JCC SEMI-ANNUAL REPORT
UNITED STATES V. PUERTO RICO
CASE NO. 99-1435 (SCC)
SEPTEMBER 2022

Benchmarks and Supplement Narrative

Office of the Joint Compliance Coordinator

I, Alfredo Castellanos, Esq., in my independent capacity as Joint Compliance Coordinator ("JCC" or "Federal Monitor"), hereby certify that the present September 2022 Semi-annual Report has been prepared by the undersigned, discharging my duty to evaluate progress of the Commonwealth of Puerto Rico ("Commonwealth") and its Department of Health's Division for Adults with Intellectual Disabilities (hereinafter referred throughout the Report as "DSPDI," "Division," or "Program") in complying with the consent decree (hereinafter referred to as the "Joint Compliance Action Plan" or "JCAP," and at other times, the "Agreement," as well as the related "Benchmarks" or "BMs"). The present Report includes and addresses the Parties input and comments as required by the directives of the Court (see Docket No. 2589). When warranted, in our role as a guiding hand, we will recommend remedial advice and action plans with the objective of assisting the Commonwealth to reach sustainable compliance, as they relate to the Agreement. The present Semi-annual Report was prepared with the input and contributions of the following party-stipulated experts, subject-matter experts, and JCC team experts (collectively referred to as "Experts")[1]:

Party-stipulated Experts:

- Dr. Emily Lauer and her team of experts at the University of Massachusetts/CDDER.

Subject-matter Expert:

- Dr. Serena Lowe (AnereS Strategies, LLC).

JCC Team Experts:

- Dr. Dimaris García, Psy. D. (Psychologist and JCC Team Expert);
- Dr. Carmelo Rodríguez, Psy. D. (Psychologist and JCC Team Expert);
- Ms. Tirsa Sosa, MSW (Social Worker and Ex-Director of the Bayamón CTS/Daily Center).
- Ms. Jeannie Castillo (Administrative Assistant/ Expert Liaison with Participants).

JCC Team:

- Ms. Diana Alcaraz, Esq./CPA (Court-appointed Special Investigator and Legal Advisor to the Federal Monitor);
- Mr. Salvador M. Carrión, Esq. (Legal Advisor to the Federal Monitor);
- Mr. Javier González (Executive Director of the Office of the JCC and Federal Monitor in Management).

Alfredo Castellanos, Esq.
JCC/Federal Monitor

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

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JCC'S September 2022 Semi-annual Assessment Report Main Highlights[2]

Specific areas where progress has been achieved:

1. **Implementation of the Six-month Action Plan**

As further explained in the Report, the DSPDI has been collaborating with the JCC Experts on a Six-Month Action Plan ("Plan") that was established to assist the Commonwealth reach higher compliance levels in the areas of High-Risk Population and Polypharmacy; Deinstitutionalization and Independent Living; Employment and Job Placement; Incident Reporting, Investigations; and other remedial action areas. This is a working plan established between the Commonwealth and the Office of the JCC; the United States has not reviewed or endorsed the Plan, nor has the United States participated in any collaborative discussions with the Commonwealth and the Office of the JCC related to the Plan.

As part of the Plan, focused DSPDI-JCC team work groups have been created for each of the above areas, where effective measures and professionally accepted standards and practices with the ID/DD population have been discussed. These collaborative efforts have produced higher compliance levels in many areas. Important work continues to be done to increase compliance levels in areas that are still deficient.

2. **Results reflected in increased compliance levels**

The effectiveness of the Plan is directly reflected in the higher compliance rates that we are reporting, **where the Commonwealth has achieved some form of compliance in almost all of the non-outcome provisions of the Benchmarks**.

Moreover, the Commonwealth has achieved a higher level of compliance with regard to most of the Benchmarks when compared to previous JCC reports, **which translates to an overall compliance level of 32% – this is the best level of compliance that the Commonwealth has achieved thus far** and represents a drastic increase when compared to the JCC's March 2021 Report, where the Commonwealth's compliance level was at an all-time low. [3]

3. **Practices to promote continuity during personnel transitions within DSPDI**

[2] The review period for this Report is January 1, 2022, through June 30, 2022.

[3] In order to respond to an inquiry that was brought up by the Commonwealth of Puerto Rico as to why we have adopted a more flexible standard in the level of compliance determination in contrast to the one that has been used in our previous Assessment Reports, the JCC clarifies that the adoption of this standard was done to properly acknowledge that the DSPDI is achieving important progress and is engaging in collaborative efforts and constructive activity necessary to attain meaningful and positive outcomes. If we would limit our assessment to those benchmarks for which the DSPDI has achieved an assessment level of "In Compliance" the DSPDI would be at a significantly low compliance level, which does not properly illustrate the progress achieved. If there is any regression in the DSPDI's compliance levels, the proper assessment will be reflected in future Reports.

Although there have been significant changes in DSPDI leadership during the period covered in the present Report (which has been a recurring issue throughout the Consent Decree), the current Administration has adopted effective transition practices which have promoted continuity, avoided disruptions in progress and helped ensure the delivery of essential services to participants.

It is important that the DSPDI formalize these parameters in a permanent institutionalized policy, by way of an administrative order for example, to ensure that unproductive disruptions do not occur during the transition of key DSPDI personnel going forward.

4. Opening of new community homes and specialized homes

During the period between January 1, 2022, and June 30, 2022, the DPSDI opened a total of five new community homes, which represent 25 new living units for participants. In addition, the Division provided a list of nine providers who are in advanced stages of the contractual process and are expected to open new homes soon for a total of 43 additional beds.

The opening of new homes has helped reduce overpopulation problems that the Program has confronted in the past, while the opening of specialized homes in both clinical and behavioral care have provided many deinstitutionalized participants with adequate services in a community integrated setting, as well as respite services for community providers and biological caregivers.

5. Retention of additional personnel for specialized services

During the last year, the DSPDI has retained the services of additional professionals to offer services in the areas of nutrition, speech pathology, neurology, vocational rehabilitation counseling, and end-of-life issues among others. The hiring of these professionals has provided positive benefits for participants, which is reflected in the level of progress that we are reporting. The JCC expects that the Commonwealth will continue to hire until the Division is properly staffed with all the professionals that are needed to render the services that are mandated by the JCAP.

6. Submitting Mortality Review Committee reports within 30 days

The Commonwealth is now generally providing the United States and the JCC with final MRC reports in a timely manner; in the past, delinquent reports had been a serious problem, prior to the appointment of the MRC Chairwoman, Dr. Yocasta Brugal.

Currently, the mortality reports are being furnished within the 30-day timeframe required by the JCAP, even when autopsies have been requested. In the cases with an autopsy though, preliminary MRC reports have later been supplemented with new information obtained from the autopsy reports.

7. Creation of the Committee for the Assessment of Polypharmacy and High-Risk Participants ("CAPAR")

The creation of the Committee for the Assessment of Polypharmacy and High-Risk Participants ("CAPAR") has proven to be a positive step towards addressing many problem areas that we had encountered in the past. Although CAPAR has much more work to do to address outstanding issues, we have seen an increasing number of referrals to CAPAR to evaluate and follow-up on incidents, falls, and changes in the health status of participants. CAPAR also conducts some medical evaluations of high-risk participants. The JCC recommends that the function of CAPAR become formalized and permanent within the DSPDI.

8. Improved services and attention from neurologists

It is positive that more participants with epilepsy are receiving services from neurologists. As required by the JCAP, CAPAR has identified a subgroup of participants that have had more than 10 seizures per year and has established them as a priority group for review; the CAPAR neurologist will be involved in reviewing the treatment plans for these participants.

9. Improved plans related to aspiration pneumonia risks

During the present period 167 participants were included in a DSPDI sub-list of participants at risk of aspiration. This constitutes a 38% increase when compared with the 121 participants that were previously identified by the DSPDI in our March 2022 Report. This increase is a reflection of the collaborative work between the DSPDI and the Office of the JCC Experts to confirm participants' correct diagnoses and improve the accuracy of information that is included in participants' records and in the Therap platform.

The Commonwealth has developed new and improved treatment plans for the majority of participants with aspiration risks, compared to prior semi-annual reports. They include more strategies that are directly responsive to aspiration risks, including appropriate and clear instructions with regard to diet texture and consistency recommendations, positioning during and after feeding, size/amount of food/liquid at a time, amount, and pace appropriate for each participant, along with individualized behavioral prompting/clues, among others.

10. Identification of participants with mental health issues

The DSPDI appears to have effectively identified all participants with mental health issues with a corresponding diagnosis properly documented in both the participants' records and in the Therap platform. Most of these participants have had new psychiatric evaluations during the past year with many face-to-face with a psychiatrist.

11. CAPAR review of psychotropic medications and polypharmacy

CAPAR clinicians have begun reviewing all prescriptions of intra-class polypharmacy, particularly in combinations identified to be of high risk. Also, the CAPAR has been conducting outreach to community-based prescribers to ask specific questions regarding assessment and treatment practices and, at times, CAPAR has proposed changes in the medication regimen prescribed for participants. (See page 78)

12. Collaboration with the Commonwealth Department of Family Affairs

Pursuant to the Interagency Collaborative Agreement signed between the Department of Education, the Department of Family Affairs ("DFA"), and the Department of Health in March 2018, the JCC has been working with the DFA to properly identify all individuals with an ID/DD diagnosis who are under DFA jurisdiction and who may qualify to receive services from the DSPDI. The DFA has cooperated and expressed its openness and shown its intent collaborate with the JCC and the DSPDI to see how DSPDI services can be provided to these individuals in light of current DSPDI resources.

For such purposes, a ledger will be prepared to properly diagnose and identify all individuals with ID/DD that are under the jurisdiction of the DFA, premised on recommendations that were made by joint party expert, Dr. María Margarida Juliá.

Specific areas where significant progress has yet to be achieved:

1. **Implementation of effective measures to meet the needs of participants subjected to polypharmacy and those with high-risk conditions**

Earlier in this Report, the JCC recognized that the Commonwealth has made some notable progress in retaining additional personnel for specialized services, conducting individualized reviews and follow up through CAPAR, and improving plans for those with aspiration risks. Nonetheless, there are still significant outstanding issues related to the *implementation* of effective measures to address the needs of participants subjected to polypharmacy and to address the needs of those participants with high-risk conditions, such as behavior problems and/or medical/health issues like a risk for bowel obstruction or risk for aspiration. Hiring personnel, conducting paper reviews, and developing paper plans is not sufficient to ensure the actual delivery of effective services and supports on the ground in the community to meet the individualized needs of each participant to ensure their health, safety, and welfare.

2. **Integrated employment**

Although the JCC recognizes that the DSPDI has made some progress in this area, we have identified outstanding and lingering compliance issues, including: findings and actions that are not consistent with recommended practices from the Psychology Division; lack of access to community-based exploratory activities and/or work experiences; and patterns of sub-minimum wages, inadequate hours, and employment that is not truly integrated. Specific recommendations to address these issues, and thus, reach higher compliance levels in this area, are provided on page 8 of this Report.

3. **Incident reporting and effective implementation of behavior plans**

The current incident reporting structure and protocols that are being used by the DSPDI in Therap are contributing to misclassification and/or confusion, resulting in improper reporting by providers. There is

also overall fragmentation of information related to incidents that are documented on hard copy forms and complaints that do not get uploaded into Therap, which may result in the exclusion of important events and incidents that are needed and highly useful when reviewing conduct patterns for individual participants to help ensure their safety and well-being.

Moreover, there is a substantial lack of written and properly implemented behavior plans for many participants to properly address the root causes of participant's aggression, self-injury, etc. Specific recommendations to address these issues, and thus, reach higher compliance levels in this area are provided on page 10 of this Report.

4. **Implementation of needed remedial measures to address issues identified by the MRC**

Although we have identified significant progress in the timeliness of the mortality reports, outstanding issues remain with regard to the implementation of needed remedial measures to address identified issues. Such remedial measures should correct individual, regional, and systemic issues so as to minimize or eliminate situations and practices that lead to preventable illness and death. Furthermore, there is no adequate means of monitoring the implementation of the needed remedial measures in existing DSPDI policy. The JCC has requested a meeting with the MRC to discuss how to address this going forward.

5. **Interventions to avoid hospitalizations during a crisis or decline**

Although the JCC Office reviewed three interventions by the mobile crisis team that potentially prevented the need for more acute intervention, most of the other interventions listed in the sample provided by the DSPDI do not reveal that the mobile team took needed action to prevent contact with a hospital or institutional setting.

The above deficiency led to a participant being placed in an institutional setting during a crisis situation, and, as a result, the participant suffered a serious adverse (and potentially criminal) outcome.

Related to the above, the JCC is currently coordinating meetings with the Commonwealth's Judicial Branch in order to address highly important issues that individuals with ID/DD are currently confronting in the Commonwealth, especially when they appear before the local judicial branch.

6. **Providing DSPDI services and supports to participants currently residing in ASSMCA and DFA homes**

There is still much more work to be done in regards to providing DSPDI services and supports to participants currently residing in ASSMCA and DFA homes; this likely will require transferring these participants to DSPDI community homes. As part of this process, the DSPDI must ensure the proper development and implementation of person-centered plans and individualized treatment plans for these participants.

II. OVERARCHING OBSERVATIONS AND EXPERT RECOMMENDATIONS

A. Implement Effective Remedial Measures

The Commonwealth needs to *implement* remedial measures to ensure that the processes and paper plans developed thus far, result in the effective delivery of needed healthcare, behavioral, and other services to ensure participants' health, safety, and welfare based on each participant's individualized needs.

B. Employment & Integrated Day Systems-Level Recommendations

The DSPDI has made progress: retaining the front-line rehabilitation staffing needed to support participants in pursuing employment-related activities in the community; working with the Experts to identify opportunities to improve internal processes and establish training plans to support integrated employment for participants; and piloting new strategies for exposing participants in real-time to the community and integrated employment experiences. But, as set out in this Report, there are ongoing areas of concern. Given this, the JCC encourages the DSPDI to focus on addressing the following issues as it continues to move forward to promote full community non-segregated inclusion and competitive integrated employment for participants.

- *Disparate findings and actions from the Psychology Division:* The DSPDI should develop and implement a protocol and internal process for the Psychology Division and Rehabilitation Counseling Division to coordinate actions to prevent the negative impact of decisions made by one division without transparent communications or collaborative solutioning. For example, this may include decisions made by the DSPDI's psychological personnel that interrupt vocational services and impede a participant's ability to pursue or maintain community employment. In one case, Participant #505had one isolated outburst of the participant in their home (threw a phone during a temper tantrum. Apparently, the participant's frustration stemmed from being unable to speak directly with the CTS Director and not having independent living desires acknowledged or supported. As a result of this, the psychology personnel decided that the participant should not be allowed to continue to work for a period of three months. This decision was made without the input of the rehabilitation staff supporting the individual in their employment, and notwithstanding the participant's employer's request to the DSPDI to reconsider the suspension from work due to the employer's satisfaction with the work rendered by the participant. This appears to be a systemic barrier due to a lack of clear policy guidance. The Commonwealth needs to develop and update internal standard operating procedures that require the Psychology Division and Rehabilitation Counseling team to work together when needed on developing participant-specific recommendations around any actions that would negatively impact the current employment, community-based discovery activities, or career planning activities of the participant. **Individual psychology assessments and follow-up visits should be face-to-face**

whenever possible, not via videoconference, to promote more effective and tailored participant interventions.[4]

- *Lack of Access to Community-Based Exploratory Activities or Work Experiences*: In its latest document submission, the Commonwealth identified 19 participants as working, all of whom may be underemployed. The Commonwealth identified at least an additional 30 participants with the potential for competitive employment. It was not evident though that the majority of the 21 participants identified as underemployed or the other 30 who are unemployed are receiving substantial access to community-based exploratory activities (such as community-based internships, job-shadowing, apprenticeships, mentoring, or pre-employment or on-the-job training). Instead, there seems to be a pervasive placement of individuals into jewelry- or craft-making workshops, which is not necessarily person-centered and does not necessarily demonstrate a reflection of the individual participants' interests as opposed to the CTS' preferences based on currently available programming and resources. The Commonwealth needs to provide sufficient community-based exploratory activities and/or work experiences to meet individualized needs, especially for those who are working but underemployed and those with identified potential to work who are unemployed.

- *Lack of Engagement of Home Providers and Families in Process*: Educating and engaging families, natural supports, and community home providers in the community-based customized employment discovery model and providing opportunities consisting of exploratory activities focused on establishing or increasing the hours of available employment for these participants is critical to overall progress. We recognize the DSPDI's recent meetings with the Commonwealth of Puerto Rico's Council on Developmental Disabilities and family advocacy groups to discuss strategies for engaging them in working with families who are resistant to transitioning participants from institutions to community living. Building on that initiative, we encourage the DSPDI to work closely with these entities to offer peer mentoring/coaching/information referral/ trainings to support families build more skills on how to advocate for and effectively engage and support the participants to achieve greater community inclusion and employment outcomes. Additionally, it is imperative that community home providers have access to training and technical assistance, again through a recommended peer mentoring model, where providers have access to other providers in the U.S. who have effectively adopted and implemented evidence-based practices that lead to stronger community integration, employment outcomes and improved quality of life for participants. Lastly, the Commonwealth needs to address the lack of available transportation options, which seems to be a huge barrier to integrated employment and increasing of work hours.

[4] The JCC and Experts agree that telemedicine services should only be used as a means to provide routine follow-up and checkups. It should not be used as a primary method of providing medical care, health services and diagnosis. There have been recent incidents that show the necessity of in-person visits rather than relying solely on virtual means. We will expand on this matter in the next Reports.

- *Patterns of Sub-minimum Wages, Inadequate Hours, and Lack of Community Integration:*

    - Seven participants continue to receive sub-minimum hourly wages ranging from $5 to $8.25.
    - While some participants have increased their hours, one-third of participants in employment are still working under 20 hours/week on average and are therefore, underemployed.
    - Exposing participants to multiple work-based learning experiences and job opportunities based on their individual strengths, interests and preferences is the single most important contributing factor to achieving long-term competitive integrated employment and full employment potential. We strongly recommend that rather than limit employment placements to the small number of partnerships that the Commonwealth has created in the community, the rehabilitation counseling team spend more time on individualized exposures in the broader community. Such an initiative may help with the sub-minimum wage and underemployment issues referenced above in this Report.

All of this should be integrated with the ongoing work of the DSPDI in improving the use of person-centered planning and practice. Addressing these concerns and providing more sufficient person-centered details of what and how key actions will be implemented will help the DSPDI progress in achieving full compliance with multiple benchmarks in this area.

C. Safety and Restraint Issues

In the first six months of 2022, **the DSPDI has made notable progress in addressing some safety and restraint issues**. For example, it is positive that DSPDI is offering crisis intervention training for provider staff. Through training and other measures, the DSPSI is making efforts to improve the completeness and quality of information related to incidents and individual-level information in Therap, which should contribute to achieving a clearer picture of the status of each participant. This will better allow clinical and medical personnel to quickly identify and promptly respond to current and emerging risks, as well as regularly conduct patterns and trend analyses. The undersigned hopes that the practice and reality of trash in-trash out will soon become a relic of the past.

The DSPDI has also taken the positive initiative to strengthen the connection of clinical resources to events and incident patterns through membership changes to the Incident and Investigations Committee, which have resulted in more clinical referrals of high-risk participants during the latter part of this period.

However, challenges remain with systemwide reporting in Therap and the quality of some reported information, especially about behavioral incidents. For the former, it was found that many participants residing in institutions and in institution-like homes receive minimal services from DSPDI and therefore documentation in Therap by these providers is virtually non-existent. **As for the latter, the current structure and guidelines around incident reporting used by the DSPDI within Therap may contribute to misclassification and/or confusion among reporting providers as to adequate and appropriate data entry**. There is also fragmentation of information related to complaints and grievances that do not get

uploaded into Therap, which may result in the exclusion of important events and incidents that are highly relevant when reviewing conduct patterns for individual participants or trends across community providers to help ensure their health, safety, and welfare. This should be remedied promptly. The undersigned continues to have faith in the DSPDI's capacity to identify problem areas and to find effective and durable solutions with the assistance of JCC team members and Experts.

There is a substantial lack of written and properly implemented behavior plans for many participants. Each behavior plan should be based upon an individualized functional analysis of the person's behaviors to properly address the root causes of participant's aggression, self-injury, etc. In conducting the functional analysis and in developing the behavior plan, the psychologist should include details about the specific interventions that have been attempted in the past with a participant; past interventions are now not included, but should be, so as to facilitate the evaluation of whether they have been effective or whether alternative methods are necessary. Throughout the performance of the functional analysis, development of the behavior support plan, and implementation of the plan, enhanced communication with other disciplines is critical to ensure success.

During the period covered in this Report, there continues to be evidence of the use of unwarranted physical and chemical restraints without clinical authorization; the Commonwealth needs to take effective steps to address outstanding issues in this area. We are confident that the above practices will continue to diminish with the commitment that the present Administration has in reaching sustainable compliance.

There is no endorsed protocol or training on the limited use of certain physical interventions in emergency situations where some form of proper intervention may be warranted. The Commonwealth should fill this gap. There is also ample opportunity for the DSPDI to work towards a positive behavioral support approach, combined with more active engagement and programming for participants to address the root causes of the incidents and hence, minimize adverse behavior without resort to the use of restraint.

