# **Health Needs Assessment**

## DIVISIÓN MADRES, NIÑOS Y ADOLESCENTES

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#### Process Description

The interim Health Needs Assessment (HNA) assessed the impact of the Covid-19 pandemic crisis on Title V in the PR jurisdiction.

The Maternal, Child and Adolescent Health Program (MCAHP) focused on the effects on Title V core services as these experienced disruptions and modifications in 2020. The MCAHP carried out 12 virtual Dialogues with 41 staffs from the core services that provide education and support to the MCA populations. The purpose was to gather first-hand information from the staff to document how each program was affected, how they faced the effects and challenges, their strengths, and their assessment of the MCA populations needs. It also conducted one interview with a home visiting nurse that gave testimony about her experience in helping families. The Dialogues were carried out by the HNA Research Team (cultural anthropologist and the maternal epidemiologist/SSDI coordinator) between November 2020 and January 2021 and the Interview in April 2021. The dialogues and interview lasted 1½ to 2 hours, were recorded, transcribed verbatim and analyzed qualitatively.

Conducting the Dialogues through the TEAMS platform presented challenges that ranged from unstable internet connection to inability to use the microphone to make comments. Yet, the HNA research Team was able to handle the problems. For example, participants unable to use the microphone wrote their comments in the TEAMS chat that were read aloud by one of the researchers.

The Children with Special Medical Needs Division (CSMND) focused on the telework system urgently implemented during the Covid-19 pandemic lockdown at the CSHCN Program. The telework system implemented at the CSHCNP includes telemedicine and tele-health services. Telemedicine was carried out by program's pediatricians and telehealth was carried out by health professionals authorized by Act 68, 2020 (physical/occupational therapists, speech and language pathologists, audiologists, psychologists, nutritionists, social workers). Care coordinators and FESAs supported families through telework. Public health staff also used telework. This survey addresses the different types of telework implemented.

A survey was carried out for state and regional CSHCN Program staff on how they felt and dealt with the telework implementation, their needs on telework capacity development, and the strengths and barriers experienced. A similar survey was administered to CSHCNP families about their experience, opinions and recommendations on the virtual services received. Two (2) questionnaires with open and closed ended questions were created, pre-tested, and distributed online to the CSHCNP staff and families during the summer of 2020. A total of 187 staff members and 387 families participated.

#### Health Status

In 2019 (IDB) the number of WRA was 806,330, while 2020 Vital Statistics (VS) reported 19,026 live births (LB). The number of children as reported by IDB by 2019 were 25,095 infants, 250,214 children 1 to 9 y/o, and 456,984 adolescents 10 to 21 y/o. According to MCH-JS (2019) the prevalence of CSHCN 0 to 17 years of age was 27.3%.

According to BRFSS 2019, the percent of women, 18 to 44 y/o, with a preventive medical visit in the past year remained almost the same as 2018 (78.5% vs. 78.7%, respectively), while PRAMS 2019 reported a 10% increase of the percent of women who had a preventive dental visit during pregnancy compared to 2018 (53.3% vs. 48.7%, respectively).

Mothers placing their infants to sleep in a safe environment slightly increased from 2018 (4.1%) to 2019 (4.5%). PRAMS 2019 also reported that approximately half of mothers usually placed their infants to sleep on a separate firm sleep surface (46.4%), followed by placing their infants on their back (42.2%). Fewer reported avoiding soft objects and loose bedding (27.8%). While SUIDs rates (VS), increased from 74.7/100,000 live births (LB) in 2018 to 98.3/100,000 LB in 2019.

About 78% of children 1 to 17 y/o reported a preventive dental visit in the past year (MCH-JS 2019). While adolescents 12 to 17 y/o reporting being bullied (including cyber bullying) had a 45% significant decrease since 2017 (YRBSS 2019: 12%).

The priorities needs remained as proposed in 2020 HNA. Some strategies of the state Action Plan were reviewed and updated according to the findings of this HNA (for details refer to section III.E.1. Five-Year State Action Plan). It should be noted that due to COVID-19, families had problems accessing services and this is reflected in the current HNA.

