more information was submitted by DSPDI.



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58	Ensure participants receive necessary health care in a timely manner to meet their individualized needs in the community (III.5.G)	The DSPDI furnished a table that combined Benchmarks 54, 55, 56, 57 and 58 including a list of nursing referrals and list of participants with significant changes in health. Other than letter issued by the Director requiring delivery to physicians of pertinent medical information from Therap, no more information was submitted by DSPDI.
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)	The DSPDI furnished a list of priority, at-risk participants with each participant's condition, risk classification, comments regarding medical evaluations, follow up- efforts with physicians, and medication (see Benchmark 59). However, no information on the implementation of 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.
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	There was not any specific information shared about these changes in terms of the number of nursing staff hired, whether the nurses are operating in a traveling program, nor documentation of nursing contacts with participants. No information was provided for this benchmark by the DSPDI.
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)	The DSPDI furnished a list of priority, at-risk participants with each participant's condition, risk classification, comments regarding medical evaluations, follow up- efforts with physicians, and medication (see Benchmark 59). However, no analysis was provided by the DSPDI to evaluate compliance with this benchmark.
64	Regularly share this information with community clinicians (III.5.J)	The DSPDI furnished a list of priority, at-risk participants with each participant's condition, risk classification, comments regarding medical evaluations, follow up- efforts with physicians, and medication (see Benchmark 59). However, no analysis was provided by the DSPDI to evaluate compliance with this benchmark.



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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)	The DSPDI furnished a list of priority, at-risk participants with each participant's condition, risk classification, comments regarding medical evaluations, follow up- efforts with physicians, and medication (see Benchmark 59). However, no analysis was provided by the DSPDI to evaluate compliance with this benchmark.
<b>Neurological Care</b>		
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)	The DSPDI furnished list of participants with an epilepsy diagnosis including medications, name of neurologist, last convulsion, and last visit. The Office of the JCC is concerned regarding the accuracy and completion of the list based on the medication regimen found.
67	Ensure that neurologists provide participants with a seizure disorder with comprehensive neurology evaluations as needed, at least annually (III.5.K)	Reference was made by the DSPDI to list furnished for Benchmark 66. However, no evidence was provided to support annual comprehensive neurology evaluations.
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)	Reference was made by the DSPDI to master list of participants with epilepsy (See Benchmark 66). The list does not provide sufficient information to identify participants with 10+ seizures in the past year or with no seizures in the past two years.
69	Ensure that neurologists provide effective care for those having 10+ seizures per year (III.5.K.1)	Reference was made by the DSPDI to master list of participants with epilepsy (Benchmark 66) and neurologists' reports (Benchmark 67). We were unable to assess this benchmark in the current report. Neurological evaluations were provided in largely illegible hand-written notes, thus the Office of the JCC and experts were unable to assess this Benchmark.
70	Ensure that neurologists provide effective care for those who have not had a seizure in the past two years (III.5.K.1)	Reference was made by the DSPDI to master list of participants with epilepsy (Benchmark 66) and neurologists' reports (Benchmark 67). However, regarding efficacy of care, the Office of the JCC and experts are unable to fully assess this benchmark in the current report. Further, information for neurological evaluations was provided in largely illegible hand-written form.
<b>CEEC</b>		
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	The DSPDI furnished a list of evaluations performed by the CEEC (See Benchmark 77). Although the Office of the JCC saw evidence that the CEEC has been supporting and offering its services, no further information was provided by the DSPDI to verify regular review by the CEEC.



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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	The DSPDI furnished a list of evaluations performed by the CEEC (See Benchmark 77). Although the Office of the JCC saw evidence that the CEEC has been supporting and offering its services, no list was provided of ongoing instances of contacting community clinicians to raise red flags/advocate for participants, summarizing results of contact.
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	The DSPDI referenced list of hospitalizations and visits to the emergency room. However, no information was provided as to CEEC providing community clinicians of recent adverse health/mental health outcomes that may implicate treatment.
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	The DSPDI referenced list of hospitalizations and visits to the emergency room (See Benchmark 80). However, no information on CEEC interventions or associated outcomes was provided by the DSPDI.
82	Implement a system wide protocol to alert licensing, ombudsman agencies of community clinician improprieties (III.5.F); compile list of alerts	The DSPDI referenced list of hospitalizations and visits to the emergency room (See Benchmark 80). However, no information on implementation of alerts to licensing, ombudsman agencies of community clinicians' improprieties was provided.
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	The CEEC consultants' availability and support is not evident in the documents submitted by DSPDI. The use of CEEC consulting services is indirectly evident in documents in were they are mentioned, as well as case notes of Therap services, attendance to conference call meetings, and consults in the fields of psychology and nursing.  Changes in consultation and support staff have occurred, however the handling and mobile crisis team is not evidenced.
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	The DSPDI referenced list of hospitalizations and visits to the emergency room (See Benchmark 80). However, no information was provided from the DSPDI regarding instances where mobile crisis teams have intervened recently, or the results of such intervention.
	<b>Mortality Review</b>	