D. Opening of New Community Homes and Payment of Providers

During the period covered in the present Report, the DSPDI has continued to develop transition plans to transition appropriate participants out of the two remaining private institutions, Shalom and the *Instituto Psicopedagógico* (IPPR), and to place them in integrated community settings. The DSPDI has also started to open specialized service homes to meet the needs of participants with complex medical and/or behavioral conditions who need more intensive services.

During this period, the DSPDI has also continued its efforts to open community homes which has resulted in transitions of six participants from institutions to integrated community settings and a decrease in the number of overcrowded homes. Five homes have been opened and nine homes are in different states of the certification and contract process to open. Proper training of staff in advance of opening new community homes is of the utmost importance; inadequate training and planning may create a life-threatening risk to transitioning participants.

The DSPDI continues to engage with the National Center for the Advancement of Person-Centered Practice and Systems (NCAPPS) through the Administration for Community Living for technical assistance on how to implement person-centered planning (PCP). With the help of this technical assistance, the DSPDI needs to make significant improvements in order to actively involve participants in all matters pertaining to the integrated services and supports they receive, matters related to their overall health, safety, and well-being, and to support them in reaching the ultimate goal of independent living, self-sufficiency, and full non-segregated community inclusion according to their individual needs and preferences.[5]

The DSPDI continues to improve its processes regarding timely payments to service providers and contract renewals. The JCC Commonwealth needs to maintain compliance in this area within the time frames agreed upon by the parties so that essential improved services continue to be provided to participants without the risk of interruptions.

E. Health Care and Mental Healthcare

During the period covered in the present Report, one of the priorities of the DSPDI has been to develop person-centered transition plans and transition appropriate participants out of the two remaining private institutions, Shalom and IPPR, and place them in integrated community settings. To achieve this the DSPDI has opened specialized health care and mental health care service homes to meet the the complex medical and/or behavioral needs of participants residing in the above institutions.

The DSPDI is engaged in an ongoing and systemic effort to address numerous challenges and weaknesses. The DSPDI is working with staff to ensure that the information that they have for each participant within Therap is accurate (ex. includes accurate and complete active diagnoses), and that more information is included about the reasons medications are being prescribed. This work, coupled with future quality control initiatives, is expected to greatly enhance the information that the DSPDI uses to deliver effective and coordinated care and related decision-making.

During the six-month period, the DSPDI has increased the number of participants that have had reviews conducted by the CEEC staff, which is very encouraging. The CEEC has retained additional clinical expertise and the newly formed the Committee for the Assessment of Polypharmacy and High-Risk Participants (CAPAR), a part of the CEEC, has been performing shadow medical evaluations and medical reconciliations, particularly of high-risk participants. CAPAR has developed certain systems-level changes, including creating an internal referral pipeline between the Incidents and Investigations Committee and CAPAR, a comprehensive review template with risk categories, templates for communication with community physicians, and tracking procedures to ensure follow-up when questions or recommendations are identified for communication with community clinicians.

[5] Examples of non-segregated community inclusion include participating in an employment environment where individuals with IDD work alongside individuals that do not have IDD; engagement in regular community activities; and the opportunity to live and exist as a contributing member of the community regardless of their disabilities.

The CEEC/CAPAR has worked to facilitate specialty referrals through their professional networks when challenges in access arise. The number of people with identified clinicians has increased, including needed specialists such as a neurologist. The DSPDI is also engaged in collaborative work in a High Risk and Polypharmacy Workgroup with JCC Experts to address key areas, such as further defining risk categories which will drive prioritization of future CAPAR reviews, systemic access barriers, staff training, and other relevant topics related to improving health and mental/behavioral health outcomes for participants.

However, many challenges persist in certain key areas related to achieving positive health outcomes. A substantial number of participants continue to be subjected to high levels of polypharmacy, including psychotropic polypharmacy. More work is needed with prescribing clinicians to better address the needs of certain participants, particularly those on high risk and problematic medication combinations, those experiencing extreme sedation or other high risk side effects, and participants at risk of adverse long-term outcomes from their medication regimens.

Further work is needed to increase systemwide awareness of high-risk participants, ensure consistency and improved skills across all staff in assessing participant welfare and risks, consulting the CEEC/CAPAR as needed, and addressing the risks in a **timely** and effective manner. Work is also needed to ensure that staff are conducting sufficient in-person visits with participants to constructively assess the person's needs and well-being, instead of more cursory and at times, remote reviews that have been observed to occur, and that there is coverage review over a greater range of community residential settings.

Most troubling, there were multiple deaths during this period due to serious preventable factors, as identified by the Mortality Review Committee. DSPDI needs to promptly review these factors and their root causes to establish and implement remedial action plans to address deficiencies and to improve the quality of proactive care systemwide, to eliminate preventable deaths. Other sentinel incidents, such as a recent failure to divert participants from risky institutional placements that resulted in harm, warrant a comprehensive root cause analysis to target and implement prevention efforts in future. All falls should be classified as a high-risk event, given that there have been falls that have led to preventable deaths.

The DSPDI needs to continue to implement systemic improvement initiatives in problem areas and needs to continue to be receptive to consultation and feedback from the JCC Office. **There needs to be systemwide improvements in the near future**. The new CEEC and CAPAR initiatives, for example, hold the promise of delivering important new problem-solving approaches by the current Administration.

BENCHMARK COMPLIANCE ASSESSMENT TABLE			
BM No.	**Benchmark**	**Assessment**	**Page No.**
1	Translate this benchmark document, as well as any updated versions, into Spanish	**In Compliance**	31
2	Disseminate both the English and Spanish versions of these benchmarks to all pertinent personnel	**Substantial Compliance**	31
3	Create a "Master List" of all participants -- all persons with DD in the Commonwealth's IDP (or successor) -- and update quarterly; provide this list and all other lists below to JCC and US initially and as they are updated	**In Compliance**	31
III.1 Community Placement From Institutions			
4	From the Master List, create a sub-list of all participants who live in an institution (e.g., Instituto Psicopedagógico, Modesto Gotay, Centro Shalom)	**In Compliance**	32
5	Issue a policy directive that all institutionalized participants can live in the community with adequate supports/services OR for each institutionalized participant, conduct and document an individual evaluation on his/her appropriateness for community placement regardless of community capacity (JCAP III.1.A) (all cites below are to JCAP)	**Substantial Compliance**	33
6	Develop a written individualized community transition plan for each participant in an institution using person-centered planning techniques (III.1.A, E)	**Working Towards Substantial Compliance – Still Under Review**	33
7	For each participant, identify and document in the transition plan the individual and systemic obstacles to community placement from the institution (III.1.B)	**Substantial Compliance**	34
8	For each participant, identify and document in the transition plan any family members/guardian opposed to community placement from the institution (if any) and the reason(s) for opposition (III.1.C)	**Substantial Compliance**	35
9	Meet with all family members/guardians opposed to community placement, provide them with education on expanded community capacity, and offer viable community residences to effect the placement of the participants from the institutions (III.1.C)	**Working Towards Substantial Compliance – Still Under Review**	35

BM No.	Benchmark	Assessment	Page No.
10	Take the opposed families/guardians on tours of prospective, successful community residences (III.1.C)	**Working Towards Compliance**	36
11	For each appropriate participant, overcome all necessary obstacles (other than entrenched guardian opposition) to effect community placement from the institution in a manner consistent with Olmstead and the CBSP (III.1.B)	**Working Towards Compliance – Still Under Review**	37
12	Monitor all participants placed in the community to ensure they receive all the necessary protections, supports, services to meet their individualized needs in community settings (III.1.E)	**Working Towards Compliance – Still Under Review**	38
III.2 Provider Capacity Expansion in the Community			
13	From Master List, create sub-list of all participants living in the community, specifying name and location of each person's residential provider and total number of individuals living in each home	**In Compliance**	38
14	Develop a systemwide plan to increase the number of community residential providers to meet participants' individualized needs (III.2)	**Working Towards Substantial Compliance**-Still Under Review	39
15	Implement the plan to reduce the number of individuals in each community group and substitute home to meet individualized needs, to increase the level of individual attention devoted to participants day-to-day, to create a more peaceful and therapeutic living environment, and to improve outcomes for participants day-today (III.2); each participant shall have a private or semi-private bedroom.	Working Towards Compliance – Still Under Review	40
16	Ensure that community homes: provide participants with adequate protections, supports, services; meet their individualized needs; ensure their health, safety, welfare; provide increased individual attention; provide a more peaceful and therapeutic living environment; improve outcomes (III.2)	**Working Towards Compliance – Still Under Review**	42
III.3 Integrated Employment and Day Activities			

17	From the Master List, create a sub-list of those who are currently working in the community, specifying the name and location of the employer, the number of hours per week the participant is working, and the participant's hourly wage or compensation rate	**Substantial Compliance**	43
18	For those working in the community, develop individualized action steps to ensure no one working in the community is underemployed (III.3.A)	**Partial Compliance**	43
BM No.	**Benchmark**	**Assessment**	**Page No.**
19	Implement the action steps to ensure that no one working in the community is underemployed (III.3.A, B) This is in addition to original benchmarks: (with the understanding that the Commonwealth cannot guarantee optimal employment, but nonetheless will continue its efforts to avoid underemployment) (III.3.A,B)	**Working Towards Compliance – Still Under Review**	44
20	From the Master List, create a sub-list of those who are currently not working in the community, but have been professionally assessed or identified in the past as able to work in the community; designate on this sub-list the date/author(s) of the most recent assessment	**Working Towards Substantial Compliance – Still Under Review**	45
21	Professionally assess or re-assess for community employment all participants who are currently not working in the community but have been professionally assessed or identified in the past as able to work in the community (III.3.C)	**Working Towards Substantial Compliance**	46
22	Develop individualized, concrete action steps with timeframes to maximize their community employment (III.3.C)	**Working Towards Compliance – Still Under Review**	46
23	Implement the action steps to ensure that: everyone who is able to work is working in the community; and everyone working in the community is not underemployed (III.3.D) This is in addition to original benchmarks (with the understanding that the Commonwealth cannot guarantee optimal employment, but nonetheless will continue its efforts to avoid underemployment) (III.3.D)	**Working Towards Compliance – Still Under Review**	47

24	From the Master List, create a sub-list of all other participants who are currently not working in the community; designate on this sub-list the date/author(s) of the most recent professional employment assessment, if any; designate those who have been professionally assessed as not able to work in the community	**Working Towards Substantial Compliance – Still Under Review**	48
25	Professionally assess or re-assess for community employment all participants who are currently not working in the community but have been professionally assessed or identified in the past as able to work in the community (III.3.C)	**Working Towards Substantial Compliance – Still Under Review**	48
26	For those with professional assessments that they can work in the community, develop individualized, concrete action steps with timeframes for these other participants to maximize their community employment (III.3.A)	**Working Towards Compliance – Still Under Review**	49
BM No.	**Benchmark**	**Assessment**	**Page No.**
27	Implement the action steps to ensure that: everyone who is able to work is working in the community; and everyone working in the community is not underemployed (with the understanding that the Commonwealth cannot guarantee employment, but nonetheless will continue its efforts to find paid employment and avoid underemployment) (III.3.D)	**Working Towards Compliance – Still Under Review**	49
28	Develop and implement a program to promote self-employment for appropriate participants, specifying the number of times per trimester each participant is to be engaged in community self-employment activities; examples of self-employment may include, but not be limited to, work at fairs and urban markets selling arts and crafts participants create.	**Partial Compliance**	49

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)	**No Compliance**	50
30	For those participants with professional assessments that they are not able to work in the community, develop individualized plans to maximize meaningful, functional community activities that foster their growth and independence (III.3.E)	**Working Towards Compliance – Still Under Review**	51
31	Implement the plans (III.3.E)	**Working Towards Compliance – Still Under Review**	51
32	For those participants who are not working in the community but attend a day program at a CTS, ensure that these participants attend the day program at least four days per week; ensure that staffing, transportation, and other resources are adequate to meet individualized needs; ensure that buses have ramps and other needed accessibility supports	**Working Towards Compliance – Still Under Review**	52
33	From the Master List, create a sub-list of those who do not work or participate in formal day program activities at a CTS and assess why they do not and remain at home (III.3.F)	**Working Towards Substantial Compliance – Still Under Review**	53
BM No.	**Benchmark**	**Assessment**	**Page No.**
34	Develop individualized plans for these participants to maximize meaningful, functional community activities that foster their growth and independence (III.3.F); ensure that participants engage in such community activities at least two times per month	**Working Towards Compliance – Still Under Review**	53
35	Implement the plans (III.3.F)	**Working Towards Compliance – Still Under Review**	54

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)	**Partial Compliance**	54
37	Implement the plan (III.3.G)	**Working Towards Compliance – Still Under Review**	55
38	Ensure that staffing, transportation, other resources are adequate and reliable to meet individualized needs for integrated day activities in the community (III.3.H); ensure that buses have ramps and other needed accessibility supports	**Working Towards Compliance – Still Under Review**	55
39	Ensure there are sufficient job coaches and job trainers to meet individualized needs in the community (III.3.I)	**Working Towards Compliance – Still Under Review**	55
III.4 Safety and Restraint Issues			
40	Using data from Therap combined with onsite assessments, conduct a safety and welfare analysis of all individual participants and their residences (III.4.A)	**Working Towards Compliance – Still Under Review**	56
41	Implement measures to ensure participant safety and welfare based on this analysis (III.4.A)	**Working Towards Compliance – Still Under Review**	57
42	Using data from Therap combined with first-hand accounts, analyze peer-to-peer interactions that create risk of harm (III.4.A.1)	**Working Towards Compliance – Still Under Review**	57
43	Implement effective measures to address peer-to-peer risk factors to prevent harm (III.4.A.1)	**Working Towards Compliance – Still Under Review**	58
44	Using data from Therap combined with first-hand accounts, identify vulnerable participants at risk of harm (III.4.A.2)	**Working Towards Compliance – Still Under Review**	58
45	Implement effective measures to minimize/ eliminate their risk factors (III.4.A.2)	**Working Towards Compliance – Still Under Review**	59
46	Using data from Therap combined with first-hand accounts, identify aggressor participants (III.4.A.3)	**Partial Compliance**	59
47	Implement effective measures to minimize/eliminate aggressor risk triggers (III.4.A.3)	**Working Towards Compliance – Still Under Review**	60
BM No.	**Benchmark**	**Assessment**	**Page No.**

48	Informed by data from Therap, develop a systemwide plan to ensure that serious incidents, per JCAP criteria, are reported promptly and investigated within 45 days, all to prevent serious incidents in the future (III.4.B)	**Working Towards Compliance – Still Under Review**	61
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)	**Partial Compliance**	62
50	Implement these systemwide plans and implement remedial measures to address any individual and/or systemic issues that arise from the investigations and incident analysis to ensure participant safety and welfare and minimize/eliminate abuse and neglect (III.4.B)	**Working Towards Compliance – Still Under Review**	63
51	Implement effective measures to minimize/eliminate use of all restraints on participants (III.4.C)	**Working Towards Compliance – Still Under Review**	63
52	Prohibit use of standing PRN or "stat" orders for chemical restraints on participants (III.4.C)	Working Towards Compliance – Still Under Review	64
III.5 Health Care and Mental Health Care			
53	From the Master List, create a list of all participants and their current community clinicians, highlighting the primary care physicians and neurologists, if applicable (III.5.B)	**Substantial Compliance**	64
54	Through Therap and/or other means, implement an effective communication system to promptly alert all community clinicians and other pertinent personnel to significant changes in the health status of individual participants across the system (III.5.A)	**Working Towards Compliance – Still Under Review**	65
55	Whenever there is a significant change in participant health status, ensure that appropriate treatment and other measures are provided promptly to meet the individualized needs of the participant	**Working Towards Compliance – Still Under Review**	66

56	Implement an effective system to gather and provide to pertinent community clinical personnel all individual participant information for use in monthly or more frequent appointments (III.5.B); participant information may be located in the home, CTS, CEEC, Central Office, and/or elsewhere.	**Working Towards Substantial Compliance – Still Under Review**	66
BM No.	**Benchmark**	**Assessment**	**Page No.**
57	Maintain effective communication with community clinicians to determine if they provide informed and comprehensive individualized evaluations and treatment that meet individualized participant needs (III.5.B); However, the original benchmark reads as follows: Monitor community clinicians to ensure they provide informed and comprehensive individualized evaluations and treatment that meet individualized participant needs (III.5.B)	**Working Towards Compliance – Still Under Review**	67
58	Ensure participants receive necessary health care in a timely manner to meet their individualized needs in the community (III.5.G)	**Working Towards Compliance – Still Under Review**	68
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	**Working Towards Substantial Compliance – Still Under Review**	68
60	Through Therap and other means, implement a systemwide plan to work with community clinicians to promptly and proactively develop and implement tailored and intensive protections, supports, services for priority at-risk participants to meet their individualized needs (III.5.I): **NOTE**, original benchmark did not mention THERAP.	**Working Towards Compliance – Still Under Review**	69
61	Monitor to ensure that priority at-risk conditions are minimized or eliminated; document and track seizures, bowel obstructions, aspiration and aspiration pneumonia, decubitus ulcers, other conditions per JCAP criteria (III.5.I)	**Working Towards Compliance – Still Under Review**	69

62	Establish a program of traveling nurses (from the CEEC and/or the CTS sites) to regularly conduct onsite visits with participants in their homes and/or day programs to assess, treat, and monitor their services and supports to ensure that the individualized needs of each priority at-risk participant are met day-to-day; these nurses are to provide ongoing technical assistance to community providers whenever needed, especially when there is a decline in health status; in biological homes, this service will be provided with the authorization of the parents, family members or custodians	**Partial Compliance**	69
63	Using data from Therap and other sources, regularly compile and analyze incident, outcome, intervention, treatment information for each priority at-risk person (III.5.J)	**Partial Compliance**	70
BM No.	**Benchmark**	**Assessment**	**Page No.**
64	Regularly share this information with community clinicians (III.5.J)	**Partial Compliance**	70
65	Maintain effective communication with community clinicians to determine how they utilize this information to implement measures to meet individualized participant needs (III.5.J)	**Working Towards Compliance – Still Under Review**	71
Neurological			
66	From the Master List, create a sub-list of all participants with a seizure disorder/epilepsy, specifying any anticonvulsant medications they receive with dosage(s) (III.5.K)	**Substantial Compliance**	71
67	Ensure that neurologists provide participants with a seizure disorder with comprehensive neurology evaluations as needed, at least annually (III.5.K)	**Substantial Compliance**	71
68	Using data from Therap and other sources, compile a sub-list of those participants who have had more than 10+ seizures in the past year, as well as a sub-list of those who have had no seizures for the past two years (III.5.K.1)	**Substantial Compliance**	72

69	Ensure that neurologists provide effective care for those having 10+ seizures per year (III.5.K.1)	**Working Towards Compliance – Still Under Review**	72
70	Ensure that neurologists provide effective care for those who have not had a seizure in the past two years (III.5.K.1)	**Working Towards Compliance – Still Under Review**	73
71	Ensure that neurologists weigh the benefits of medication use and adequately document the rationale for anticonvulsant medication (III.5.K.2)	**Partial Compliance**	73
72	Ensure the use of intra-class polypharmacy is minimized and fully justified (III.5.K.2)	**Working Towards Compliance – Still Under Review**	74
73	Formalize a relationship with the Epilepsy Foundation of Puerto Rico and use the relationship to improve neurological care and outcomes for participants (II.5.K.3)	**In Compliance**	74
Aspiration Risks			
74	From the Master List, create a sub-list of those participants at risk of aspiration and/or aspiration pneumonia	**Substantial Compliance**	78
75	Implement individualized plans to eliminate unsafe mealtime practices, per JCAP criteria, to minimize risk of aspiration/pneumonia (III.5.L)	**Working Towards Compliance – Still Under Review**	75
BM No.	**Benchmark**	**Assessment**	**Page No.**
76	Implement individualized plans to keep non-ambulatory individuals in proper alignment to minimize risk of aspiration/pneumonia (III.5.L)	**Working Towards Compliance – Still Under Review**	75
CEEC			
77	Ensure CEEC regularly evaluates all participants (III.5.C); compile list of ongoing evaluations	**Substantial Compliance**	76
78	Ensure CEEC regularly reviews the adequacy and appropriateness of individualized community health care and mental health care (III.5.C); compile list of ongoing reviews	**Partial Compliance**	77

79	Ensure CEEC promptly raises red flags and actively advocates on behalf of individuals when community services do not meet their individualized needs (III.5.C); compile list of ongoing instances of contacting community clinicians to raise red flags/advocate for participants, summarizing result of contact	**Partial Compliance**	77
80	Ensure CEEC informs community clinicians of recent adverse health or mental health outcomes that may implicate treatment (III.5.E); compile list of ongoing instances where CEEC informed community clinicians, summarizing result of contact	**Partial Compliance**	78
81	Develop and implement effective systemwide plan for CEEC to promptly communicate concerns to community clinicians that improve outcomes (III.5.E); compile list of improved outcomes after CEEC intervention	**Working Towards Compliance – Still Under Review**	78
82	Implement a systemwide protocol to alert licensing, ombudsman agencies of community clinician improprieties (III.5.F); compile list of alerts	**Partial Compliance**	79
83	Ensure CEEC serves as a mobile crisis team, providing prompt, effective, flexible, individualized, mobile, expert support, services, and advice at community sites during emergencies, crises, transitions 24/7 to meet individualized needs (III.5.C); compile list of mobile crisis team visits/interventions, summarizing result	**Partial Compliance**	79
84	Ensure CEEC mobile crisis team is comprised of multi-disciplinary group of DD professionals (III.5.D)	**Working Towards Substantial Compliance – Still Under Review**	80
85	Ensure CEEC mobile crisis services maximize individuals' ability to live successfully in the community (III.5.D); compile list of instances where mobile crisis team intervention resulted in diversion from an institutional setting or prevented an adverse outcome	**Working Towards Compliance – Still Under Review**	80
BM No.	**Benchmark**	**Assessment**	**Page No.**
Mortality Review			