### Findings

The findings are organized by program and/or staff category. Due to character and page limitations, it is not possible to present all the complexities of the situations the staff faced in 2020. The full report is available upon request to <u>mariancruz@salud.gov.pr</u>. PROGRAM: Home Visiting Program (HVP) HEALTH DOMAINS: Women/Maternal, Perinatal/Infant, & Child

The HVP serves pregnant and parenting women, their children up to age 2, and their families. The Home Visiting Nurses (HVNs) offer case management, care coordination, support, and education on maternal and infant/child health topics; perform screenings (maternal depression, intimate partner violence, substance use, oral health, and child development); and make referrals and follow up to ensure completion. Families that do not qualify for services are helped as non-participants.

**Dialogue Participants:** 11 staff- Central Level Team (Coordinator, Evaluator, Mental Health Consultant) and 7 Region Level Supervisors of the HVNs. The Testimonial Interview with 1 HVN was included.

#### Facing the Effects

When the HVP was ordered to stop the home visits, uncertainty about program and employment continuity prevailed among the regional staff. As a HVN supervisor said:

"The first days [of the lockdown] there was uncertainty, I would rather say fear; we were disoriented because we didn't know what we would be doing"

By April 2020, the HVP had developed a protocol to guide services during the pandemic, thus making a quick adaptation from home visits to virtual services. The HVNs used their phones to continued services via texting or calls. The staff reported difficulties and challenges in virtual interventions. Inability to retrieve HVP forms and participants' files was a difficulty while offices were closed. To handle this barrier, the HVNs were instructed to use a notebook to keep detailed records of their interventions. The data was transferred to participants' records once the HVNs returned to in-office work.

The staff also noted service limitations as the HVNs were not able to perform all screenings, particularly those that asked sensitive questions. Another difficulty reported was the inability to observe the home environment. Likewise, services via telephone hampered the HVNs ability to have visual clues of infants' development. The HVNs handled this challenge by using the WHATSAPP or by asking mothers to send videos or describe infants' motor movements. The staff also reported other challenges in the provision of virtual services such as contacting participants, participants' distractions while receiving the service, and

confidentiality. Coordinating services with providers was also a challenge as health and other services experienced disruptions.

Despite the challenges, the HVP provided as much continuity of services as possible as well as responding to participants' emergent needs such as support to access online services (WIC, Demographic Registry, Medicaid). To help families, the HVNs had first to learn the ropes of virtual platforms as the HVN reported:

"I won't deny that at a certain moment I had a headache and felt stressed and I said to myself it is going to be very difficult because I don't know how to do it. First, I took some sort of mini-course with each program [services] so that they could give me an update on the new format so that I could explain her [participant] in the simplest way possible"

Other emergent situations among families as reported by the HVNs to their supervisors included: job loss or reduce work hours, little or no access to health services, anxiety over COVID-19 infection, and fear of giving birth without companions, among others. The HVNs dealt with these situations by listening with empathy, contacting collaborators, and addressing participants' anxieties under the guidance and support of their supervisors and the Central Level Team. Staff reported retention of participating families and the enrollment of new ones owed to the HVNs dedication. Noteworthy, the HVNs- on their own accord - answer participants' calls beyond work hours (weekend, night, evening).

The supervisors pointed out that remote work was particularly challenging since they could not perform file review and field evaluation, thus they had to trust that the work was done. Yet, some commented having undergone positive changes as they became more understanding, more communicative, and more involved with the HVNs work.

The staff reported they had to learn the use of digital platforms that allowed them to hold meetings and trainings productively. Yet, they had challenges in terms of devices and access to internet services. They also spoke about listening sessions facilitated by the Mental Health Consultant that allowed the staff to speak freely about their worries.

#### Staff Strengths

A dedicated, qualified, and committed staff was mentioned as key strengths during the pandemic. The staff also emphasized the ability to adapt to new ways of working, communicating, and providing services as a major asset. As one stated:

"...I think the main strength is that the program has been able to adapt to meet the new needs of the population. That we have been able to make the necessary structural changes to continue offering the services, albeit limited and different."