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94	Ensure participants receive necessary mental health care in a timely manner to meet their individualized needs in the community (III.5.G)	The DSPDI furnished list of participants specifying illness diagnosis(es). However, no information was provided for this benchmark.
96	Ensure that no participant receives psychotropic medication in the absence of a clinically justifiable diagnosis of mental illness (III.5.M)	For this Benchmark the DSPDI furnished (i) Polypharmacy Project Status Report, (ii) Draft Letter to Community Doctors, (iii) Polypharmacy Directive. At present, there is still no change in the medications of the DSPDI participants and they continue to be exposed to the risks that polypharmacy imposes on their health and quality of life. Further, the list of participants with psychiatric diagnoses was not provided by DSPDI.
99	Minimize use of intra-class psychotropic medication polypharmacy (III.5.M)	The DSPDI referenced documents provided for Benchmark, 96. However, there is not sufficient information to review the justification of the intra-class polypharmacy.
<b>III.6 System wide Reforms</b>		
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)	The DSPDI furnished the Participant Health, Safety and Well-being Protocol. However, there is no information or evidence of implementation has been evidenced at this time. The DSPDI further referenced documents furnished for Benchmark 40 (List of High-Risk Participants in Therap) Benchmark 41(Incident Report and Recommendations), Benchmark 42 (List of Peer to Peer Interactions), Benchmark 44 (List of Vulnerable Participants at Risk of Harm) Benchmark 46 (List of Aggressor Participants), Benchmark 48 (Incident Data Entry Manual) and Benchmark 49 (Analysis of Incident Patterns from Therap Data).
104	Create and maintain toll-free crisis hotline, staffed 24/7 by qualified professionals that can effectively help to resolve issues (III.6.B)	The DSPDI furnished a list with a log of calls to the crisis hotline, reason for call and action steps. However, there is no evidence of a plan or schedule for staffing the hotline 24/7.



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**EXHIBIT C: SEPTEMBER 15, 2021 COURT HEARING DEADLINES (SEE DOCKET NO. 3533)**

- 1. The transfer of all participants from Shalom Institution to community home settings (“CHS”) and the status of transferring participants from Instituto Psicopedagógico (“IPPR”) to CHS.**  
Court Deadline: Deadline for transfer of participant is February 28, 2022.  
Must keep the Office of the JCC informed on a monthly basis.
- 2. Eradicating overcrowding of participants in community and biological homes.**  
Court Deadline: February 28, 2022.  
Must keep the Office of the JCC informed on a monthly basis.
- 3. The opening of new community homes with the expanded Court-approved budget.**  
Court Deadline: February 28, 2022 for 75%  
June 30, 2022 for 25%  
Must keep the Office of the JCC informed on a monthly basis.
- 4. The opening of respite homes for complex cases, dual-diagnosis cases, medication tapering spaces, and transition centers (See Docket No. 3499).**  
Court Deadline: February 28, 2022 for the tapering and transitional centers.  
June 30, 2022 for the rest of the homes.  
Must keep the Office of the JCC informed on a monthly basis.
- 5. The Status of the CEEC Mobile Crisis team, as required by Section III, Paragraph 5 (C) of the JCAP.**  
Court Deadline: December 31, 2021.  
Must keep the Office of the JCC informed on a monthly basis.
- 6. Status of specific steps taken by the DSPDI to eliminate the problems that that were addressed in Dr. Roberto Blanco’s Polypharmacy Report.**  
Court Deadline: July 30, 2022 to end the polypharmacy issues.  
Must keep the Office of the JCC informed on a monthly basis.
- 7. Potential labor challenges being confronted by the DSPDI (“Division”) in its reopening efforts, including community homes, daily centers (CTS), the Division and employed participants.**  
Court Deadline: December 31, 2021, second deadline is of February 28, 2022.  
Must keep the Office of the JCC informed on a monthly basis.
- 8. Status of provider payments and contracts, and any other pending financial issue that may affect the continuity of services rendered to participants, including the use of available rollover funds and the Court-ordered reserve funds.**  
Court Deadline: N/A  
Must keep the Office of the JCC informed on a monthly basis.



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**9. Dental Clinic status and the opening of a new clinic in Aguadilla.**

Court Deadline: N/A

**10. DSPDI action plan to provide the third dose of the COVID-19 vaccine to participants and DSPDI staff members, contractors, service providers, and family members of participants, etc.**

Court Deadline: N/A

**11. Status of pending mortality reports and related matters.**

Court Deadline: N/A

**12. Specific transformative steps that have been taken to ensure that the principles of Person-Centered Planning as addressed by the Court at Docket No. 3510 are being implemented for the benefit of every participant's right to make the necessary decisions towards the aspiration of independent living.**

Court Deadline: February 28, 2022.

Must keep the Office of the JCC informed on a monthly basis.

**13. Other Mattes: ASG purchases and bids/auctions**

Court Deadline: Commencing on September 30, 2021, the DSPDI shall inform the JCC every 15<sup>th</sup> and 30<sup>th</sup> of the status of matters before ASG.

DSPDI shall keep in constant communication with the Office of the Governor of bids and purchases so that the needed priority is always given.