86	Create and maintain a mortality review committee comprised of well-respected health care and quality review personnel, headed by an independent chairperson (III.5.N)	**In Compliance**	81
87	Ensure MRC meets regularly and conducts an in-depth review of each death, per JCAP criteria, identifying individual and systemic issues related to each death (III.5.N.2, 4); compile list of MRC meetings and death reviews	**In Compliance**	82
88	Ensure MRC has access to all pertinent people, information related to the course of care leading up to the death (III.5.N.3)	**In Compliance**	82
89	Ensure MRC performs a root-cause analysis to identify any preventable causes of illness and death (III.5.N.5)	**In Compliance**	82
90	Ensure MRC issues a final report on each death promptly, per JCAP criteria, with root-cause analysis and recommendations to address outstanding issues (III.5.N.5)	**Substantial Compliance**	82
91	Monitor to ensure prompt and effective implementation of all MRC recommendations and continue to monitor until full implementation (III.5.N.7); compile tracking table of recommendations and implementation status	**Working Towards Compliance – Still Under Review**	83
92	Monitor to ensure MRC process is effective to avoid preventable illnesses, deaths for similarly situated individuals (III.5.N)	**No Compliance**	83
Mental Health			
93	From the Master List, create a sub-list of all participants with mental illness, specifying their mental illness diagnosis/es (III.5.G)	**In Compliance**	84
94	Ensure participants receive necessary mental health care in a timely manner to meet their individualized needs in the community (III.5.G)	**Working Towards Compliance – Still Under Review**	85
95	Ensure that all mental illness diagnoses are consistent with DSM criteria and justified in the record (III.5.M)	**Partial Compliance**	86
96	Ensure that no participant receives psychotropic medication in the absence of a clinically justifiable diagnosis of mental illness (III.5.M)	**Working Towards Compliance – Still Under Review**	86
97	Ensure that type, dosage of psychotropic medication are appropriate and needed for each participant, per JCAP criteria (III.5.M)	**Working Towards Compliance – Still Under Review**	86

BM No.	Benchmark	Assessment	Page No.
98	Minimize use of typical/first generation psychotropic medication (III.5.M)	**Working Towards Compliance – Still Under Review**	87
99	Minimize use of intra-class psychotropic medication polypharmacy (III.5.M	**Working Towards Compliance – Still Under Review**	87
III.6 Systemwide Reforms			
100	Implement a comprehensive quality assurance program to track, analyze, and ensure participant safety, welfare, health care, mental health care issues and outcomes (III.6.A)	**Working Towards Compliance – Still Under Review**	87
101	Implement prompt and effective measures to address patterns and trends that adversely impact participant safety, welfare, health, and mental health (III.6.A)	**Working Towards Compliance – Still Under Review**	89
102	Ensure that each participant receives adequate and appropriate monitoring and oversight by a service mediator to meet individualized needs; per existing Court orders, ensure that each service mediator serves no more than 24 participants at any time	**Working Towards Compliance – Still Under Review**	89
103	Work with family members of participants on a plan to address quality issues that impact participants	**Partial Compliance**	90
104	Create and maintain toll-free crisis hotline, staffed 24/7 by qualified professionals that can effectively help to resolve issues (III.6.B)	**Working Towards Compliance – Still Under Review**	90
105	Create and maintain a systemwide email system to facilitate prompt communication to all pertinent individuals, per JCAP criteria to resolve outstanding issues (III.6.C)	**Working Towards Compliance – Still Under Review**	91
106	Develop a family support program consistent with the criteria in the CBSP (V) that includes service mediators for participants living at home, as well as a subsidy and respite program; participation in the program will be voluntary with prior authorization in private homes	**Working Towards Compliance – Still Under Review**	91

"*The JCAP constitutes the culmination of months of intense discussion, review and evaluations between the United States Department of Justice, the Commonwealth Department of Health, and the Court Monitor. 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
  August 19, 2011

I. INTRODUCTION

As referenced above, the Commonwealth has made some progress during the review period. The undersigned commends the DSPDI and the Department of Health for their achievements, which translates to improving the lives, safety, and well-being of the participants. The increasing quality of services creates a constructive pathway towards integrated independent living.

The progress that we are seeing is a result of the collaborative approach that was adopted by the DSPDI to work with Experts. Now that the Six-Month Action Plan is being implemented, and the above collaborative approach has proven successful, we have set out in this Report our assessment of each of the non-outcome Benchmarks, providing a specific narrative justifying our compliance conclusions. Throughout, the Office of the JCC, in its role as a guiding hand, will furnish specific recommendations on ways for the Commonwealth to improve their compliance levels.

Notwithstanding the above, there is a significant amount of work to be done in order to reach full and sustainable compliance, particularly, in those areas of the Benchmarks that pertain to the outcome provisions. As always, we look forward to continuing to assist the DSPDI and the Department of Health as they continue to develop and implement needed reforms.

Standard of Assessment

For each particular benchmark, the JCC will assign an assessment of In Compliance, where the DSPDI has achieved compliance with all items of the benchmark; Substantial Compliance, where almost all of the benchmark items have been met; Partial Compliance, where some items of the benchmark have been complied with; and No Compliance, where none or a negligible portion of the items of the benchmark has

been met.[6] The assessment is based on interviews conducted with parents and family members of participants, direct caregivers and service providers, DSPDI Central Office and CTS personnel, on-site visits, observations, direct communications with participants and review of information and documents furnished by the DSPDI and/or obtained by the Office of the JCC. The JCC will also provide a narrative in each benchmark explaining the level of compliance assigned.

Before we address each benchmark item, there are several preliminary matters that warrant a brief discussion.

A. Changes in DSPDI Leadership

At the beginning of the year, the sitting DSPDI Director was replaced. This resulted in a period of reorganization within the Division, with multiple changes to established guidelines and procedures. In spite of the changes, the JCC must recognize the unwavering commitment to the participants of the Secretary of Health, Hon. Carlos Mellado, the Department of Health's Auxiliary Secretary of Family Health (Integrated Services and Health Promotion), Dr. Marilú Cintrón Casado, the DSPDI's Compliance Officer, David Rodríguez Burns, Esq., DSPDI Interim Director, Mr. Danniel Soto, and their Department of Health team. Collectively, they worked diligently to improve the lives of participants, thus enabling significant progress to be achieved.[7]

Changes in DSPDI leadership have been constant throughout the history of this case, often producing disruption and at times obstruction of more enlightened policies, practices, and reforms that were proving beneficial to the Division, and, more importantly, to the health, safety, and well-being of the participants.

As referenced above, the DSPDI should establish a policy, by way of an administrative order, to avoid future disruptions in the continuity of progress and delivery of essential services and supports to participants, as failure to do so will cancel past accomplishments and could lead to regression in compliance levels.[8]

B. Interagency Collaborative Agreement/Growing ID/DD Population

In recent months, the JCC has discovered that there are hundreds of people with ID/DD under the care of the Department of Family Affairs ("DFA") and the Department of Education, which sister agencies to the Department of Health – all under the umbrella of the Commonwealth. (See Dockets Nos. 3604, 3606 and 3609).

[6] As repeatedly mentioned throughout the years in multiple semi-annual reports, compliance in all areas must be sustainable. Temporary compliance that is not sustainable may expose participants to the detrimental effects of potential regression in core areas that could negatively impact their health, safety, and welfare.

[7] The JCC expects that the DSPDI will maintain continuity during the transition from Mr. Rodriguez Burns, who recently resigned as the DSPDI's Compliance Officer.

[8] See the JCC's March 2021 Semi-annual Report.

After receiving the DFA's list of individuals with an ID/DD diagnosis under their jurisdiction, the JCC conducted an initial evaluation and preliminarily identified 498 individuals with ID/DD diagnosis.

The Office of the JCC is working with the DFA to identify the precise number of people with ID/DD and to better determine the needs of each individual and how the DSPDI can support them going forward. All this is consistent with the Interagency Collaborative Agreement that was signed between the DFA, the Department of Health, and the Department of Education in March 2018, with the objective of exchanging data that could establish which people with ID/DD could benefit from the DSPDI services and supports in order to comply with the mandates of the JCAP. (See Docket No. 2233).

The JCC will continue to work with the DFA (which has been receptive at all times to input and assistance from the JCC and Experts) and the DSPDI to determine the best way to serve the above individuals in light of current DSPDI resources.

Given the progress in compliance levels that we are currently seeing, the DSPDI is now in a position to be able to serve a wider number of individuals with ID/DD that are eligible for its services, including individuals who are on the DSPDI wait list and those that are under the jurisdiction of the DFA and the Department of Education. All of this is consistent with the representations made by the previous DSPDI Director, Dr. Suzzane Roig, that the DSPDI would provide services to all individuals with ID/DD that would qualify for them.[9]

As of 2018, per the Collaborative Agreement, the Department of Education informed us that there were thousands of special needs students under its jurisdiction, many of whom would likely require services from the DSPDI in future; particular focus should be placed on the subset of students that are in a transition-age range so that the Division can start planning to serve them as they exit the jurisdiction of the Department of Education. The Commonwealth, through its Department of Education, needs to provide us with an updated student list, given that, at the moment, we cannot determine the exact number of students that have an ID/DD diagnosis as of 2022.

C. Labor and Inflationary Challenges

As anticipated and discussed in prior JCC reports, many providers are confronting high employment turnover, recruitment challenges and inflationary pressures (minimum wage adjustments and basic utilities expenses in, for example food, water, electricity, and transportation costs, among many others) which could trigger the interruption of essential services in the program which would ultimately affect the safety, well-being, and protections of all participants.[10] Failure to address the above situation, in practical terms, may nullify of the improvements that have been achieved through the Burns & Associates Rate Assessment Study.[11]. We strongly recommend that the DSPDI and the Department of Health adhere to

[9] The above statements are included in the JCC Monthly Meeting minutes of December 2021.
[10] See JCAP, Sec. II-C. "The Court reminds the Secretary of Health that, as agreed by the parties, the services to the participants shall remain uninterrupted unless otherwise ordered".
[11] The Rate Assessment Study was prepared based on provider information from 2019 and does not take into account the current challenges.

the Burns & Associates' recommendations that in general terms, all rate assessment studies should be periodically refreshed.

Consistent with the above, and as recommended in past JCC reports, prior to issuing the next contracts for FY24 and at least every few years thereafter, the DSPDI should re-examine their rate structure and review the assumptions made in the Rate Assessment Study so that they align with the current cost and labor challenges and to guarantee that all services remain uninterrupted.

If the current inflationary rates dissipate, which would lower the cost of living, as well as the cost of essential supplies and services, adjustments could very well be made to address said decreases in a manner that is favorable to the DSPDI and the Department of Health's budgetary considerations. The above should also be looked upon as a temporary adjustment to guarantee the continuation of services. It would be dangerous to wait until home providers can no longer afford.

D. Pending Matters for the Remainder of the Year

i. Use of $10M Budgetary Reserve- The JCC expects the DSPDI to develop, in conjunction with the United States, an action plan for the best use of the $10M reserve established by the Court since fiscal year 2021-2022. (See Dockets Nos. 3499 and 3602);

ii. Individuals with ID/DD in the local court system- The JCC has arranged a meeting with the Administrator of the Office of Court Administration ("OAT") to continue discussions that were started prior to the breakout of the COVID-19 pandemic. This meeting will address several important issues that individuals with ID/DD are confronting in the local judicial branch, including but not limited to: establishing a curriculum for the Judicial Academy to create awareness and sensitivity to the needs of people with ID/DD, to educate judges about the JCAP mandates, and to explore mechanisms to have sister government agencies work together to divert persons with ID/DD from the judicial/law enforcement system and instead towards a mix of individualized services and supports in the community. If this is not achieved, the Department of Health may end up potentially violating the JCAP, given that court-ordered community placements are typically accomplished without individual transition plans ("ITPs"), and too often lead to placement in highly congregated living settings;

iii. Continuation of Town Hall Meetings- The JCC recently informed the Court that the Office of the JCC will be resuming the Town Hall Meetings throughout the island starting in November 2022. The JCC will be presiding at these meetings. (See Dockets Nos. 2377, 2382 and 3617);

iv. Relocation of Participants Residing in ASSMCA and DFA Homes- There is still much work to be done in regards to providing needed DSPDI services and supports to participants currently residing in ASSMCA and DFA homes; this may require relocating these

individuals to DSPDI homes. The DSPDI must ensure the proper implementation of person-centered plans and individualized treatment plans for these participants.

v. Administration of new COVID-19 booster shots- Given that the new COVID-19 booster shots have been approved and recommended by the CDC, the JCC expects that eligible participants will receive them promptly, consistent with DSPDI practice with previous vaccines and boosters.

II. RATINGS OF COMPLIANCE WITH SPECIFIC PROVISIONS OF THE AGREEMENT

Benchmark 1 – "Translate this benchmark document, as well as any updated versions, into Spanish"

Level of Compliance: In Compliance

The DSPDI has translated the benchmark document into Spanish. The Office of the JCC believes that the translation is accurate and complete.

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

Level of Compliance: Substantial Compliance[12]

The DSPDI has disseminated both versions of the benchmarks to its employees and has provided orientations to new hires, providers and home personnel. From the JCC's reviews, interviews and visits, there have been some instances where community home, private home[13] and other support personnel providing direct services to participants lacked understanding and knowledge of the JCAP and the Benchmarks ("BM"). The Commonwealth should provide the Spanish version of the BMs to all existing and any new direct support professionals and provide them with orientation as needed so that they understand what is required of them. The DSPDI should ensure that all individuals providing frontline services to participants understand the JCAP requirements and how to undertake necessary actions to identify and comply with such requirements and to ensure essential services and needs are being met. On July 13, 2022, the United States provided guidance to the Commonwealth on the importance of getting translated versions of the BMs to all direct support professionals.

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"

[12] In their response to the JCC's first draft of the present Report, USDOJ presented compelling arguments which persuaded us to change the current compliance rate to Substantial Compliance. The JCC shares USDOJ's opinion that caregivers are amongst the "pertinent personnel" that should receive the Benchmarks document.
[13] ASSMCA and DFA homes.

Level of Compliance: In Compliance

The DSPDI provided a Master List that included 649 participants. The total, broken down by residence type, is summarized below.

	CURRENT As of 6/30/2022		As of 12/31/2021		As of 6/30/2021	
Home Classification/ Living Unit	**No. of Participants**	**%**	**No. of Participants**	**%**	**No. of Participants**	**%**
Biological Homes	215	33.1%	212	33.2%	209	33.2%
Group Homes (Puerto Rico and Florida)	305	47 %	296	46.3%	284	44.1%
Substitute Homes	40	6.2%	38	5.9%	48	7.2%
Institutions	65	10%	73	11.4%	83	13%
Independent Living	3	.5%	2	.3%	2	.3%
Private Homes (ASSMCA, DFA, Hospitals)	21	3.2%	18	2.8%	15	2.2%
Total	**649**	**100%**	**639**	**100%**	**641**	**100%**

This is a summary of data from the Master List document the Commonwealth produced at BM3. The Master List is a useful table that includes helpful details and information. However, the Commonwealth also produced sub-lists at BM13, which reveal some discrepancies in the overall figures. The Commonwealth should review all of the lists and sub-lists and then resolve the discrepancies so as to report consistent names and numbers on all lists. The DSPDI should also continue its efforts to ensure that the ID diagnoses in the list are consistent with what is reported in Therap, eliminate the recording of multiple ID diagnoses, and clarify the diagnoses of participants currently classified as having "no intellectual disabilities" (participants #292, #505[14], #903, #1072, #1154).

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)"

Level of Compliance: In Compliance

The DSPDI provided a list of 65 participants living in institutions, which is summarized below:

[14] Participant was evaluated on November 7, 2019, by Party-stipulated expert Dr. Margarida Julia, Clinical Neuropsychologist, and diagnosed as having mild intellectual disabilities.

	CURRENT As of 6/30/2022		As of 12/31/2021		As of 6/30/2021	
Home Classification	**No. of Participants as of June 30, 2022**	**%**	**No. of Participants as of December 31, 2021**	**%**	**No. of Participants as of June 30, 2021**	**%**
IPPR	29	45%	33	45%	38	46%
Shalom	36	55%	40	55%	45	54%
Total	**65**	**100%**	**73**	**100%**	**83**	**100%**

This does not include participants living temporarily in a psychiatric hospital or other congregate setting. During the period covered by this report, seven participants were transferred out of institutions (four from IPPR[15] and three from Shalom). As of June 30, 2022, of the 649 participants receiving services from the DSPDI, about 10% are still living in institutions.

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

Level of Compliance: Substantial Compliance[16]

On August 1, 2022, the Commonwealth provided us with an Administrative Order that is currently in draft form. As of today's date, it has not been signed by the Secretary of Health. It is expected that this directive will properly address the requirements of this benchmark, but the final version of the same still needs to be properly analyzed and discussed in order to provide a final compliance assessment. The United States has requested, and the Commonwealth has agreed to provide, a certified translation of the draft Administrative Order. Once the parties have discussed the policy and agreed upon final language, the Commonwealth will be in compliance with this BM.

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)**

Level of Compliance: Working Towards Substantial Compliance – Still Under Review[17]

The DSPDI provided the following: (i) a copy of the current Person-Centered Planning ("PCP") Protocol (which, according to the DSPDI, is being evaluated as part of the technical assistance they are receiving

[15] One of the four participants transferred out from IPPR was egressed to biological home in the state of Florida.
[16] In their response to the JCC's first draft of the present Report, the DSPDI requests that "the Office of the JCC re-consider its assessment of this benchmark and assess the same as "In Compliance". The JCC is not persuaded by the argument presented by the DSPDI and stands by the narrative regarding the assessment evaluation.
[17] In their response to the JCC's first draft of the present Report, USDOJ presented compelling arguments which persuaded us to change the current compliance rate to "working towards substantial compliance-still under review". The Office of the JCC will be vigilant that the ITPs strictly comply with PCP principles. Failure to adhere to this benchmark's mandates will entail a potential regressive assessment in the next Report.

from the National Center on Advancing Person-Centered Practices and Systems (NCAPPS); (ii) norms regarding the procedures for the preparation of the Individual Transition Plans (ITPs) and the transfer of participants; (iii) lists of participants transferred as new homes open; and (iv) a draft of the De-institutionalization Protocol that is being prepared by the DSDPI.

The Office of the JCC pulled a report from Therap with all the ITPs prepared. The DSPDI has made good progress in the preparation of ITPs for all participants living in Shalom and IPPR. While this is very positive, there is still some more work to be done. For example, as of June 30, 2022, some of the ITPs were over a year old and some of the interdisciplinary teams' recommendations on community placement were recorded in the Therap case notes, but not incorporated into the ITPs. The DSPDI should continue its efforts to ensure that the ITPs identify the participants' current needs and desires.

The preparation of a De-Institutionalization Protocol is a positive step in the process of de-institutionalization, as it sets forth uniform procedures. The JCC recommends that an in-depth discussion of the draft protocol take place at upcoming meetings of the Deinstitutionalization and Independent Living Work Group.

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)

Level of Compliance: Substantial Compliance[18]

The DSPDI has stated that the main systematic obstacle to community placement is family opposition which is discussed in BMs 8 and 9. Various approaches to working with families and addressing their needs are currently being evaluated and discussed in the De-institutionalization and Independent Living Work Group.

We reviewed the ITPs of participants with family members opposed to community placement, as well as documents provided by the DSPDI providing further detail on the interventions with such families (See BM 9). We found that the main reasons for oppositions include: (i) the participant is used to living in the institution and does not easily adapt to change; (ii) perceptions that the DSPDI does not have community homes available that can adequately and safely manage the participant's health and behavioral needs; and (iii) the distance of the proposed home from family members. To address these concerns, the De-institutionalization and Independent Living Work Group has begun discussion of ways to better educate family members about what is now available in the community and to build greater familiarity and integration into the community for people currently living in institutions through opportunities of individual and peer-to-peer exposure to community living. It has been recommended that the DSPDI build

[18] In its response to the draft report shared with the Parties, the DSPDI argues and requests that "the DSPDI respectfully requests that the Office of the JCC re-consider its assessment of this benchmark and assess the same as "In Compliance". The JCC is not persuaded by the argument stated by the DSPDI and stands by the narrative regarding the assessment evaluation.

momentum by showcasing transition success stories. We are also discussing ways to address proximity concerns.

In addition to family opposition, another systematic obstacle continues to be the lack of available community homes. Although the DSPDI has made some progress opening new homes, many referrals made to the DSPDI's Service Determination Committee (CDS, for its Spanish acronym) and placements are still pending. See BM 15.