#### <u>Staff Needs</u>

- 1. Some Dialogue participants see the need to digitalize (forms and participants' records) and furnish the HVNs with tablets and/or laptops.
- 2. A Supervision Protocol for the HVN supervisors.
- 3. Digital skills building trainings.

#### HNA Researchers' Comments on the HVP

- The HVN in her testimony stressed the usefulness of the webpage <u>www.encuentrodemivida.com</u> during the pandemic. Rather than just referring women to visit the page, she took screenshots of the educational materials and sent them over to participants.
- The purchase order to buy mobile phones for each HVN took months to be completed as it commonly happens in government. These were distributed in early 2021.
- The staff learned to use the virtual platforms through basic official training and/or self-training.
- One HVN supervisor thinks that virtual services could be an option to participants that may be reluctant to return to or begin (in the case of those enrolled during the pandemic) to home visits.
- The MCAHP could consider incorporating into the Action Plan a strategy related to emotional health and stress management for <u>all staff</u>.
- The MCAHP could consider incorporating into the Action Plan a strategy related to build digital skills for <u>all staff</u> to enable and/or enhance the use of virtual platforms.

#### PROGRAM: Perinatal Services (PS)

HEALTH DOMAINS: Perinatal/Infant

Education and support on maternal and infant health to women in birthing hospitals. Services include referrals and recruitment into the HVP. The PNs are supervised by the HVN supervisors.

**Dialogue Participants:** 8 staff - *Perinatal Nurses (Regional Level)* 

#### Facing the Effects

The perinatal services were completely disrupted as hospitals ceased nonemergency services. The PNs reported having maintained communication with each hospital in their respective regions to make inquiries about COVID-19 birthing protocols as well as protocols and dates for resuming the PS.

By July 2020, the PNs had resumed services in most of the hospitals they serve. The exception were the PNs from the Metro Region that up to the time of the Dialogue (November 2020) had not been granted permission from hospitals' administrators to resume their services because "this is the region where COVID-19 patients concentrate". According to the Metro PNs they sent flyers with information and telephone number to be posted in the hospital's bulletin board so that women could contact them. They further explained that two hospitals made some concessions to access women. One hospital would send lists of women and their phone numbers (who had given permission) so the PNs could contact them for telephone orientations and education. The other hospital would include a flyer with the PS information in the discharge packet.

Once services were resumed, some PNs had fears of being infected and in turn infect members of their families. As one indicated:

"At the beginning [once services were resumed] to visit hospitals because I have two daughters, one is three years old and the other is eight years old. My mother who is a senior takes care of my daughters. I was afraid to be infected and then infect my daughters or my mother."

The PNs said they had to adjust the ways they normally carried out their services in hospitals which they vividly described in the dialogue. They wear personal protective equipment (PPE) like face masks, gloves, and hair nets and in some hospitals, shoe covers and kept distance while providing services. They pointed out they now give the telephone number (personal and office phone) to women in case they have any further questions after the educational session. From their comments, women did seem to contact them via telephone to ask questions mainly on breastfeeding, baby care and nutrition. They commented that providing breastfeeding education and support under distancing measures was a challenge since it requires helping women how to latch their babies.

Besides the usual health topics covered, the PNs offered information and support related to accessing critical online services like the Demographic Registry. A PN, who is also a HVN, described the hurdles of registering babies:

"...people have no knowledge of the new platform Online Renovations. There you have to create an account and then go to the Demographic Registry to request register the baby. What happens? After they [women] fill out all the information, they have to wait for the local Demographic Registry Office to contact them for an in-person appointment where they must bring all documents to register the baby. I have one [participant] whose baby was registered in months, but others took longer....they become stressed and I calm them by saying 'look, this is what is happening, let's be calm, don't worry that your baby is not going to be left out of registering".

This account points to how stressful it is for families to register infants that adds to other life stressors. The PNs address women's worries and anxieties that include apprehension to take their babies to their first pediatric visit (fear that the baby could become infected) and questions about if a woman infected with the virus could breastfeed.