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)

Level of Compliance: Substantial Compliance

As indicated in BM 6, there are 65 participants living in institutions. Of these 65 participants, the DSPDI has identified 19 participants with family members opposed to community placement. Opposition by a family member is recorded in the ITPs by having the family member complete a form titled "Certification of Reasons to Accept or Oppose Placement in a Less Restrictive Placement" which is uploaded to Therap and made part of the ITP of the participant. Although the form prompts the family member to write a brief narrative to document the reason for opposition, most forms specify/document no concrete reason for opposition or the rationale is very general.

The DSPDI should consider revising this form to facilitate documentation of the specific reason for the opposition of the family member to community placement by including some generic reasons and an open-ended text box. In addition, the DSPDI should consider including in the draft Deinstitutionalization Protocol concrete policies and procedures that outline the frequency, the number and types of interventions to be made with family members to address such opposition.

Also, the DSPDI should continue its efforts to discover the specific reasons why families are opposing community-based living options for the participants so that it can develop and implement an action plan to address those specific concerns. As previously referenced in BM 7, various approaches to working with families and addressing their needs are currently being evaluated and discussed in the De-institutionalization and Independent Living Work Group.

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)

Level of Compliance: Working Towards Substantial Compliance- Still Under Review[19]

[19] In their response to the JCC's first draft of the present Report, USDOJ presented compelling arguments which persuaded us to change the current compliance rate to "working towards substantial compliance-still under review".

For this benchmark, the DSPDI provided: (i) material shared with family members regarding services offered by the DSPDI; (ii) a certification with brief narratives regarding efforts made with family members; and (iii) a list of family members that oppose community placement that includes details of communications held between them and the DSPDI, an ITP, and an action plan.

We reviewed the list of family members opposed to community placement, as well as the summary certification and documents provided by the DSPDI providing orientation to such families (See BM 9). We found that during the period covered by this Report the DSPDI, through the Specialized Services Area under the Regulatory Unit, identified and met and or contacted with 19 family members who continue to be opposed to community placement. By the end of the period, 11 family members remained opposed to community placement.

As previously referenced in BM 7 and BM 8, various approaches to working with families and addressing their needs are currently being evaluated and discussed in the De-institutionalization and Independent Living Work Group.

In addition to the efforts to address unfamiliarity with the community described in BM 7, the DSPDI is working to open new specialized community-based homes with adequately trained direct support staff and clinical providers to address the needs of participants with complex conditions who may need more intensive services and supports, including those participants with mental and behavioral health needs. Given the families' concerns about geographic distance, the DSPDI should map out where families desire community-based living options to better assess whether new residential living options can be aligned with their desires and the needs of the participants.

On a positive note, the Puerto Rico Medicaid Program applied for, and was awarded, $5 million dollars in Medicaid's Money Follows the Person (MFP) program by the U.S. Centers for Medicare & Medicaid Services. This is the first time a US territory received an MFP grant in program history. The purpose of the MFP program is to support transitions from institutional care for people with disabilities to home and community-based services. This initial MFP award to Puerto Rico will focus on a comprehensive needs assessment, technical assistance, and capacity building to progress toward building a better long-term service and supports system in Puerto Rico. It will be essential that this phase of work consider the needs of participants with intellectual and developmental disabilities residing in institutional settings, as well as the concerns of their family members.

The Office of the JCC will be active in evaluating all relevant Commonwealth documents and plans as they relate to the use of MFO funds and their specific goals to ensure that the needs and perspectives of the participants and their families are included in the needs assessment and plans to increase capacity.

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

Level of Compliance: Working Towards Substantial Compliance[20]

Of the 19 families opposed to the relocation of participants living in institutions, one was taken on community tours, while six declined the Commonwealth's invitation due to lack of interest or because they have already toured community homes. As previously mentioned in BM 7, various approaches to working with families and addressing their needs are currently being evaluated and discussed in the De-institutionalization and Independent Living Work Group.

The JCC encourages the DSPDI to maintain and/or strengthen its efforts to take family members/guardians on tours of community settings and highlight the progress that the DSPDI has achieved so far in terms of expanding and enhancing community options that may not have been available in the past, as well as compliance with the JCAP in an effort to change the longstanding notion among various family members that the Program does not have the adequate resources or facilities to provide the services that the participants require in a community-based setting.

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)

Level of Compliance: Working Towards Compliance – Still Under Review[21]

The DSPDI provided a table summarizing its additional efforts to educate and provide orientation to families opposed to community placement, which according to the Division, is the primary systematic obstacle to community placement.

Of the 13 re-orientations conducted between January 1, 2022, and June 30, 2022, all 10 families agreed to community placement subject to certain conditions, such as: that the DSPDI assign one to one continuous support to a participant, that the home be operated by the institution directives, and that the community home be close in distance to the family. It would be helpful for the DSPDI to continue communications with family members to better understand the condition that community homes be operated by the institution directives and develop a plan to address such concern.

With regard to the opening of new community homes by the IPPR and Shalom, as stated in the prior JCC reports, the DSPDI should carefully monitor the transition process, the settings of the new homes, and the service delivery models implemented in these homes to ensure that they do not replicate institution-like conditions, practices, or environments.

The DSPDI should include guidelines and procedures regarding overcoming obstacles in the Deinstitutionalization Protocol.

[20] The JCC considers that the DSPDI is working towards substantial compliance.

[21] In their response to the JCC's first draft of the present Report, USDOJ presented compelling arguments which persuaded us to change the current compliance rate to "working towards compliance-still under review".

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)

Level of Compliance: Working Towards Compliance – Still Under Review[22]

The DSPDI provided adjustment and progress reports for seven participants transferred from an institution to a community home (four from IPPR and three from Shalom). The adjustment and progress reports were drafted by members of the interdisciplinary team from the CTS (or Central Office in case of specialized service homes) who are assigned to the new community home, indicating each participant's adjustment to the new home within a 30-day period, as provided for under the Commonwealth's Norm Regarding Transfers and Transitions provided for in BM 6.

Review of the adjustment reports revealed great variations between and among the interdisciplinary teams that engaged in the adjustment period and prepared the reports and it revealed that not all members of the interdisciplinary team participated in the reporting and monitoring of the adjustment period. A comprehensive review of the adjustment period which should include heightened monitoring, is needed in order to ascertain that all the participants' needs are met for a successful transition and adjustment to the community setting.

Given that the DSPDI is in process of revising its protocols and developing a deinstitutionalization protocol, this would be an opportunity to go into more detail on how the process of adjustment should be conducted, what are the needs of the participant (as identified in the ITP) that should be monitored, the supports that the participant and home may need, and tools it should have in place to support that adjustment period. Creating an individualized deinstitutionalization and adjustment plan per participant may be very beneficial in this process as well.

III.2 Provider Capacity Expansion in the Community

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"

Level of Compliance: In Compliance

The DSPDI provided three separate lists, one for group homes, one for substitute homes and one for biological homes. Below is a summary of participants per home.

[22] In their response to the JCC's first draft of the present Report, USDOJ presented compelling arguments which persuaded us to change the current compliance rate to "working towards compliance-still under review".

	CURRENT As of 6/30/2022			As of 12/31/2021			As of 6/30/2021		
Home Classification	**No. of Homes**	**No. of Part.**	**%**	**No. of Homes**	**No. of Part.**	**%**	**No. of Homes**	**No. of Part.**	**%**
Group Homes (including specialized group homes) (Puerto Rico)	50	305	88%		296	89%	44	284	86%
Substitute Homes	18	40	12%		38	11%	20	48	14%
SubTotal	**68***	**345**	**100%**		**334**	**100%**	**64**	**332**	**100%**
Biological Homes		215			212			209	

*As of June 30, 2022, the Erikmar Group Home, Catalina Group Home and Substitute Home Liara Lopez had no participants and provider contracts were not renewed. As such, these were not considered in the number of group homes shown. See also BM 14.

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

Level of Compliance: Working Towards Substantial Compliance-Still Under Review[23]

The Commonwealth has developed a revised plan to open new homes for the period 2021-2023. Overall, the plan reflects a reasonable approach. It creates new homes/beds to enable the placement of participants from the two remaining private institutions – Shalom and IPPR – and to eliminate the overcrowding in existing community homes. The plan projects a budget of over $5M. There is a lingering concern with the plan though, as it may endorse compelling participants to move from their homes if their condition changes or they reach a certain age (over 59). The Commonwealth's system should accommodate the individualized needs of each participant, allowing them to remain in their homes; the Commonwealth's system should conform to their needs and the participants shouldn't lose their homes based on arbitrary administrative or other criteria.

[23] In its response to the draft report shared with the Parties, the DSPDI argues and requests that "the Office of the JCC re-consider its assessment of this benchmark and assess the same as "In Compliance". The JCC is not persuaded as the plan does not address concerns raised by the USDOJ in Court filing nor does it incorporate evidenced based practice modes currently used in the ID/DD field where for instance, group homes have five participants and substitutes homes have a census of two. In addition, the fact that two of the newly opened homes already closed raises concerning questions regarding the DSPDI screening of new providers. However, the JCC reconsidered its original assessment and deems that the DSPDI is "Working Towards Substantial Compliance-Still Under Review" in this BM.

In addition to the above, the Division provided a list of nine homes/providers that are in advanced stages of the contractual process and are expected to open soon for a total of 43 additional home units. Currently, the DSPDI is using prior year rollover funds to open the new homes. As the DSPDI continues to open new homes, it has the opportunity to address issues of overcrowding within current group homes and re-evaluate existing home placements and participant requests to be in a home closer to family members, which could result in better pairing of participants' needs.

There is still progress to be made in this benchmark though, as there are more than 40 participants[24] still living in private institutions for which the only obstacle to transition is the lack of available community homes providing the services and supports that participants need. Once a referral for community placement has been made to the DSPDI's CDS, the JCC recommends that participants be placed on the DSPDI wait list, so the CDS has a clear understanding of the urgency and continued need for opening new homes that provide adequate services and are in reasonable proximity to participant support circles. In addition, the plan does not address concerns raised by the USDOJ regarding Person-Centered Planning process and homogeneity of homes.[25]

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"

Level of Compliance: Working Towards Compliance – Still Under Review[26]

For the period beginning on January 1, 2022, to June 30, 2022, the DSPDI opened the following homes:

Name of Home	Date Opened	Type of Home	No. of home units
Hogar Belen I	1/26/2022	Specialized Behavioral Home	6*
Hogar Brisas del Paraiso II	1/25/2022	Specialized Health Care Home	6*
Hogar Casa Aaron	5/11/2022	Group Home	6
Hogar Huellas de Amor	5/31/2022	Specialized Health Care Home	6
Substitute Home Alberto Ortiz	12/31/2021	Substitute Home	1

[24] Participants for whom family members have approved the transfer to community living or do not oppose placement.
[25] See Docket 3042 and 3209 for USDOJ's position on the opening of new homes.
[26] In its response to the draft report shared with the Parties, the DSPDI argues that "assessing this Benchmark as "No Compliance" means that the Office of the JCC does not recognize the efforts being made towards reaching full compliance. Thus, the DSPDI respectfully requests that the Office of the JCC re-consider its assessment of this benchmark and assess the same as "Partial Compliance". The JCC reconsidered its original assessment and deems that the DSPDI is "Working Towards Compliance-Still Under Review" in this BM.

Total home units created			**25**

*As of June 30, 2022, these group home had seven participants each.

Homes closed from January 1, 2022, to June 30, 2022:

Name of Home	Date Closed	Type of Home	No. of home units
Catalina's Home	Participants were transferred out on 5/11/2022. Home opened since 12/6/2021	Group Home	6
Erikmar Group Home	Participants were transferred out on 2/26/2022. Home opened since 8/21/2003	Group Home	7
Substitute Home Liara Lopez	Participant was transferred out on 2/3/2022. Home opened since 12/1/2021	Substitute Home	2
Total home units			**15**

So, unfortunately, the net gain during the six-month period was only 10 beds.

Comparison of available community homes per semester:

Type of Home	As of 6/30/2022	As of 12/31/2021	As of 6/30/2021
Group Homes (Excluding Catalinas Group Home and Erikmar Group Home)	50	49	44
Substitute Homes (Excluding Substitute Home Liara Ortiz)	18	16	20
Total	**68**	**65**	**64**

As of June 30, 2022, the following homes were overcrowded:[27]

	Name of Home	Municipality	No. of Participants	Over
1	El Olám II	Aguadilla	7	1
2	Nueva Vida	Corozal	7	1

[27] We have been flexible in allowing the Commonwealth, for the time being, to accept six participants per group home even though a broad consensus exists that community group homes should be comprised of no more than four participants with no more than one participant in substitute homes.

3	Hacienda Isaí	Manatí	7	1
4	Jehovah Yireh I	Toa Alta	8	2
5	Janick	Morovis	7	1
6	Nueva Esperanza	Aguadilla	7	1
7	Rayo de Luz	Vega Baja	8	2
8	Hogar Belen I	Toa Alta	7	1
9	Brisas del Paraiso II	Aguadilla	7	1
10	Dulce Amanecer II	Corozal	7*	1
Total No. of Participants				12

* On June 14, 2022, participant #570 was transferred from Hogar Modesto Gotay I to Dulce Amanecer II due to a health-related emergency. According to the ITP (in draft form, last updated on June 22, 2022) placement is temporary until a bed opens in a specialized health care home better able to provide the services needed by the participant (referred to CDS on February 20, 2022 due to health needs of participant). As of the date of filing of this Report, participant still resided in home for a total of seven participants.

Of the 50 group homes, 9 continue to be significantly overcrowded by having a census of 7 to 8 participants, and a third of the 18 substitute homes are also overcrowded by having a census of 3 participants.

It is imperative that the DSPDI continue to open high-quality community homes that address the needs of the participant and are truly integrated in the community. The Division should provide options for participants to move to integrated homes, supporting their right to make decisions which will ultimately result in fulfillment of an individualized and person-centered process, as mandated by the Court. (See Docket No. 3510).

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)

Level of Compliance: Working Towards Compliance – Still Under Review[28]

There is much more work to be done to reach compliance with this BM.

III.3 Integrated Employment and Day Activities

[28] In their response to the JCC's first draft of the present Report, USDOJ presented compelling arguments which persuaded us to change the current compliance rate to "working towards compliance-still under review".

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"

Level of Compliance: Substantial Compliance

The Master List includes a total of 21 participants, of which only 19 are currently working (3.2% of total participants). This figure represents close to a 35% increase in the percentage of employed participants in comparison to the March 2022 Report (which documented 14 participants as being employed). Nine of these participants were carried over from the previous six-month period. From the current sub-list's case notes, participants #577 and #178 were terminated for reasons ranging from theft to unjustified excess absences. Lastly, as has been historically noted, most participants on this list have either mild or moderate IDD. Three participants work at a CTS location, which may not be an integrated community setting.

Nine participants have achieved competitive integrated employment and are receiving the minimum wage of $8.50/hour. Of these nine participants, one is working full-time status at approximately 40 hours/week; one is working 30 hours/week; and seven are working 20 hours per week. Additionally, one other individual is making $8.25/hour at 20 hours per week.

Of the nine participants carried over from the last six-month period, four experienced an increase in hours ranging from 6 to 20 hours, while two experienced a decrease in hours. With respect to hourly wages, four participants received an increase in hourly pay ranging anywhere from $0.25 to $1.25. This increase correlates with the Governor's enactment of the Minimum Wage Act (Act No. 47-2021) that increased minimum wage to $8.50 from $7.25 at the start of 2022 in Puerto Rico. Unfortunately, other participants are still being paid sub-minimum wages and, thus, do not count as a competitive, integrated employment outcome. Three of the 21 participants listed had a vocational report dated in 2022—all other reports were completed within the last 6 months of 2021.

With respect to the list, it is unclear if the 'Start Date' field is reflective of when the participant began working or was enrolled into Vocational Rehabilitation Counseling Services Area (ASCERV) services. This list should also include the location where the participant resides. Finally, there needs to be a clear distinction between a Work Capability Assessment and a Vocational Evaluation, including what criteria is used in each of these tools/processes to determine employability potential for participants.

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)

Level of Compliance: Partial Compliance

All 21 participants listed in Benchmark 17 ("Participants Currently Working in the Community") are also listed in the underemployment list for Benchmark 18. The DSPDI provided a plan of action for each participant divided into three phases to address underemployment:

- Phase 1: Initial Engagement Phase - The rehabilitation counselor will make a home visit for interview and screening. Offer individual counseling to identify areas of need.
- Phase 2: Support Phase - Advocate or manage according to identified needs. Examples include:
    - Employment promoter will identify another job if necessary; and
    - Explore increase in hours.
- Phase 3: Follow-up according to the support phase in the sustained employment training phase.

The plans, however, are generic in nature, lack sufficient detail and do not adequately describe appropriate individualized action steps that would feasibly lead to an increase in employment for these participants. Specifically, the action plans do not provide the following information:

- Status of the progress made in each of the three phases for each participant;
- Sufficient details describing **what** will be completed in each of the phases, and **how;**
- Unique steps for individual participants based on their own needs, preferences, and strengths, including any information from a person-centered service plan or supplemental documentation;
- Any specific recommendations from rehabilitation staff that have worked with each participant regarding skill development and additional support; and
- Information regarding completion target dates for each of the action plans.

Upon reviewing case notes and files in Therap, we identified several concerns that will further impede progress in securing increased employment for participants who are currently working. These concerns include: disparate findings and actions from the Psychology Division that prevented participants from continuing employment activities; variation in participants' access to community-based activities and employment experiences; lack of engagement of home providers and families in the employment exploration process; and pattern of continued sub-minimum wages.

Addressing these concerns and providing more sufficient person-centered details of what and how key actions will be implemented will help the DSPDI progress in achieving full compliance with Benchmark 18.

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)

Level of Compliance: Working Towards Compliance – Still Under Review[29]

The level of information provided in the Commonwealth's documents was inconsistent. In some plans, there was evidence of numerous visits and activities with the participant, and in other cases, follow-up after plan development was minimal. This suggests a lack of clarity in expectations and guidance to the various rehabilitation specialists on level of effort, types of activities, and reporting requirements with respect to plan completion.

[29] In their response to the JCC's first draft of the present Report, USDOJ presented compelling arguments which persuaded us to change the current compliance rate to "working towards compliance-still under review".

Overall, most of the plans lacked clarity in terms of confirming progress with implementing each of the three phases of activities, and it was difficult for the review team to determine what phase of the plan a participant and their support team was currently focused on. As discussed in BM 18, the lack of detail about what and how key actions would be implemented likely exacerbated continued ambiguity in understanding overall progress.

The protocol outlined the frequency of meetings and case discussions between and within Central Level and ASCERV. Specifically, the DSPDI schedules monthly meetings with job promoters to discuss the individualized plans of the participants who are currently working or in the process of obtaining employment. Additionally, meetings between rehabilitation counselors, promoters, and trainers are scheduled every two months to discuss employment and underemployment. From these meetings, recommendations are issued and integrated within the participant's individualized plan to provide optimal and appropriate services to avoid underemployment.

All action plans should be consistent in addressing the following:

- Participant-centered plans include the development of SMART[30] goals, including clear goals that incorporate the participant's interests, goals, and strengths; employment promoters and employment trainers must be fully aware of each participant's person-centered plan;
- Employment placement should be based on participants' interests and strengths based on exploration of numerous options, rather than on more limited arrangements a CTS has made with only 1-2 employers;
- Identifying the available supports and needs (e.g., transportation) of the DD system and integrating it within the employment development process;
- Evaluating how committed the employer is to the participant prior to securing employment;
- Assuring that the participant is meaningfully engaged and participating in the exploration of employment alternatives, the identification of transportation benefits and other supports needed to be successful in employment, and final decision making relative to employment;
- Consider other needs and desires of the participant, such as family contact, recreational activities, triggers and interventions for stressor management and independent living; and
- Creating an itinerary of participants' personal activities according to their employment schedule (planning).

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"

Level of Compliance: Working Towards Substantial Compliance[31]

[30] SMART is a tool that is used to plan and achieve goals.

[31] In their response to the JCC's first draft of the present Report, USDOJ presented compelling arguments which persuaded us to change the current compliance rate to "Working Towards Substantial Compliance".

The DSPDI furnished a list of participants, including those that are currently working (a total of 19 participants) and those that are not (a total of 629 participants). According to the list, 89 of those not working have been previously assessed as able to work.

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)

Level of Compliance: Working Towards Substantial Compliance

The DSPDI furnished a table that combined Benchmarks 20, 21, 24 and 25. The list included 648 participants; one additional participant was identified after submission (the difference to the Participant Master List at BM 3 is due to participant #1171 admitted per Therap on June 29, 2022, residing in a biological home), making the overall total 649 participants. In the list, 629 participants were identified as not currently working.

As it pertains to this benchmark the report furnished shows that 614 participants have been evaluated between 2014 and 2022 and 484 have been re-evaluated from May 2021 to June 30, 2022. Our finding reveals that of those not currently working, 71 participants were determined as having potential for employment. Of the 71 assessed as able to work, 52 were re-assessed between 2014 and 2022 and 18 were identified as not having potential for employment.

The current instruments that the Rehabilitation Counseling division uses to evaluate employability have been reviewed by the subject matter experts, and recommendations have been made regarding how to improve the processes to assess participants. This includes use of other models in Vocational Rehabilitation to assess and support the employment of people with intellectual/developmental disabilities. Additionally, training is being scheduled to increase the knowledge and improve the strategies used by job promoters and developers. It is imperative that in the future, measurable goals and objectives flow from the assessments to help participants pursue and/or increase focus on job placement and employment sustainability. These goals should have rigorous timelines attached so that participants are not waiting for prolonged periods of time to pursue employment activities. Any challenges to placement in employment should be identified more consistently in the assessment process.

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

Level of Compliance: Working Towards Compliance – Still Under Review[32]

[32] In their response to the JCC's first draft of the present Report, USDOJ presented compelling arguments which persuaded us to change the current compliance rate to "working towards compliance-still under review".

The Commonwealth document furnished at BM 22 23 26 27 did not provide any detailed action steps with respective timeframes to maximize community employment for participants not working that were professionally assessed or identified in the past as able to work in the community. It did, however, indicate that all 40 participants on this list had implemented plans to maximize employment, of which 21 were developed and implemented within the first half of 2022. All but one of the participants on the list are consistently identified as "having potential for employment."

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)

Level of Compliance: Working Towards Compliance – Still Under Review[33]

Similar to BM 22, the document furnished did not provide any detailed action steps with respective timeframes with regards to maximizing community employment or addressing underemployment. Again, it states that all 40 participants on the list have had their plan implemented, but there are no case notes that highlight the specifics for each case. However, there were other documents provided that demonstrate some positive progress and new efforts by the DSPDI that are noted below.

- The Commonwealth provided a list of newly established and prospective relationships with both private and public employers. Specifically, in the six-month review period, ASCERV successfully secured a total of seven new relationships with employers across the island and have three other promising leads. Most of these employers are nearby - in the same or in surrounding towns of the local CTS. Roughly a quarter of these job opportunities have been fostered with local municipal offices and agencies throughout the island, which is likely linked to the Governor's Executive Order from February 2022, that encourages government agencies to serve as model employers of adults with IDD.
- The "Employee for the Day" initiative was launched in the spring of 2022 and has exposed participants to various work experiences. In one instance, this has led to the promise of a job placement for a participant within one of the Department of Health's seven regional offices. Participants who have gained new employment experience through this initiative will showcase that experience to other participants to encourage broader participant involvement in the future, especially through the CTS in Rio Grande and Fajardo in the fall of 2022.

The review of other documentation confirmed that while Vocational Rehabilitation counselors have identified phases for helping those participants who are working to remain in their jobs, there continues to be a gap in focus on helping participants to explore other professional opportunities, increase the hours they are working, and increase wages over time.

[33] In their response to the JCC's first draft of the present Report, USDOJ presented compelling arguments which persuaded us to change the current compliance rate to "working towards compliance-still under review".

The JCC encourages a stronger focus on identifying community-based employment opportunities that result in participants achieving socio-economic advancement and greater autonomy. This will require exposure to increased skills-development and job training opportunities in collaboration with the Commonwealth's vocational rehabilitation and workforce development systems to better prepare participants to compete in the labor market.

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"

Level of Compliance: Working Towards Substantial Compliance-Still Under Review[34]

The census for the period from January 2022 to June 30, 2022, is 649 participants of which 629 are not currently working. Of those not working, 446 have been assessed not able to work It is concerning that a significant number of participants have not been professionally assessed since 2019 -- some as far back as 2014; indeed, dozens have no prior or current reevaluation listed in the Commonwealth's table. For those that have not been evaluated, the majority are in their 20s or 30s, and 14 of them have either a mild to moderate IDD diagnosis.

The DSPDI furnished the JCC with a document entitled 'BM 24 Vocational Workshops (All Participants)' that was reflective of activities from April through June of 2022. Within this three-month timeframe, a total of 649 workshops were delivered to over 133 participants. Please note that not all entries included within this list are necessarily formal as there are some entries reflective of 'Individual Counseling.'

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)

Level of Compliance: Working Towards Substantial Compliance[35]

The DSPDI furnished a table that combined Benchmarks 20, 21, 24 and 25. The list included 648 participants; one additional participant was identified after submission (the difference to the Participant Master List at BM 3 is due to participant #1171 admitted per Therap on June 29, 2022, residing in a biological home), In the list, 629 participants were identified as not currently working,

[34] In their response to the JCC's first draft of the present Report, USDOJ presented compelling arguments which persuaded us to change the current compliance rate to "working towards substantial compliance-still under review". The JCC will address USDOJ's concerns regarding this benchmark for the next Report and notes that the DSPDI should be able to achieve compliance by then.

[35] In their response to the JCC's first draft of the present Report, the DSPDI presented compelling arguments which persuaded us to change the current compliance rate to Working towards Substantial Compliance. The same standard was applied to BM 21.

As it pertains to this benchmark the report furnished shows that 614 participants have been evaluated between 2014 and 2022 and 484 have been re-evaluated from May 2021 to June 30, 2022. Our finding reveals that of those not currently working our 533 participants were determined as not having any potential for employment, 71 as having potential for employment and 25 that have yet to be determined. See comments in BM 21 regarding evaluation tools concerns.

Additionally, there are still participants in homes of the Department of the Family and ASSMCA who have not been evaluated. This population does not yet benefit at the moment from Rehabilitation Counseling services, but the JCC hopes that these participants will have access to rehabilitation supports in the future.

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)

Level of Compliance: Working Towards Compliance – Still Under Review[36]

Of the 71 participants identified as having employment potential, only 40 are recorded as having Individualized Plans for Rehabilitation Counseling Services to maximize their chances of attaining employment. The document furnished also fails to outline concrete action steps and timeframes regarding their plan to maximize community employment, as previously mentioned in other benchmarks.

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)

Level of Compliance: Working Towards Compliance – Still Under Review[37]

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"

Level of Compliance: Partial compliance

A total of 58 participants were included in the "Self-Employment List," most of whom reside in biological homes (31 participants). However, the listed self-employment activities are not taking place in integrated

[36] In their response to the JCC's first draft of the present Report, USDOJ presented compelling arguments which persuaded us to change the current compliance rate to "working towards compliance-still under review".
[37] In their response to the JCC's first draft of the present Report, USDOJ presented compelling arguments which persuaded us to change the current compliance rate to "working towards compliance-still under review".

community settings, with most participants engaged in self-employment activities at the CTS locations. Individualized plans were developed for the majority of participants (48) in 2022, and the Commonwealth reported that nearly half of all plans have been implemented (23). However, the range of activities for 11 of the 23 participants with implemented plans were not included in the documentation provided. For the remaining 12 participants with implemented plans, the activities completed ranged anywhere from just once a week to once a month, never surpassing more than two hours per activity. Self-employment activities mainly included making artisanal soap, washing cars, and recycling cans. Only five of the 58 participants earned income, each earning less than $70 in a six-month period. Given that only a handful of participants are earning money, it is not clear that we can conclude that the Commonwealth's report of 23 implemented self-employment plans is valid. Moreover, given the low volume and low frequency of income-generating activities and the nominal amount of money earned, it is recommended that these participants also be included in the underemployment list.

ASCERV provides a two-hour orientation to participants using a Spanish program. The CTSs with the smallest census (Cayey and Aibonito) combined have the largest representation in this list (total of 24 participants).

A further examination of the guidelines and protocols around self-employment also suggest that there is an absence of person-centered planning principles integrated throughout the entire ASCERV process, including self-employment. For example, the protocol states that for those participants deemed ineligible for competitive employment, they are then only considered for continuous work experiences and/or self-employment. Both competitive integrated employment and entrepreneurship should both be considered at the forefront when directly and indirectly gathering information about the individual's interests, hopes, strengths, and dreams.

Further, the self-employment workshops documented appear to be the same ones offered in the past (e.g., jewelry, soap making, and horticulture) and what is offered often is limited and contingent upon a CTS's available resources. One area of opportunity, which has been noted in previous reports, is leveraging local community colleges for continuous work experience and skill development. Exposing participants to different small businesses and to entrepreneurs in the community is an important step toward community integration.

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)".

Level of Compliance: No compliance[38]

For this period, 19 participants (3% of the total population) are identified, as being employed, and 13 participants meet the criterion of working between 20-40 hours/week. This is an increase of three participants from 2020. The goal of having 25% of the participant population employed has not yet been met**.**

The field entitled, "TOTAL NUMBER OF PARTICIPANTS OF WORKING AGE (20 TO 40 WITH MILD OR MODERATE INTELLECTUAL DISABILITY)" highlights a previously noted concern that DSPDI only considers those with Mild or Moderate or no IDD for ASCERV services. In addition, the working age group should not be limited to those 20-40 years old but should be extended to adults aged 18-65 per U.S Department of Labor's Bureau of Labor Statistics and retirement and/or the decision "not to work" should be person centered.

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)

Level of Compliance: Working Towards Compliance – Still Under Review[39]

Although individualized plans were not provided, a list was included in the documentation for BM 30 outlining community activities that had been provided and completed over the past six months. There continues to be concerns among the subject matter experts regarding the overly broad criteria applied to determine participants unable to work, rather than focusing energy on how to apply their skills or strengths into community-based employment. Strategies for addressing social determinants and environmental barriers (e.g., transportation) should be developed. The DSPDI should also identify alternatives for those participants with difficulties in communication, cognitive functioning, temperament, and epilepsy or other comorbidities.

The Commonwealth's list of vocational workshops and activities includes activities at the CTSs of Bayamón and Vega Baja that offer services just once a week. A once-a-week workshop/skill development activities are not sufficient for a person with ID/DD to maximize meaningful and functional community activities that foster their growth and independence. Indeed, CTS services are by their nature not integrated community activities. The Commonwealth needs to identify community organizations where participants' interests, skills and preferences are an effective match. Community organizations could also offer constructive support in the community in skill building related to employment opportunities.

Benchmark 31 – "Implement the plans" (JCAP III.3.E)

[38] In their response to the JCC's first draft of the present Report, USDOJ presented compelling arguments which persuaded us to change the current compliance rate to No Compliance. The Office of the JCC and Experts are willing to assist the DSPDI in all matters related to this BM.

[39] In their response to the JCC's first draft of the present Report, USDOJ presented compelling arguments which persuaded us to change the current compliance rate to "working towards compliance-still under review".

Level of Compliance: Working Towards Compliance – Still Under Review[40]

There is much more work to be done to reach compliance with this BM.

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"

Level of Compliance: Working Towards Compliance – Still Under Review[41]

Although individualized plans were not provided in time to be included in this review, other documents supplied by the DSPDI were reviewed and site visits and interviews completed at the regional CTS and with participants. As a result of these activities, the following points are noted with respect to BM 32:

- Need for Additional Vehicles: The DSPDI recently acquired Ford transit units for all regional CTSs (two per center) in 2021. However, the units were delivered without ramps for people with needs or stirrups. A more comprehensive needs assessment of gaps in assistive technology and adaptable equipment needs to be completed and gaps addressed over the next six months. Even though good progress has been made in obtaining over a dozen new vehicles to safely transport participants to daily centers, most CTSs do not have sufficient accessible vans/automobiles to effectively and safely transport all participants with complex health needs to the community to participate in inclusive, integrated activities. The Commonwealth's document at BM38 reveals that out of a total of 54 CTS vehicles, a dozen or so ae not available for use (many in the repair shop). In addition, about half of the 54 vehicles have very high mileage – over 100,000 miles – potentially rendering them unreliable or obsolete.
- Need for equipment and technology: (Validated in visit to the Vega Baja CTS – August 2022) The CTSs lack adequate equipment for employees to perform daily work tasks, and lack sufficient assistive technology to enable participants to engage more meaningfully in community-based activities. The Commonwealth's document at BM32 reveals that there is a need for over 100 computers given current staffing levels.
- Distribution by CTS: The participant census varies by region, but the available resources are not equitably distributed in accordance with the existing census, thereby, creating unmet needs where resources are not adequate to meet the needs of the participants. In addition, the Commonwealth's document at BM32 reveals dozens of vacancies at the CTSs (47), but only a few in the process of hiring.

[40] In their response to the JCC's first draft of the present Report, USDOJ presented compelling arguments which persuaded us to change the current compliance rate to "working towards compliance-still under review".
[41] In their response to the JCC's first draft of the present Report, USDOJ presented compelling arguments which persuaded us to change the current compliance rate to "working towards compliance-still under review".

Certain key challenges in this area need to be prioritized and addressed over the next six months, including:

- The frequency CTSs provide assistance to participants to enable them to engage in activities in the community, and the frequency/variation in exposure opportunities in the community.
- Services identified in the community that are subject to limitations on start dates.
- Acquisition of needed transportation, materials, equipment, and assistive technology.
- Placement of ramps and stirrups on vehicles purchased in 2021, to assure 100% accessibility for all participants.
- A study of the vehicle needs of each CTS taking into consideration the individual needs of participants served in each CTS.

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)

Level of Compliance: Working Towards Substantial Compliance- Still Under Review [42]

The DSPDI included a list per CTS of participants that did not attend the CTS for the period of January to June 2022. The list includes 104 participants (16% of the 649), 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). Of the 103 not attending the CTS, seven are currently working.

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"

Level of Compliance: Working Towards Compliance – Still Under Review[43]

There is evidence at BM 35-36 of a list of participants who do not attend the CTS but have had access to community activities over the reporting period. At an individual level, however, it is not always clear whether the planned community activity was achieved or what the outcome was for those that were completed. For example:

- "Participant flew kites and shared with his peers." Only the objective is presented.
- "Develop body movement and physical activity through athletics skills." There is no evidence of evaluation of their activity, progress or needs.

[42] In their response to the JCC's first draft of the present Report, USDOJ requested that we change the current compliance rate to Partial Compliance. However, the JCC reconsidered its original assessment and deems that this benchmark is currently Working Towards Substantial Compliance.

[43] In their response to the JCC's first draft of the present Report, USDOJ presented compelling arguments which persuaded us to change the current compliance rate to "working towards compliance-still under review".

Benchmark 35 – "Implement the plans" (JCAP III.3.F)

Level of Compliance: Working Towards Compliance – Still Under Review[44]

A list of activities is evident. However, similar to feedback in BM 34, progress in implementation of proposed activities is unclear and problematic to identify.

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)

Level of Compliance: Partial Compliance

The Commonwealth provided a draft of the SUPPORT PROGRAM FOR SOCIAL INCLUSION (PAÍS, for its acronym in Spanish). Overall, the initiative is positive. The Proposal plans to have a satellite staff that supports the community inclusion of participants, especially for those that do not reside near a CTS and for those that live in biological homes that are situated in remote locations where access to community resources is limited. It also proposes to have collaborative agreements with public and/or private agencies.

Office of the JCC and the Experts recommend the Commonwealth address the following issues to complete the Draft Plan:

- Update the definition of ID, as required by the American Association of Intellectual Disabilities and Development, Issue 12;
- Clearly define each problem or need with statistical data (e.g., many participants are not accessing or are meaningfully engaged in community activities);
- More clearly state the goals of the program;
- Define the geographical areas that will be impacted;
- Identify the distribution of EID versus participants to be assigned;
- Identify the location of the office;
- Indicate start dates and attach timelines to each goal area;
- Include an evaluation plan with an independent evaluation mechanism;
- Establish organizational structure and levels of communication; and
- Outline implementation phases, to include technical assistance/training for front-line staff and providers on:
    - Culture and Inclusion Policy;
    - How to develop/scale models;
    - Phases for inclusion;
    - Promotion of independent living strategies and skills development;

[44] In their response to the JCC's first draft of the present Report, USDOJ presented compelling arguments which persuaded us to change the current compliance rate to "working towards compliance-still under review".

- Development of People First language/culture; and
- Addressing accessibility needs (units with ramps, equipment, assistive technology).

Benchmark 37 – "Implement the plan" (JCAP III.3.G)

Level of Compliance: Working Towards Compliance – Still Under Review[45]

Now that the DSPDI has developed a draft systems-level plan for promoting social inclusion and community integration of participants in meaningful day activities, the subject matter experts will work with the team on implementation strategies over the next six months. See feedback in BM 36 for more details.

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"

Level of Compliance: Working Towards Compliance – Still Under Review[46]

See feedback in BM 32.

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

Level of Compliance: Working Towards compliance – Still Under Review[47]

The JCC notes with commendation the tremendous progress that the DSPDI has made to fully staff the Rehabilitation Counseling team and to employ job developers/coaches connected to each of the regional CTS. Further, during the Employment/Integrated Daywork group meetings over the past several months, the team has been working to develop a training plan to be implemented over the next six months.

Moving forward, the DSPDI should focus on implementing the formal training in partnership with the Experts, re-evaluating and addressing tasks/job descriptions to assure clarity in the services individual staff are providing and addressing any gaps in skills or bandwidth/capacity. It would also be good for DSPDI to invest in team-building activities to facilitate a more cohesive culture among the rehabilitation staff, and to create opportunities for regular touch-bases with other divisions to discuss opportunities for stronger collaboration, coordination, and improvement. The Commonwealth should be able to achieve this in a relatively short period of time.

[45] In their response to the JCC's first draft of the present Report, USDOJ presented compelling arguments which persuaded us to change the current compliance rate to "working towards compliance-still under review".
[46] In their response to the JCC's first draft of the present Report, USDOJ presented compelling arguments which persuaded us to change the current compliance rate to "working towards compliance-still under review".
[47] In their response to the JCC's first draft of the present Report, USDOJ presented compelling arguments which persuaded us to change the current compliance rate to "working towards compliance-still under review".

For the purposes of person-centered planning, it is critical that the Employment Promoter and Employment Trainer are engaged and included in the development of the PCP and its evolution/implementation. Strategies must be identified to assure that these professionals know the strengths and needs of the participant, in an integrated manner. This will require these professionals to learn discovery as part of their upcoming formal training in customized employment strategies.

III.4 Safety and Restraint Issues

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)

Level of Compliance: Working Towards Compliance – Still Under Review[48]

The DSPDI has begun concerted efforts to improve the quality and amount of information in Therap. A substantial part of the work of the incident committee has been focused on gaining greater consistency, quality, and accuracy of the information in Therap, as well as developing other infrastructure changes related to this benchmark. The DSPDI is working to improve its protocols and manuals related to incident reporting. It is expected that these strategies will result in greater improvements going forward.

At this stage though, the quality of much of the information continues to be substantially deficient and some information is simply incomplete; this negatively affects the accuracy of the safety and welfare analyses the Commonwealth has been undertaking, as well as delays the progress of systemic improvements, including risk mitigation and preventable deaths. It is not yet evident that accurately informed safety and welfare analyses are being conducted for all participants.

The DSPDI has reported progress on the implementation status of seven newly introduced modules to the DSPDI's Therap data management system; the Commonwealth asserts that three of the seven have been marked as complete: Appointments, Care Plans, and Individual Document Storage.

Trainings About Therap Services:

During this past six-month period, the Commonwealth provided training across the community system:

- Eight Therap trainings covering the incidents, T-Logs, Health Tracking, Personal Focus Worksheet, and Individual Support Plan modules delivered to 181 providers and provider personnel from 39 group and substitute homes, including two homes where the DSPDI requested a corrective action plan due to the home providing inconsistent documentation (Psicopedagógico I and Psicopedagógico III). This represents roughly 53% of all community homes (39:73) that have received formal training on these Therap modules.

[48] In their response to the JCC's first draft of the present Report, USDOJ presented compelling arguments which persuaded us to change the current compliance rate to "working towards compliance-still under review".

- Five Therap trainings covering Therap's 'Individual' and 'Health' components delivered to 116 nursing and EID professionals and other personnel across all seven CTSs and Central Office.

While provider access to Therap to report incidents and other critical information has improved over time, gaps persist. Roughly 79% (58:73) of all group or substitute homes report that they use Therap, which is a slight decrease from what we reported in March 2022 (84%). The homes that do not yet use Therap cite various reasons for lack of access, including: poor internet access (2), blocked Therap accounts (4), or that the home has no assigned participants (5). The Commonwealth reports that four of the 15 homes have been cited as providing inconsistent documentation and offering inadequate reporting. The DSPDI has requested that each of these 15 homes submit a corrective action plan to address their non-compliance and to rectify these outstanding issues related to use of Therap. The JCC Office will be following up on the preparation and implementation of the above corrective action plans and will be assessing the same in our next Semi-annual Report.

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

Level of Compliance: Working Towards Compliance – Still Under Review[49]

The DSPDI has improved the composition of its incident committee to include clinicians, and during this period has started to make more referrals from the incident committee to the CAPAR for clinical follow-up, which is a positive development. As discussed in the incident committee meetings, there is some evidence of Commonwealth efforts to improve individual safety and welfare. As a more adequate and complete plan is finalized in BM 40, this outcome benchmark will have a greater opportunity for progress.

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)"

Level of Compliance: Working Towards Compliance – Still Under Review[50]

During this six-month period, the DSPDI provided a list of 116 distinct peer-to-peer incidents listed across 68 participants, categorized as either victim or aggressor. A JCC team review of the Therap Event Summaries and related case notes for this period yielded a total of 161 'individual/individual' incidents across 84 participants.

There are some challenges with how data about peer-to-peer incidents are entered into Therap that make it challenging to analyze patterns with these incidents. The 116 DSPDI-reported incidents appear to represent a smaller number of unique incidents than is appropriate because there is supposed to be a

[49] In their response to the JCC's first draft of the present Report, USDOJ presented compelling arguments which persuaded us to change the current compliance rate to "working towards compliance-still under review".
[50] In their response to the JCC's first draft of the present Report, USDOJ presented compelling arguments which persuaded us to change the current compliance rate to "working towards compliance-still under review".

separate incident report for each participant -- separate reports are supposed to be submitted for both the victim(s) and aggressor(s) in each incident. The Commonwealth may benefit from a review of whether there is a more efficient way to report and analyze incidents involving multiple participants.

Adding to the confusion, in Therap, a peer-to-peer incident is categorized as 'individual/individual' or 'Was it Individual against Individual?: Yes.' In some cases, incidents are being reported as 'Was it Individual against Individual?: No,' and then the field 'other event summary' describes that it was a peer-to-peer incident; because these incidents are often incorrectly categorized in Therap, there are challenges to accurately finding and then addressing these types of incidents. There may be benefit to a review of how peer-to-peer incidents are reported and categorized.

The JCAP requires an action to eliminate the cause of a non-conformity and prevent recurrence. When reviewing the information in the Commonwealth's document at BM42, specifically the column titled "Corrective Actions," we found that there is some information provided, but the extent of the information varies. In many cases, 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.

Frequently, the corrected action listed is a dialogue with the participant or assessment for injury. While these immediate responses may be beneficial and appropriate, there is little discussion of strategies to prevent reoccurrence or examine the root causes. In some isolated incidents, there is a more in-depth description of the actions that DSPDI and/or the provider is taking to implement a preventive strategy, which is progress from the information provided in prior monitoring periods.

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

Level of Compliance: Working Towards Compliance – Still Under Review[51]

There is much more work to be done to reach compliance with this BM. Part of the problem is that the Commonwealth has not provided adequate behavior plans for all participants that need them. For those that do exist, they are too often inadequate with gaps in the plans such as the failure to take into account important diagnoses (ex. that the person has autism). Case notes frequently do not describe what recommendations are made in response to events, just that recommendations were made. This lack of detail can present important gaps in interdisciplinary team work, in assessing whether the recommendations were effective, and capturing that detail in the event of staff turnover. It is not clear for most participants what is being done to address risk factors, nor whether they are effective.

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

[51] In their response to the JCC's first draft of the present Report, USDOJ presented compelling arguments which persuaded us to change the current compliance rate to "working towards compliance-still under review".

Level of Compliance: Working Towards Compliance – Still Under Review [52]

The Commonwealth identified vulnerable participants based on the criteria of vulnerability to aggression by the EID and incidents reported in Therap, where individuals have been the victim of an aggression or suffered an injury. The DSPDI provided a list of 70 participants characterized as 'vulnerable.' Of the 70 participants, 25 reside in Shalom. However, the list is incomplete, as it omits, for example, participants that were removed from their homes due to allegations of negligence and mistreatment (e.g. #800, 199, 153).

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

Level of Compliance: Working Towards Compliance – Still Under Review[53]

The DSPDI has an Incident Committee that regularly reviews incident patterns. The committee has provided training to nursing, institutional, and biological providers on proper Therap incident reporting. Further training on identifying and managing risk would be highly beneficial.

This committee has also begun making referrals to CAPAR, as early as March 2022 (e.g., participant # 513 was referred to CAPAR for increased fall incidents), for participants needing a clinical review. Related to this and upon the advice of JCC experts, the DSPDI added Dr. Camacho to the Incident Committee to provide clinical review and input in individual cases. These are positive developments that help ensure an adequate and thorough response to individual incidents and incident patterns.

In the future, the Commonwealth should better document what is being done for all of the vulnerable participants, and the Commonwealth should evaluate whether these strategies are effective. For example, many of the vulnerable participants do not appear to have risk plans to address their vulnerability,

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

Level of Compliance: Partial Compliance

[52] In its response to the draft report shared with the Parties, the DSPDI requests that "the Office of the JCC re-consider its assessment of this benchmark and assess the same as "In Compliance". The JCC and experts are not persuaded by the argument stated by the DSPDI, thus the JCC stands by the narrative regarding the assessment evaluation. However, the JCC reconsidered its original assessment and deems that the DSPDI is "Working Towards Compliance-Still Under Review" in this BM.

[53] In their response to the JCC's first draft of the present Report, USDOJ presented compelling arguments which persuaded us to change the current compliance rate to "working towards compliance-still under review".

The DSPDI uses the following criteria to define an aggressor: "The criteria used for the identification of aggressor participants were behavioral history and incidents reported at Therap Services of altercation and aggression to others." The DSPDI provided a list of peer-to-peer incidents for Benchmark 42, and a list of aggressor participants for Benchmark 49 including 42 participants. The information provided is an improvement from prior periods and identifies more participants than in previous periods.

The group of participants identified is not inclusive of all participants with recent aggressive behavior though. For example, between lists of aggressor participants and those with aggressor incidents, there were only 11 matches of participants (participants #239; #246; #596; #746; #928; #991; #1005; #1052; #1094; #1123; and #1126).

Through a deeper analysis of events and case notes, the JCC team identified a total of 79 participants (excluding those listed as self-aggression) that should be listed as aggressors due to altercations/assaults towards others, including peers, staff, and family members. Combining this information with the DSPDI lists for the other benchmarks, we have determined that there is a total of 108 distinct participants properly categorized as 'aggressor' that were either primarily involved in an altercation or an assault with another peer(s), staff, and/or family member. (As an example, #79 is missing on the list, and had incidents of aggression in June 2022).

There was some variation observed in the Therap reporting which may make the identification of aggressor participants more challenging for the DSPDI. For example, it may be beneficial to clarify when to categorize incidents as aggression vs. assault vs. altercation, as these terms seem to be used interchangeably based on our review of the case notes, as well as to clarify how to describe who was involved. Further definition of incident categories would also likely be beneficial for this benchmark and is part of the work being undertaken in the collaborative DSPDI-JCC Expert workgroup on Incidents and Investigations.

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

Level of Compliance: Working Towards Compliance – Still Under Review[54]

The DSPDI has conducted training for providers on topics including High-Risk Behavioral Management and Crisis Intervention; Crisis Interventions and Management Strategies in Participants with ID; and Behavioral Management. The JCC team did not have access to the content or learning objectives from these trainings, but topically they address needed content areas pertaining to this benchmark. The JCC team is working with the DSPDI to review the material, as the DSPDI has agreed to share and consider the content as part of ongoing collaborative workgroups with the JCC team. For the trainings provided, it is also not clear that the knowledge that was gained was evaluated.

[54] In their response to the JCC's first draft of the present Report, USDOJ presented compelling arguments which persuaded us to change the current compliance rate to "working towards compliance-still under review".

Of the incidents involving aggressor participants listed in documents provided for benchmark 46, follow up was listed as being conducted within seven calendar days for 70 of the incidents and within 26 calendar days for 23 of the incidents. However, very little detail is recorded within the DSPDI systems on what is done in response to incidents and whether these strategies are effective to minimize or eliminate aggressor risk triggers.

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 JCAP criteria for serious incidents includes: allegations of abuse, allegations of neglect, serious injuries, fractures, lacerations, bruises, risk of harm, aggression, self-injuries, elopements or attempts, PICA, sexually inappropriate behaviors, use of restraints, suicides or attempts, and property damage.

Level of Compliance: Working Towards Compliance – Still Under Review[55]

There are more incidents being reported in Therap than in previous periods, which, from a data collection perspective, is a positive development. There was a total of 650 entries reflective of 408 distinct high-level incidents and related Therap GER records spread across 231 participants. The Commonwealth reported at least 77 separate serious incidents with a "High" notification level plus "Injury." The top 15 high-level incident event types and respective counts include:

Communicable Disease (129); Injury (101); Hospital (97); Altercation (79); Behavioral Issue (76); Change of Condition (50); Assault (41); Accident no apparent injury (17); Property Damage (9); Sensitive Situation (8); Aggression (8); AWOL/Missing Person (6); Serious Illness (6); Medication Error (5); Seizure (5).

The Commonwealth reports that roughly 70% (449:650) of all high-level incidents are given follow-up within seven calendar days.

There is evidence that the reporting of incidents in Therap is incomplete. From the minutes of the incident committee, there appears to be a gap in reporting of incidents of hospitalization from the Shalom Institution. There is also evidence in the mortality reviews from this period that there is under-reporting of serious incidents from at least some providers.

The information the Commonwealth furnished did not include any information regarding allegations of abuse or neglect, which is most unusual. In a review of data in Therap, there were two high-level notification incidents that indicated "abuse suspected" and one as "neglect suspected." In conversations

[55] In its response to the draft report shared with the Parties, the DSPDI argues and requests that "the Office of the JCC re-consider its assessment of this benchmark and assess the same as "Substantial Compliance". The JCC and experts are not persuaded by the argument stated by the DSPDI. However, provided that the present benchmark continues to be under evaluation by the Office of the JCC, compliance is amended to "Working Towards Compliance – Still Under Review".

with the DSPDI, it was confirmed that allegations of abuse and neglect that come in as "complaints" or "grievance" are typically not recorded as incidents in Therap, and the investigations are handled outside of Therap. Incidents that occur in highly congregated community homes are also not recorded in Therap.

These investigations are handled individually, separate and apart from the Commonwealth's incident management system and are not centralized in any reporting system. There is a need for the Commonwealth to revisit how these allegations are reported and tracked, to utilize the features of Therap to better support the reporting of allegations of abuse and neglect and those involving multiple participants, while still adequately protecting sensitive information to encourage reporting. The goal should be to enable the DSPDI to handle these complaints sensitively, while also permitting better tracking and reporting so as to provide a more comprehensive picture of events and risks related to participants with a central system.

The DSPDI provided the following information about these "complaints," which are currently recorded outside of the Therap system: from January through June 2022: there were three complaints and 13 additional grievances reported anonymously or with disclosure of identification to the DSPDI. The Commonwealth reported that the time to resolve complaints took anywhere from one day to three weeks. Of the 16 complaints and grievances, the Commonwealth reported that eight were found not to be substantiated.

Recent training for providers on the need for vigilant and proper incident reporting is a positive development and should be part of a broader scope of work to improve serious incident reporting and investigation. The DSPDI and the JCC Experts will continue to work collaboratively in a workgroup on Incidents and Investigations that will address many of the challenges in this area as part of a system-wide approach.

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)

Level of Compliance: Partial Compliance – Still Under Review

The Commonwealth provided a short plan at BM49. The Commonwealth also provided an incident pattern and trend report filled with a lot of helpful data and information, including where incidents occur, the most frequent types of incidents, and perhaps most importantly, which participants are having the most incidents.

There is some evidence of Commonwealth analysis of recent incidents, and some individualized patterns are discussed at the incident committee. As referenced in previous benchmarks, this committee has put forth numerous strategies to improve the accuracy and completeness of data in Therap, which will help facilitate more regular and informative analysis of incidents. The Commonwealth now requires each CTS to have its own regular review of incidents and then to report analysis on pattern and trends to the central Incident Committee; this is a positive development that the JCC team anticipants will improve

implementation as part of a system-wide approach. The JCC recommends that these groups look at both high risk participants (ex. monthly) and broader incident trends (ex. quarterly).

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)

Level of Compliance: Working Towards Compliance – Still Under Review[56]

As a result of recent remedial efforts, there have been more incidents reported in Therap, and in some cases, incident reporting is more complete. The Incident Committee's regular forum and its interdisciplinary membership is positive. It is positive that the services of a clinician have been retained and added to this committee. The DSPDI has also conducted some individualized response to instances of abuse and neglect allegations during this period. Going forward, demonstrating more systemic and preventive measures related to areas of risk for participants will be important to gain compliance.

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

Level of Compliance: Working Towards Compliance – Still Under Review[57]

Related to this benchmark, the DSPDI reported that "there were no inappropriate physical restraints reported during the evaluation period." No restraints were submitted by DSPDI as evidence for this benchmark.

This Benchmark includes all kinds of restraints, including, physical, mechanical, and chemical. (We note that some restraints may be necessary in emergency situations to prevent harm to a participant or other person.) Through the JCC team's own analysis, multiple instances of restraints did occur through this period.

The Commonwealth's Therap Event Summaries report revealed that most restraints were being captured only in case notes and were not being officially categorized under "other event type." In part, this may be due to a limitation in Therap that only permits a single event type to be selected. Despite this and after filtering for common terms referring to restraints such as "Non-Violent Crisis Management Techniques," "Therapeutic Hold," "Protective Technique," and "PRN," the following counts of each type were found: PRN (4); Physical Restraints (28). The latter is of significant concern.

[56] In their response to the JCC's first draft of the present Report, USDOJ presented compelling arguments which persuaded us to change the current compliance rate to "working towards compliance-still under review".
[57] In their response to the JCC's first draft of the present Report, USDOJ presented compelling arguments which persuaded us to change the current compliance rate to "working towards compliance-still under review".

There is some evidence that not all of these restraints were appropriate. For example, in June, a participant (DVT) was tied to bed as advised by a psychiatrist as an appropriate approach to addressing the person's behaviors. There are also other examples of incidents during the period where PRN chemical restraints were given without the required clinician authorization.

It is positive that the Commonwealth provided training on crisis intervention techniques to providers; the JCC Experts are currently reviewing the content of this training. The Division acknowledged that more training in this area would be beneficial. The JCC team agrees, and underscores, for example, the risk of having providers implement physical restraints or holds without training given the risk of injury to both participants and staff in these situations. The JCC team also encourages the DSPDI to put more emphasis on implementing positive behavior supports to prevent escalation and aggression and to minimize or eliminate the need for restraints of any type.

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

Level of Compliance: Working Towards Compliance – Still Under Review [58]

In an analysis of incidents and case notes, the JCC team discovered at least four instances of the use of chemical restraints during participant behavioral incidents (ex. #1005).

We also learned that a new Medical Home provider has requested sedating medication for participants to be prescribed during the period of meal preparation to address inadequate staffing at those times (one staff member to prepare meals, one staff member to work with participants). This practice is most inappropriate and needs to be eradicated immediately.

III.5 Health Care and Mental Health Care

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)

Level of Compliance: Substantial Compliance

[58] In its response to the draft report shared with the Parties, the DSPDI argues and requests that "the DSPDI understand that the policy rejecting the use of chemical restraints is known and is being operational in most cases. Thus, the DSPDI respectfully requests that the Office of the JCC re-consider its assessment of this benchmark and assess the same as "Partial Compliance". The JCC and experts are not persuaded by the argument stated by the DSPDI for the reasons stated in the narrative of the benchmark. However, provided that the present benchmark continues to be under evaluation by the Office of the JCC, compliance is amended to "Working Towards Compliance – Still Under Review".

The Commonwealth provided a long list of participants and their community clinicians. One or more clinicians were listed for 637 participants. This is a good list with helpful contact information. But, a total of 649 participants is listed in the Master List, so at least 12 participants are missing from the list.

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)

Level of Compliance: Working Towards Compliance – Still Under Review[59]

During the report period, there were 23 instances of significant changes in health status documented and communicated by the DSPDI. All participants included did have actual significant changes in the health status. However, there is no correspondence between the list of communication with community clinicians and these significant changes in health status (ex. #179's ER visit in January, no communication with PCP noted nor ER visit noted, nor f/u visit referral; another example: #646 lithium poisoning in January – no communication noted with PCP). There are also more changes in conditions reported in Therap than those that are included in the above list of instances of changes.

There is evidence that the DSPDI has been making nursing referrals during this period for a subset of participants, but it is not clear that any or all of them were in response to a significant health change as required by this BM. A total of 411 nursing referrals were made between January – June of 2022, for 229 participants. Of these participants, 19 were on the list of CAPAR reviews. There were substantially fewer nursing referrals made during this period compared to last period where 639 nursing referrals were made. Nine participants with referrals were not on the master list of referrals from BM #3.

The reasons for these referrals ranged from follow-ups and evaluations, to emerging issues including response to abnormal labs, specialist referrals, signs/symptoms of illness.

There appear to be some gaps in communication with community clinicians in certain cases, such as communication back with a PCP when there are significant changes in health status (ex. someone is hospitalized). There has also been under-recognition of people with significant changes in health status during the period (see BM 55).

The DSPDI is in the process of revising the "Manual de Servicios de Enfermería" (Nursing Services Manual) 2018 version.

[59] In its response to the draft report shared with the Parties, the DSPDI argues and requests that "the Office of the JCC re-consider its assessment of this benchmark and assess the same as "Substantial Compliance". The JCC and experts are not persuaded by the argument stated by the DSPDI for the reasons stated in the narrative of the benchmark. However, provided that the present benchmark continues to be under evaluation by the Office of the JCC, compliance is amended to "Working Towards Compliance – Still Under Review".

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"

Level of Compliance: Working Towards Compliance – Still Under Review[60]

In the next review period, the Experts will work collaboratively with the DSPDI to clearly define significant changes in health conditions, how promptly alerts must be made, how treatments must be provided, all to aid in more consistent identification and follow-up on these changes by providers and CTS staff, in conjunction with CEEC/CAPAR reviews.

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"

Level of Compliance: Working Towards Substantial Compliance[61]

As recommended by the JCC in 2020, the DSPDI has created a Health Passport within Therap and a structured referral form that is completed at each medical visit. Social workers and nursing have been instructed to provide family members, providers, and companions of participants to medical visits the following documents: full referral in all its parts, printed copy of "health passport" and the "consultation form" from the Therap Services platform.

The health passport includes the person's immunization history, allergies, active diagnoses, physicians, family contacts. It also has a place to indicate major safety issues and risk factors including certain conditions (ex. seizure disorder), risks (ex. falls risk) use of assistive devices, recent changes and some health-related behaviors. The consultation form includes the person's active diagnoses, medication list, recent vitals, and a place to record findings and recommendations, and the need for a follow-up appointment. The addition of this system is a positive development in standardizing the format of information provided and setting expectations for relevant health information exchanged.

To achieve compliance with this benchmark, improvements in the quality of the information in these documents will be required. For example, there are important health conditions that either present high risk to the participant, or high risk of contagion to other participants and people that are not listed on these sheets (i.e. contagious viruses (participants #1093, #267, and #268), contagious bacterial infections (participant #399), and other major health conditions such as Degenerative Diseases. Additionally, there

[60] In their response to the JCC's first draft of the present Report, USDOJ presented compelling arguments which persuaded us to change the current compliance rate to "working towards compliance-still under review". The JCC notes USDOJ's concerns and will address the same in our next Report.

[61] In their response to the JCC's first draft of the present Report, USDOJ requested us to change the current compliance rate to Partial Compliance. However, the JCC notes USDOJ's concerns and reconsidered its original assessment to Working Towards Substantial Compliance.

is frequently information missing regarding sections pertaining to family medical history, surgeries, prostheses, prior substance abuse and sections pertaining to risk. The above deficiencies should be rectified expeditiously.

The inclusion of the Major Safety Issues and Risk factors on a health passport is a beneficial change. However, the DSPDI should review the accuracy of the information and whether the above actually indicates the issues and risks present for each participant. For example, in the example passport provided, participant (#189) had a serious condition (heart disease, per the active diagnosis list) but it was not indicated in the passport. The DSPDI should promote quality reviews between active diagnoses and the above important high-risk indicators.

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)

Level of Compliance: Working Towards Compliance – Still Under Review[62]

Communication with community clinicians is performed primarily by DSPDI Nursing staff through visits and referrals. In addition, the newly formed Committee for the Assessment of Polypharmacy and High-Risk Participants (CAPAR), which is a part of the CEEC, has been performing shadow medical evaluations, particularly of high-risk participants. It is important to acknowledge that the initiation of shadow medical evaluations performed by the CEEC CAPAR Committee is a very positive development.

It is also noteworthy that these evaluations have started to include in-person assessments (i.e. neurology), which is a component that was previously lacking and is a very important part of the present assessment (rather than a review limited to paper and electronic files). CAPAR has also developed an evaluation template to further standardize their reviews and have been receptive to collaborative feedback for enhancements of this tool by JCC experts.

CAPAR has also built more consistent templates for communication with community physicians to help prompt response and action and improve the rate of reception and response to their suggestions by community practitioners. During their reviews to date, CAPAR has been able to identify needs for service plan alterations, identify new medical conditions and make referrals to prescribing healthcare providers to change or reduce medications.

As part of the High Risk and Polypharmacy Workgroup with JCC experts during the next period, the DSPDI will work to further define risk categories which will drive prioritization of future CAPAR reviews. There have also been discussions of how to distribute these risk categories across the DSPDI's daily centers and staff so that there is more consistent referral to CAPAR for reviews of people with these risks. The JCC expects that these systemic investments in processes and clinical expertise will yield increased compliance

[62] In their response to the JCC's first draft of the present Report, USDOJ presented compelling arguments which persuaded us to change the current compliance rate to "working towards compliance-still under review".

in the next period as the CAPAR is able to apply the review tool to more reviews, inclusive of in person assessments, and act on the needs of a greater proportion of participants.

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

Level of Compliance: Working Towards Compliance – Still Under Review[63]

While the DSPDI provided a certification that all participants receive annual PCP visits, the details (e.g., dates of the visits for participants) for each participant would provide more compelling evidence of compliance with this benchmark. Annual PCP visits were validated for a sample of participants (e.g. participant #175). For some participants residing in substitute or community homes a lack of nursing notes regarding annual physicals and large gaps in clinical notes (ex. 3+ months) (e.g., participant #156).

A record of dental visits for the period was provided indicating dental visits for nearly half of participants in this six-month period. In future, dental visit information should include the control number of each participant.

From the JCC's reviews, there have been some examples of participants not receiving the necessary health care in a timeline manner, including examples of not getting neurology care in timely fashion, delays in medical care for injuries after falls, and behavioral incidents (ex. Participants #161 and #156).

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"

Level of Compliance: Working Towards Substantial Compliance – Still Under Review [64]

One list was provided of 559 participants with entries about their risk type. Of the participants listed, 11 have five different at-risk categories identified, 36 had four types, 126 had three types, 187 had two types, and 198 had one at-risk category identified.

The lists continue to improve but remains incomplete. For example, there is a participant with a cancer diagnosis and treatment during the period (participant #745) that was not listed on the list of people with cancer, and other participants hospitalized for relevant conditions (e.g., seizures) that do not appear on the corresponding condition list participant (#768).

[63] In their response to the JCC's first draft of the present Report, USDOJ presented compelling arguments which persuaded us to change the current compliance rate to "working towards substantial compliance-still under review".
[64] The JCC considers that the DSPDI should achieve substantial compliance with this Benchmark by the next Semi-annual Report.

There were also 28 instances where there are discrepancies between the diagnoses listed in MH sub-list in comparison to other sub-lists of participants. Other discrepancies include 166 participants on the aspiration risk list vs. 126 participants on a list of those with Aspiration/Dysphagia.

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)

Level of Compliance: Working Towards Compliance – Still Under Review[65]

The work that CAPAR is doing through shadow evaluations and work with community clinicians, as described previously, is promising, and has yielded some positive results.

The DSPDI has stated that they are working on hiring a graduate nurse to work on clinical information included in Therap.

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)

Level of Compliance: Working Towards Compliance – Still Under Review[66]

Recent work by the CAPAR in this area is promising, and the shadow evaluations and recommendations should be prioritized for continuation. The DSPDI is in the process of hiring more nursing staff to support the CAPAR in this work.

The JCC has observed some instances where these evaluations have resulted in lowering risk, however, there are still many participants who need support to reduce these risks.

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"

Level of Compliance: Partial Compliance – Still Under Review

[65] In their response to the JCC's first draft of the present Report, USDOJ presented compelling arguments which persuaded us to change the current compliance rate to "working towards compliance-still under review".
[66] In their response to the JCC's first draft of the present Report, USDOJ presented compelling arguments which persuaded us to change the current compliance rate to "working towards compliance-still under review".

Nurses from the CTS centers have been conducting onsite visits with participants in their homes in community and substitute homes.

There are some gaps to address in this practice, such as:

- During this period, participants that reside in locations that are run by ASSMCA or the Department of Family Affairs ("DFA") do not receive these services or an equivalent service;
- There are gaps in the quality of the documentation such as the failure to include relevant details. In some instances, the notes are also missing major health-related events (ex. missing notes of multiple hospitalizations for a participant in clinical notes);
- There are other gaps, for example:
    - If the community home has a nurse, then the CTS nurse does not conduct visits, even though these programs serve participants with some of the highest health-related needs. A monthly call is placed by the social worker instead; and
    - Nursing is not necessarily visiting participants on a monthly basis and instead visits may be done only every two months. Many providers report that CTS nurses conduct 2-3 monthly telephone consultations, then visit in person the following month.

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)

Level of Compliance: Partial Compliance

The DSPDI states that there are multiple DSPDI clinicians and areas that utilize data from Therap and other sources in addressing the needs of participants with high-risk conditions. These include, speech pathologists, nutritionists, nursing staff, CEEC clinicians, and the CAPAR Committee, among others. Each of these clinicians and areas utilize such information according to their particular duties and functions.

The JCC finds that the corresponding analysis required by this benchmark is not being done comprehensively, thus there is missing information regarding identification of many at-risk participants.

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

Level of Compliance: Partial Compliance

The sharing of information with community clinicians has improved from prior periods with the introduction of the health passports, the referral form, and the CAPAR evaluations and correspondence with clinicians. However, further work is needed to address the quality and completeness of the information, particularly in the health passports and referral forms, to gain compliance in this area. Additionally, further work to compile and analyze data as described in BM 63 will enable the communication of this synthesized material to clinicians for priority at-risk participants. The passports

need to include details on recent incidents and events to put the PCP in the best position to make informed decisions about the course of treatment for the participant.

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)

Level of Compliance: Working Towards Compliance – Still Under Review[67]

The CAPAR has instituted new procedures for follow-up with community clinicians after recommendations are made, which is a positive improvement. CAPAR has also revised the format of how they correspond with community clinicians to better direct their attention to items needing response or action and has supplemented written communication with other outreach methods to help facilitate communication. These are all positive developments that will likely improve the effective communication with community clinicians for a larger proportion of participants as CAPAR reviews progress in future periods.

For priority at-risk participants that have not had a CAPAR review, it is the primary responsibility of the CTS nurse to relay important information to treating clinicians and maintain subsequent communication to assess whether they have implemented relevant measures. This appears to be happening with variable degrees of success. There is evidence of CTS nurse communication with community clinicians, but there are also cases where there is no evidence of communication by nursing with community clinicians after major medical events. There is more evidence needed to assess whether measures are being implemented to meet individualized needs.

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)

Level of Compliance: Substantial Compliance

The DSPDI provided a list provided of 257 participants with a seizure disorder/epilepsy, which is similar to the number of participants reported in prior periods. While reviewing this information in Therap, the JCC team identified 267 people listed with active epilepsy (G40) diagnoses in their electronic record; additionally, not all participants on the DSPDI's sub-list for seizure disorder/epilepsy had a diagnosis of seizure disorder/epilepsy on their active diagnosis list in Therap. This means that the DSPDI did not identify 10 people with active epilepsy, and this has implications for monitoring the management of the condition and contact with appropriate clinicians. The above must be clarified and rectified promptly.

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

[67] In their response to the JCC's first draft of the present Report, USDOJ presented compelling arguments which persuaded us to change the current compliance rate to "working towards compliance-still under review".

Level of Compliance: Substantial Compliance

There has been significant progress in this benchmark, with more participants with epilepsy receiving medical services from neurologists and more participants receiving visits. Out of the 257 participants listed as having epilepsy, 54 participants (21%) did not see their neurologist in the last year and did not have an appointment to see them in the near future. Of these, 49 people had not had recent seizure activity since 2020. Five participants had more recent seizure activity.

Nevertheless, there is still progress to be made in this benchmark. For example, one participant was identified as having 10+ seizures annually (participant #791), but had not seen a neurologist in over a year (April 2021), despite the ongoing and recent seizure activity. The frequency of seizures has been increasing for this participant, which creates a more urgent need for a visit to a neurologist. Another participant had 14 seizures between January-June 2022, as recorded in the Therap Seizure reporting module, but was not identified on the list of people with 10+ seizures and has not had an appointment with a neurologist in more than a year. The above facts raise serious concerns.

In at least two instances, it appears that the neurologists did not advise that participants return for a follow-up visit annually.

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)

Level of Compliance: Substantial Compliance

The Commonwealth provided each of these sub-lists, but, as noted above in BM 67, there were some discrepancies with participants having 10+ seizures during the reporting period when compared to those compiled in the DSPDI's submitted list of participants that meet this criteria.

It may be helpful for the Division to continue to review the use of Therap's seizure reporting module. The DPSDI Incident Committee's meeting notes mention the variable use of this module by service providers. The JCC team discovered that there were 18 participants that had seizures reported in this module during the six-month period. However, there is evidence from a death during the period that the participant's seizures were not reported, which may have ultimately contributed to a preventable death. Given the number of people with epilepsy with seizures in the past year, we suspect that seizures are being underreported in Therap.

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

Level of Compliance: Working Towards Compliance – Still Under Review[68]

There is some evidence that some participants with 10+ seizures per year may not be receiving effective care by neurologists. For example, there are two participants with 10+ seizures per year who have not seen their neurologist in more than one year. Additionally, one participant was reported to have had 165 seizures in this six-month period (participant #258); the participant is being treated with a maximum dose of one medication and a dose that exceeds the maximum allowance of a second anticonvulsant. It is unclear what other medication regimens have been considered by the treating neurologist.

It is positive that CAPAR has identified this subgroup of participants as a priority group for review, and that a CAPAR neurologist will be involved in reviewing the treatment plans for these participants.

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)

Level of Compliance: Working Towards Compliance – Still Under Review[69]

There is currently not enough evidence to show more than partial compliance with this benchmark. There are many participants that remain on antiseizure medications who have not had seizures in the past two years. This may reflect appropriate treatment for some participants, but sufficient detail about the clinical decision making or longer-term treatment plan surrounding the care of these participants is not available. CAPAR will be conducting a review of individuals in this group as the prioritization and resources allow and hence improvements are expected to be noted in our next Semi-annual Report.

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

Level of Compliance: Partial Compliance

The rationale for the use of anticonvulsant medication is supposed to be clearly written in each participant's record. Nonetheless, the DSPDI has instructed its staff who accompany participants to their medical appointments to specifically ask as to the reasons why medications have been prescribed, and the answers are updated in Therap. Progress on improving the quality of information that DSPDI has about the reason for each medication's use is ongoing. The above is an important component of reviewing the use of anticonvulsants which can have other therapeutic or negative effects.

As previously noted, CAPAR clinicians have begun reviewing the care of a limited number of participants with poorly controlled seizure disorders, including a review of their medications. On an as-needed basis,

[68] In their response to the JCC's first draft of the present Report, USDOJ presented compelling arguments which persuaded us to change the current compliance rate to "working towards compliance-still under review".
[69] In their response to the JCC's first draft of the present Report, USDOJ presented compelling arguments which persuaded us to change the current compliance rate to "working towards compliance-still under review".

CAPAR is posing questions and/or making recommendations to prescribing clinicians where there are concerns. The Commonwealth should formalize a mechanism to address situations in which differences arise between the CEEC/CAPAR and the prescribing doctors if there are concerns for the health, safety, and welfare of the participants.

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

Level of Compliance: Working Towards Compliance – Still Under Review[70]

There remains a substantial group of participants on intra-class polypharmacy, particularly psychotropic intra-class polypharmacy, including people being prescribed high risk combinations of medications.

It is positive that CAPAR clinicians have begun reviewing some of the medication regimen of those subjected to intra-class polypharmacy, particularly in combinations identified to be of high risk, and that CAPAR has been conducting some outreach to community-based prescribers to ask questions and propose changes in prescriptions. This work is ongoing, but is still limited, so more participants will need these types of consultations and considerations for changes in their medication regimen.

As CAPAR has encountered some instances of indifference and/or resistance from the prescribing clinicians, it is positive that CAPAR is continuing to refine its approach and trying various strategies to gain more receptivity from clinicians to consider necessary changes. For some participants, the limited formulary list of medications that are covered under the government health plan limit options for the use of more appropriate medications (like those that have fewer side effects both short- and long-term, and those that may be more therapeutic for the participant's particular health conditions, etc.).

For participants that are undergoing medication changes, it would be beneficial to review the strategy being employed to change medications to ensure that changes are not made too quickly, and that changes focus on a single medication at a time. There may be a role for CAPAR in advising community clinicians on professionally accepted standards for the ID/DD population for these medication changes to ensure that they are safer and more effective for participants needs.

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)

Level of Compliance: In Compliance

The Commonwealth provided a copy of the current Collaborative Agreement, dated July 1, 2021, between the Commonwealth and the Epilepsy Foundation.

[70] In their response to the JCC's first draft of the present Report, USDOJ presented compelling arguments which persuaded us to change the current compliance rate to "working towards compliance-still under review".

Aspiration Risk

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

Level of Compliance: Substantial Compliance

During the period covered in the present Report, 167 participants were included in a DSPDI sub list of participants at risk of aspiration. This represents a 38% increase when compared with the 121 participants previously identified by the DSPDI in our March 2022 Report. This increase is a reflection of the work the DSPDI has conducted over the current period to confirm participant diagnoses and improve the accuracy of information that is included in participant records.

There is a subset of participants that do not appear on the DSPDI sub list for this period, but have risk factors for aspiration, among others, an active diagnosis of dysphagia, GERD, or aspiration pneumonia listed in Therap (participants #22, #255, #346, #354, #410, #907, #932, #971, #1047, #1111, and #1162).

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

Level of Compliance: Working Towards Compliance – Still Under Review[71]

The plans provided for the majority of the participants with aspiration have improved greatly since prior semi-annual reports were published and appear to include more strategies that are directly responsive to aspiration risk including more appropriate, clear instructions inclusive of diet texture and consistency recommendations, positioning when feeding, size/amount of food at a time, amount and pace of liquids and behavioral prompting/clues.

There is a small set of participants that have a diagnosis placing them at risk of aspiration, but no plan exists to address the same (i.e. participants #652, #167, #228, #298, and #959).

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

Level of Compliance: Working Towards Compliance – Still Under Review[72]

Individualized plans have been prepared for all identified participants (10). It is positive that the DSPDI is offering training and education associated with high risk factors, such as Dysphagia – Speech Pathology.

[71] In their response to the JCC's first draft of the present Report, USDOJ presented compelling arguments which persuaded us to change the current compliance rate to "working towards compliance-still under review".
[72] In their response to the JCC's first draft of the present Report, USDOJ presented compelling arguments which persuaded us to change the current compliance rate to "working towards compliance-still under review".

10 participants were identified by the DSPDI as non-ambulatory. According to a spreadsheet provided by the Division, Plans are in place for all identified participants. A review of Therap found that only four of these participants had the Individual Care Plan (ICP) for Risk of Aspiration. However, this list is incomplete.

The JCC team found in Therap that a total of 21 participants had a code indicating they were bedridden (Z74.01). Additionally, participants in Substitute Home Beatriz Perez Substitute, a provider who specializes in bedridden participants which has 2 bedridden participants (#180, #181), were not included in the list provided by DSPDI, and do not have the diagnosis code identifying them as bedridden in Therap.

CEEC

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

Level of Compliance: Substantial Compliance

The DSPDI has made substantial progress in this area, particularly through the newly formed CAPAR group of the CEEC. With continued work in the near future, we expect the Division to reach compliance as it relates to this benchmark.

CEEC Re-Evaluations of Participants by CTS:

Based on an analysis of multiple documents, the JCC team concluded that a total of 520 participants from the DSPDI's current census (80%) had documented evaluations by one or more disciplines in the CEEC, completed mainly in 2021 and/or 2022.

About 129 participants (20%) from DSPDI's current census have yet to be evaluated by any area of the CEEC, including, but not limited to, the following disciplines: OT, vocational rehab, speech pathologist, recreational therapist, social work, and psychologist. It is not always clear that the evaluations resulted in a team-based review or discussion of participants, which is an important component of the function and efficacy of the CEEC model.

CEEC Area	2022 Count of Evals/Re-evaluations[73]
Occupational Therapy	85
Vocational Rehab Counseling	99
Speech Pathology	115
Recreational Therapy	3
Social Work	146

[73] During this period, the CAPAR conducted 40 in depth interdisciplinary reviews of participants.

Psychology	34
YTD 2022 CEEC Evals	**482**

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"

Level of Compliance: Partial Compliance

Of the 649 participants in the DSPDI's current census, CAPAR has categorized 40 of them as either having high (19), medium (12), or low (9) risk indicators due to various contributing factors ranging from aspiration, polypharmacy, dangerous drug interactions, among others.

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"

Level of Compliance: Partial Compliance

As a result of CAPAR's consistent outreach efforts to community providers, the DSPDI has successfully contacted 33 community providers informing them of their risk-related concerns regarding some aspect of participants' current clinical care.

Given these efforts, CAPAR, with the approval and/or feedback of the participant's community provider, has been able to justify or adjust medication regiments for participants #703 and #632, which has proven to significantly improve the safeguarding and health of these participants (e.g., reduction in falls). It has been noted that these outreach efforts are ongoing with the hopes to directly address CAPAR concerns with community providers.

The list of CAPAR activities does not explain how red flags are addressed or communicated to community providers. However, there is evidence that CAPAR has conducted reviews during this period for a subset of participants (40) that include changes in participants' health status and general records, including, but not limited to, alterations in biometrics and laboratory results, and incidents.

Furthermore, given the lack of specialty providers available through the Commonwealth's subsidized healthcare system, "*Plan Mi Salud,*" the DSPDI has successfully subcontracted medical services from specialty providers, such as a neurologist, as well as established an internal pipeline of referrals to nutritionists and speech and language pathologists.

In pursuit of a more systemic approach to identifying and addressing red flags, there have been ongoing discussions in the High Risk and Polypharmacy group about refining risk categories for participants and disseminating these categories out to the CTS staff to ensure greater consistency in reporting high risk events and conditions.

The JCC team expects this work, and other strategies such as including clinicians in the Incident Committee will aid progress in this benchmark. In addition, further improvements in the use of in-person CTS staff reviews with participants, training of clinicians to identify and address these flags, and better documentation across interdisciplinary staff going forward should all support progress in this benchmark by providing more accurate, timely information with which to identify report and communicate red flags.

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"

Level of Compliance: Partial Compliance

The DSPDI provided a list of Hospitalizations and Visits to Emergency Rooms which included 83 unique events reflective mainly of hospitalizations for 64 participants between the months of April through June of 2022. Reasons for hospitalizations ranged from fall-related injuries, low blood oxygenation levels, behavioral changes, and seizures.

About 25% of these entries (21 entries) reflected notes containing orders to follow-up with the participant's primary care physician. These notes did not specify whether the CEEC ensured that such orders were conducted. For some participants, the result is unknown (participants #125, #1111 and #1123).

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"

Level of Compliance: Working Towards Compliance – Still Under Review[74]

The DSPDI has indicated that they have developed a system which consists mainly of written and mailed communications and/or phone calls with clinicians. The CEEC director and/or CAPAR chair are reported to communicate concerns to community doctors.

In addition, the CEEC CAPAR Committee is performing weekly shadow medical reviews and communicating recommendations to community doctors to improve outcomes as described in previous benchmarks. The CAPAR Committee has conducted work toward the end of this period and beginning of the next period to create a tracking system to facilitate follow-up with clinicians including those for whom they did not receive an initial response. However, the frequency and methods of follow-up communications for CEEC outreach more generally to community providers are unclear.

[74] In their response to the JCC's first draft of the present Report, USDOJ presented compelling arguments which persuaded us to change the current compliance rate to "working towards compliance-still under review".

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

Level of Compliance: Partial Compliance[75]

The DSPDI furnished the Department of Health's protocol on complaint reporting of improprieties to Puerto Rico's licensing, ombudsman agency, the Assistant Secretariat for Regulation and Accreditation of Health Facilities (Spanish acronym is SARAFS). Per the protocol, written and verbal complaints can be submitted through SARFAS' online portal, via postal mail, or by phone. Once received and vetted for SARAFS purview and jurisdiction validation, they are formalized and investigated.

These comprehensive onsite or remote investigations are conducted by an Investigator or a group of Investigators. The investigation findings and determination of whether there was indeed a violation is documented in a formal 'Deficiency Report' and reported back (within 20 days after complaint filing) to the complainant and the defendant. The defendant then in turn has 10 days to submit a Corrective Action Plan. The Inspector will follow up by conducting a final review within 90 days to make a final determination. Any complaint related to a situation of imminent danger should be investigated within a period not exceeding two days, from the receipt of the complaint.

No list of alerts to licensing, ombudsman agencies were furnished.

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"

Level of Compliance: Partial Compliance

Rather than having a CEEC mobile crisis team, the DSPDI has established at each of the seven CTS sites a crisis team unit, led by a CTS Clinical Director. The DSPDI notes that by having crisis teams in each CTS, the teams can respond to emergencies involving nearby participants in the CTS region in a timelier fashion, and DSPDI reports that the CTS nursing staff and clinicians have more first-hand knowledge of each participant's mental, behavioral and health conditions.

[75] In its response to the draft report shared with the Parties, the DSPDI argues, and requests as follows "The absence of alerts in this Benchmark should not be deemed as lack of compliance, but as lack of incidents that required issuing such alerts. During the evaluation period there was no need to file a complaint with the licensing, ombudsman agencies. Thus, the DSPDI respectfully requests that the Office of the JCC re-consider its assessment of this benchmark and assess the same as "In Compliance". The JCC and experts are not persuaded by the argument stated by the DSPDI. Currently there is not enough information to verify that the absence of alerts fully reflects an actual absence of the need for any alerts.

The DSPDI furnished a sample list of 16 unique Mobile Crisis Team Interventions that occurred during the months of April through June 2022. The types of incidents reported include those related to altercations (5), assaults (1), behavioral issues (1), communicable disease (1), hospitalization (5), and injury (3).

Every intervention had a non-detailed description of EID team member involvement, including, but not limited to nursing, social work, and psychology. For example, for Participant #189, the CTS team intervened directly, with the participant going to the hospital for a psychiatric evaluation resulting in a discharge the same day with medication adjustments that managed to reduce their acute symptoms and aggression. The place/locality of the intervention and the corresponding result of eight of these interventions are unknown.

Some delays in response were observed during this period (i.e. Participant #156 acute event), resulting in delays in assessing the medical attention that a participant with an open wound received after an altercation with staff.

While in some cases there is a noted consultation with CEEC members by CTS staff during crises, it is unclear how the CEEC consistently directly supports and/or provides oversight to the responding CTS teams during crisis response. While basing the crisis response at the CTS may provide more localized response and knowledge of the participant, there is still an important opportunity for the CEEC to support in crises where the CTS staff may need additional support, and/or the response of the CTS teams may be inadequate, ineffective, or requiring more expertise.

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

Level of Compliance: Working Towards Substantial Compliance – Still Under Review[76]

The CTS teams are designed to have both nursing staff and CTS clinicians (psychologists, social workers, etc.) as prescribed by the JCAP. However, the document does not specify if any of the CTS have any vacant positions directly related to their Mobile Crisis Team which is very important because the DSPDI has designated the CTS teams as the mobile crisis team.

According to the furnished information, the CEEC at the Central Office has the following positions that are vacant: 2 general nurses, psychiatrist, clinical psychologist, and an administrative clerk.

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"

[76] In their response to the JCC's first draft of the present Report, USDOJ presented compelling arguments which persuaded us to change the current compliance rate to "working towards substantial compliance-still under review". The JCC notes USDOJ's concerns and will address the same in our next Report.

Level of Compliance: Working Towards Compliance – Still Under Review [77]

In three of the interventions listed (participants #175, #1107 and #1117) by the CTS mobile team or CEEC members, the interventions potentially prevented the need for more acute intervention, though it's unclear if this would have met the threshold for institutional-level care. For most of the other interventions listed in the sample provided, they do not reflect a scenario where the CEEC Mobile Crisis team resulted in the diversion from an institutional setting. Instead, there was at least one instance of a participant being placed in an institutional setting (involuntary admission (408) to a psychiatric hospital) as a result of a crisis situation, and a serious adverse (and potentially criminal) outcome occurred to this participant (participant #39).

Mortality Review

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)

Level of Compliance: In Compliance

As certified by the DSPDI on July 26, 2022, the MRC members are Dr. Yocasta Brugal (Chairwoman), Mr. Danniel Soto (DSPDI interim director), Dr. Carolina Carmona (DSPDI physician), Ms. Mayra Santana (Nutritionist), Ms. Quiudinashka Ramos (Nursing Coordinator), Ms. Nereida Robles (Speech Patologist), Ms. Gloribel Rosario (Director of Community Home/Expansion Unit), Ms. Maria Filiberty (Nurse), Ms. Afife Torres (Clinical Services Coordinator), Dra Diana Camacho (Director of the CEEC) and Keishla Núñez (Nurse from Community Home and Monitoring Unit). An updated list of deceased participants as of June 30, 2022, was also included.

The Federal Monitor's Office will be present in future MRC meetings to try to better understand and monitor the remedial plans that, when implemented, will lead to system-wide reforms and significantly reduce preventable deaths.

Mortality Rate:

Year	Death	Population	Mortality Rate (per 1000)
As if June 30, 2022	6	649	

[77] In its response to the draft report shared with the Parties, the DSPDI argues and requests that "it is the DSPDI's understanding that assessing this Benchmark as "No Compliance" does not accurately reflect the work that has been done. Thus, the DSPDI respectfully requests that the Office of the JCC re-consider its assessment of this benchmark and assess the same as "Partial Compliance". The JCC and experts are not persuaded by the argument stated by the DSPDI for the reasons stated in the narrative of the benchmark. However, provided that the present benchmark continues to be under evaluation by the Office of the JCC, compliance is amended to "Working Towards Compliance – Still Under Review".

2021	24	639	39.12%
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"

Level of Compliance: In Compliance

During the six months of 2022, the MRC met on a monthly basis, except for January; the meeting for January was cancelled due to the DSPDI change in its director (February was virtual so the meeting was held, but no minutes were taken). 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)

Level of Compliance: In Compliance

As confirmed by the MRC Chairwoman, the MRC has access to all pertinent 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)

Level of Compliance: In Compliance

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)

Level of Compliance: Substantial Compliance

See Benchmark 91.

As it pertains to the issuance of the MRC final reports, during the period covered in the present report, all MRC reports were issued within 30 days of each death. In cases where autopsies are being processed, Dr. Brugal has issued reports to be supplemented as needed once the autopsy report is received, per JCAP directives.

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"

Level of Compliance: Working Towards Compliance – Still Under Review[78]

The DSPDI is maintaining a table of action plans taken in response to MRC reviews, and some activities have occurred in response to deaths reviewed during this period. However, the activities that are being tracked are generally partial steps toward implementation (referral to another area), or not recorded with enough detail to indicate what action was actually taken to demonstrate the completion of necessary and effective actions.

For example, it is frequently stated that "corrective action" is taken with no further description about what actions are entailed. Being more specific about the actions that were taken would be of greater benefit to the Division to monitor whether those actions were sufficient and are being sustained. Additionally, after stating that cases are referred to another group (ex. the quality area) there is no further discussion about related actions.

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

Level of Compliance: No Compliance[79]

The number of deaths this year to date is down substantially. However most had preventable factors and had serious quality of care issues contributing to death. This casts doubts over the effectiveness of the remedial plans, given that this BM requires implementing system-wide reforms to avoid preventable illnesses or deaths. Related to the comments for BM 91, there is not sufficient documentation of the actual activities taken, and correspondingly, there is no information about whether those efforts were effective.

Beyond the mortality review, there are likely further steps that the DSPDI needs to take to further identify root causes and substantially direct durable corrective and preventive strategies. For example, retraining staff may not be sufficient to prevent further similar issues. Retraining of institutional staff is mentioned, as another example, but there is no evidence of the completion of the training or whether staff gain needed knowledge as a result of the training. It is not entirely clear whether a lack of knowledge was the root cause of the issue, or whether there were other contributing factors.

Given the very serious care gaps identified in recent deaths, the DSPDI should consider whether providers involved in recent deaths involving neglect and poor care quality should be under heightened monitoring

[78] In their response to the JCC's first draft of the present Report, USDOJ presented compelling arguments which persuaded us to change the current compliance rate to "working towards compliance-still under review".
[79] The JCC and Experts are available to assist the DSPDI in all matters related to this BM.

for a period of time going forward to ensure that problem areas that have been identified do not persist for other participants.

Mental Health

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)

Level of Compliance: In Compliance

The DSPDI provided a sub-list of participants with mental health diagnoses. After removing participants not included in BM 3 and any duplicates, 458 participants were listed with a total of 1,044 distinct diagnoses. Of these participants, 435 had anywhere from one to 10 mental health diagnoses documented, which represents roughly 67% (435:649) of the DSPDI's current census. 24 participants on the sub-list did not have a diagnosis code listed.

In the document, there was a total of 106 distinct diagnoses codes listed for 435 participants. Below is a chart of the 20 codes with the highest counts for this subset of participants:

Code	Description	Count
F41.9	Anxiety disorder, unspecified (DSM-5) (Billable)	135
F84.0	Autistic disorder (DSM-5) (Billable)	74
F23	Brief psychotic disorder (DSM-5) (Billable)	74
F63.9	Impulse disorder, unspecified (Billable)	60
F32.8	Other depressive episodes	55
F20	Schizophrenia	54
F51.05	Insomnia due to other mental disorder (Billable)	54
F63.81	Intermittent explosive disorder (DSM-5) (Billable)	50
F29	Unspecified psychosis not due to a substance or known physiological condition (DSM-5) (Billable)	50
F20.9	Schizophrenia, unspecified (DSM-5) (Billable)	41
F31	Bipolar disorder	34
Cont.		
Code	**Description**	**Count**
F20.0	Paranoid schizophrenia (Billable)	24
F41.1	Generalized anxiety disorder (DSM-5) (Billable)	24
F51.01	Primary insomnia (DSM-5) (Billable)	23
F33	Mayor depressive disorde recurrent	17
F25.9	Schizoaffective disorder, unspecified (Billable)	15

F20.3	Undifferentiated schizophrenia (Billable)	13
F33.9	Major depressive disorder, recurrent, unspecified (DSM-5) (Billable)	11
F33.1	Major depressive disorder, recurrent, moderate	10
F33.3	Major depressive disorder, recurrent, severe with psychotic symptoms (DSM-5) (Billable)	10

Lastly, in the document, the following five codes were highlighted as high-risk mental health and behavioral codes (see count below). Only one participant (#189) had more than one of these high-risk codes listed in their record: F63.81 and F60.2.

Code	Description	Count
F63.81	Intermittent explosive disorder (DSM-5) (Billable)	50
F91.9	Conduct disorder, unspecified (DSM-5) (Billable)	4
F60.2	Antisocial personality disorder (DSM-5) (Billable)	3
F91.3	Oppositional defiant disorder (DSM-5) (Billable)	3
F91.8	Other conduct disorders (DSM-5) (Billable)	1
Grand Total		61

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)

Level of Compliance: Working Towards Compliance – Still Under Review[80]

The vast majority of people with mental illness had a visit with their psychiatrist in the past year. For a small subset of participants that live in biological homes, their family manages their medical care and would not provide information to the DSPDI despite multiple requests (participants #52, #905, #948, and #1008).

There are five participants (#925, #1057, #1068, #1083, and #1128) that do not have a mental health care professional identified. For example, there is a participant with multiple mental health diagnoses and their care is managed by a neurologist only (participant #54). All but four have had a psychiatric evaluation (participants #925, #1057, #1068, and #1128) in 2022.

It is important to note that there are numerous challenges presented by the generic community mental health system for those with government insurance in Puerto Rico (which is the majority of participants), including extremely short appointment times (about five minutes), a very limited formulary, and restrictions on the practitioners that can be accessed under the managed care system. These challenges have been part of the ongoing discussions and work of the collaborative High Risk and Polypharmacy

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workgroup inclusive of DSPDI and JCC experts and will be part of continued efforts to ensure access to timely, necessary and high-quality care in the community for all participants.

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

Level of Compliance: Partial Compliance

As previously anticipated, the DSPDI has made positive strides towards reaching this benchmark in the current period compared to prior periods. CAPAR has instituted practices to confirm diagnoses through clinical reviews and has done outreach to community clinicians to clarify diagnoses particularly related to prescription medication use. Continuing this work to review more participants going forward will contribute towards reaching a higher compliance assessment in this benchmark. Other strategies can be explored within the collaborative workgroup on High-Risk Conditions and Polypharmacy that may include enhancing the skills of community-based clinicians in diagnosing mental health conditions in people with ID/DD, and/or other strategies to ensure participants are receiving diagnoses from clinicians skilled in working with this population.

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

Level of Compliance: Working Towards Compliance – Still Under Review[81]

As previously addressed, the DSPDI is working on improving the information they have about the diagnosis associated with each prescribed psychotropic medication by instructing staff to ask about this during appointments, and through direct correspondence with prescribing clinicians (via CAPAR). This is necessary information to then evaluate whether the prescribed psychotropic medication is justified as treatment for a valid mental health condition. CAPAR reviews contribute to progress in this benchmark for a subset of participants, but more work is required to evaluate and justify the medication that is being used for other participants.

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

Level of Compliance: Working Towards Compliance – Still Under Review[82]

The DSPDI has noted formulary challenges (for those on government insurance, which is the majority of participants) in changing psychotropic medications away from first generation medications with more

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adverse side effects to newer medications. The DSPDI has stated that many doctors generally only prescribe drugs that are within the formulary, particularly for people on the government health plan which has a very restrictive formulary. Currently, it is challenging for participants to access certain newer generation medications because they are not currently covered by their health plan and would be very costly to prescribe and administer.

This topic has come up as part of the collaborative workgroup on High-Risk Conditions and Polypharmacy. The workgroup is exploring the feasibility of various strategies to expand participant's access to more optimal medications (effective, safer, lower risk of side effects, etc.). This is a high priority area that the JCC encourages the DSPDI to continue to pursue, with the support of Experts. The JCC applauds the DSPDI's willingness and openness to discuss and potentially pursue strategies to address these large and longstanding barriers to optimal care for participants.

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

Level of Compliance: Working Towards Compliance – Still Under Review[83]

See notes for other benchmarks above.

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

Level of Compliance: Working Towards Compliance – Still Under Review[84]

See notes for other benchmarks above.

III.6 System wide Reforms

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)

Level of Compliance: Working Towards Compliance – Still Under Review [85]

BM 100 Health, Safety and Well-Being Protocol:

The Quality Assurance Program Protocol that was furnished was developed and implemented under the prior administration in March of 2021. It includes the following three sections that should be updated to

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reflect the new improvement initiatives stemming from the DSPDI's four technical assistance priority work groups developed in the spring of 2022.

Participant Health Protocol: We recommend that this protocol be updated by including the CAPAR's newly established or better defined high-risk medical and behavioral categories, e.g., significant health change, morbid obesity, controlled vs. uncontrolled epilepsy, and series of critical incidents within a certain timeframe. Additionally, the protocol should be reflective of the referral process and associated communication chain as to how the EID of each CTS determines what health-related events should be marked as red flags and how this information should subsequently be relayed to DSPDI's Quality of Services Area and to other committees (e.g., MRC, CAPAR, and/or Incidents and Investigations Committee) as needed.

It should also state how the Quality Area and/or any other committee will intervene and provide support to the EID and related participant(s). Lastly, it has been noted that DSPDI is making strides towards cross communication improvement and overall oversight and surveillance of high-risk participants. One example of the former is the Incident Management Committee recommended that the EID team of each CTS hold monthly meetings to discuss monthly incidents, to notify CAPAR or MRC as needed, and that Quality will intervene as needed. One example of the latter is the list of CAPAR's current caseload of 40 participants, of which half are categorized as high-risk due to varying concerns related to health and/or behavior; CAPAR reviews will continue in the following period prioritizing high risk participants.

- *Safety of Participants Protocol:* Currently, incident reports developed by the DSPDI's Quality of Services Area are developed and archived as hardcopies and are not entered into Therap. Given the above, we recommend that the DSPDI explores incorporating these incidents within Therap using the platform's features to protect sensitive information, address the involvement of multiple participants, etc. that are reasons cited as to why these incidents generally do not get entered into Therap. Also, the investigations of these incidents could also be uploaded in Therap with proper access controls.

  There are known quality issues in the incidents entered into Therap that affect the ability to reliably analyze and interpret trends and patterns. DSPDI did conduct some training on reporting incidents during this period, but further efforts will likely be necessary to improve data quality. A formal quality data management plan, for example, may be beneficial to ensure all parties responsible for incident-related data entry is done consistently, timely, and accurate.

- *Welfare of Participants Protocol:* Any complaints or grievances that the DSPDI's Quality of Services Area receives should also be formally documented in Therap based on the DSPDI's Therap data entry guidelines, though currently these are not consistently being entered into Therap.

BM 100 Summary of Quality Area Objectives:

This document states that DSPDI's Quality of Services Area is planning on developing a Continuous Quality Improvement manual (from September 2022 through March 2023) that covers the following topics that

are associated to the different components of DSPDI's *PROTOCOL OF HEALTH, SAFETY AND WELL-BEING OF THE PARTICIPANT*.

- Opportunities to improve attention to participants (Increase service satisfaction standards);
- Identify areas prone to high-risk indicators (prevention);
- Manage situations in the direct services offered to participants;
- Quality of care provided to the participant through compliance with the clinical measures included in the participants' "Health Plan", using as a reference Massachusetts Department of Developmental Services Adult Screening Recommendations 20191 updates to 2017 revision, Preventive Health Recommendations for Adults with Intellectual Disability;
- Assess participants' experience in health care;
- Participation of employees in the training;
- Data analysis; and
- Methodology for continuous quality improvement, among others.

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)

Level of Compliance: Working Towards Compliance – Still Under Review [86]

The DSPDI's Incidents Committee meets monthly to discuss all incidents reported from each CTS, including those documented in Therap and on paper via the Incident Form, that occurred during the previous month. Additionally, per the *Safety of Participants Protocol*, clinical personnel of the Quality of Services Area are charged with conducting their own (final) analysis of each red flag scenario.

Moreover, it is to be noted that CAPAR's chairperson, Dr. Carolina Carmona, officially joined DSPDI's Incident Committee with the purpose of improving and facilitating more efficient and rapid communication between committees, as well as addressing participant or community home related issues more promptly. It is recommended that systemwide incident trends and patterns could be reviewed at a regular interval (e.g., quarterly) with recommendations to develop corrective action plans or other initiatives as needed.

While access to Therap to report has improved over time, gaps persist (see BM 40), which will affect the completeness of information contained in Therap to inform these patterns and trends.

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"

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Level of Compliance: Working Towards Compliance – Still Under Review[87]

Per the Mediator Distribution List, there are a total of 69 community homes and 351 participants assigned across 17 Service Mediators. Caseloads per Service Mediator range anywhere from 8 to 24 participants. A total of 5104 Service Mediator Case Notes were recorded in Therap during the current three-month period. Case Notes per Service Coordinator ranged substantially from 68 to 501. A total of 620 Service Mediator home visits occurred during the referenced three-month period. Home visits per Service Coordinator also ranged widely from 6 to 75 visits. Of all community homes included in this list (68), 38 of them were visited anywhere from 1 to 10 times and the remaining homes were visited anywhere from 11 to 21 (Psicopedagógico II) times. Furthermore, 90 visits were related to some type of incident.

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

Level of Compliance: Partial Compliance[88]

As cited in the September 2021 report, 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. Only 3 participants (#919, #1117, and #1130) living in biological homes were provided respite services in 2022. No updated respite program protocol nor document indicating DSPDI's current respite capacity were furnished.

Deinstitutionalization Efforts that Address Family Opposition:

During this period, the Deinstitutionalization and Independent Living work group attempted to collaborate with APIADI to support them in their efforts on education opposing families to be more receptive to community-based living and support services; unfortunately, APIADI respectfully declined. Alternatively, the DSPDI is making efforts to forge a stronger collaborative relationship with Puerto Rico's newly revamped State Council on Developmental Disabilities for support in this area.

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)

Level of Compliance: Working Towards Compliance – Still Under Review[89]

The DSPDI developed the Crisis Hotline Guide in late 2021. The DSPDI stated that despite the Hotline being a professional service offered outside of normal business hours by the Central Office's CEEC and that it is

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[88] The JCC considers that the DSPDI is working towards Substantial Compliance in this benchmark.
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promoted by DSPDI's Social Worker and Community Home Liaison and during employee trainings and orientation, it is rarely used as most providers prefer directly contacting the EID team of their respective CTS for consultation and support, as well as to report behavioral, emotional, or physical crises that occur. The JCC recommends that any Hotline phone call along with the completed phone call registry and danger assessment forms be documented in Therap under the participant's record. Further, upon interviews held by the Office of the JCC to providers, guardians, and direct care takers, it was found that it is not commonly known that the DSPDI has a crisis line answered by professionals 24/7.

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)

Level of Compliance: Working Towards Compliance – Still Under Review[90]

All Therap users have access to its Secure Communications (SComm) tool, which facilitates the sharing of sensitive and confidential information through a HIPAA-compliant chat platform. During this monitoring period, it was noted that occasional referrals between CTS disciplinary areas are conducted through SComm, however, they are not formally documented in any other Therap module such as Case Notes. Given this information, it is highly recommended that these referrals be documented in the appropriate Therap module to ensure the completeness of each participant's record. Lastly, all DSPDI personnel has a personal email with the Health Department Outlook 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"

Level of Compliance: Working Towards Compliance – Still Under Review[91]

The DSPDI has service mediators for participants living in biological homes. The DSPDI described the services they provide to participants living in biological homes, including, clinical and habilitative evaluations and follow-ups, access to the Crisis Hotline, CTS day programming, DSPDI community home based respite, and in-home respite provide through the "*Ama de Llave*" program. It was noted during this six-month period that the contract with "*Ama de Llaves*" was discontinued suddenly, which will be an area for the DSPDI to explore an alternative solution to going forward.

III. CONCLUSION

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As evidenced from our assessment, the DSPDI has achieved significant improvement in many Benchmark areas, obtaining a higher compliance rate in many individual benchmarks in comparison to our previous assessment.

The above numbers demonstrate that the Commonwealth has been properly implementing a majority of the Experts' recommendations and technical assistance and that it is in the correct path towards reaching full compliance with the mandates of the Consent Decree.

Once again, the JCC commends the efforts of the Secretary of Health, Hon. Carlos Mellado; the Department of Health's Auxiliary Secretary of Family Health, Integrated Services and Health Promotion, Dr. Marilú Cintrón Casado; the DSPDI's Compliance Officer, Mr. David Rodríguez Burns, Esq.; the DSPDI's Interim Director, Mr. Danniel Sotto; and the DSPDI staff for working in a collaborative and efficient manner with all experts and JCC team members for the benefit of all participants of the DSPDI program, and for maintaining open, effective and transparent communication channels with our Office.

These efforts have been instrumental in the significant progress that the Commonwealth has achieved in the present Report and the JCC is confident that the same will continue to bear fruit in the future. Said efforts are also a perfect example of the swift progress that the Commonwealth can achieve for the benefit of all participants by leaving behind the obstructionist approach adopted by its previous legal counsel and working in a collaborative manner with the Office of the JCC and Experts.

As always, the JCC would also like to thank the various family organizations, especially the Association for the Inclusion of Adults with Intellectual Disabilities ("APIADI", for its Spanish acronym) and its President, Ms. María Juliana Vilá, for their valuable contributions, commitment, and support for the benefit of the entire ID/DD population in the Island.

The JCC is optimistic that with the assistance of all experts, the Office of the JCC and DSPDI leadership, the Commonwealth will continue to show significant progress in their results in regards to the ultimate goal of reaching compliance with the Consent Decree. The commitment to the reform of the present administration has proven that a meaningful, healthier, safe, and independent life can be obtained for all participants. The DSPDI, as always, can count on the Office of the JCC and Experts' assistance in all benchmarks that can be addressed in a collaborative manner.