#### Staff Strengths

In speaking about their strengths, the PNs emphasized availability, disposition, commitment, and empathy as key attributes in carrying out their services. They all showed hope and pride as perinatal nurses. The following comment best expresses these feelings:

"...I embrace the words of my co-workers that are present; it is the love for my profession and commitment toward our participants. And I congratulate you all because each one loves and is committed to this program, to what we studied, to what we are."

#### <u>Staff Needs</u>

Printed educational materials to distribute as their supplies were dwindling.

#### HNA Researchers' Comments on the PS

- The Dialogue served to gather the PNs as one group as they generally have little or no contact among themselves.
- Unlike the HVNs, the PNs have no written PS protocol with standard rules.
- Suggestions: 1) Develop a written protocol to enhance the PS; 2) Organize periodic PS meetings attended by the PNs and their supervisors to share knowledge and experiences.

#### PROGRAM: Health Promotion and Community Outreach (HPCO)

HEALTH DOMAINS: Women/Maternal, Perinatal/Infant, Child, and Adolescent

Offers community and professional health education and training, prenatal and parenting courses, and mass campaigns. The Health Educators (HEs) design educational materials, offer trainings to professionals, offer workshops and courses, and provide technical assistance to the Community Health Workers (CHWs). The CHWs recruit participants to the HVP, make referrals, and provide community health education including prenatal and parenting courses. A Curricula Consultant oversees media/internet campaigns, curriculum development and the courses.

**Dialogue Participants:** 14 staff - Curricula Consultant, 5 Health Educators (HEs) and 6 Community Health Workers (CHWs), and one MCAHP Regional Director who is a Health Educator. The health promotion efforts of the Pediatric Consultant were included.

### Facing the Effects

#### HEs, CHWs and Curricula Consultant

The health promotion and outreach staff were hit hard by the pandemic as all in-person educational and outreach activities (e.g., workshops, trainings, talks, dissemination of educational materials, parenting courses and prenatal course) were completely stopped. Consequently, the staff experienced surprise and uncertainty about what to do.

The staff said they had turned to virtual modalities (e.g., telephone calls, online platforms, webpage, among others) to perform health promotion and outreach tasks albeit limited. The HEs developed and provided virtual trainings and

refresher presentations to other staff such as the HVNs. They also offered trainings and presentations on health topics to the staffs of other agencies like Head Start and Early Head Start. The HEs also created pandemic related educational materials targeted at families (e.g., handling children's emotions, unintentional injury prevention tips, and tips for making home baby wipes). According to the staff, these materials could not be disseminated (via online) due to the electoral ban that mandates government agencies to submit to the State Commission on Elections all publicity and educational materials for approval. The HEs informed they never received a response which caused frustration in them.

The CHWs – unable to do in-person outreach - used their own cell phones to contact collaborators and families. They reported that families faced difficulties accessing health services and vaccines. Registering babies have been particularly difficult for families with limited or no internet connection to access the online services of the Demographic Registry. They commented families had to wait several months to register babies. The CHWs were instrumental in helping families to access online services and like the HVNs and the PNs had to learn first how to use them.

The limitations imposed by the novel situation put a strain on the staff that somewhat felt out of place for not being able to assume their duties properly. A CHW expressed the way she felt:

"Personally, sometimes I feel anxiety because I can't do much of what I used to do before [the pandemic], especially the workshops. We are just in the office searching for referrals from programs...I call them [women] and then refer them to the nurse [HVN]. But there could be only one per week or five per week and it is not the quantity that one would like.

The staff reported that the use of virtual platforms for meetings and internal communications posed challenges including inadequate equipment, weak internet signal, and longer meeting time compared to in-person meetings.

The trying times required to push further virtual health promotion. To this end, two digital educational tools were created. One, is a 3-minute video clip on safe sleep that is available in the Department of Health (DOH) Facebook and webpage. This video, shown to the HNA researchers can be characterized as being simple, concise, clear, and visually attractive. The Curricula Consultant reported the video was shown in October 2020 (DOH Facebook) reaching over 65,000 views.

The other tool is a 24- minute digital version of the prenatal course that was created to fill the void left by the paralysis of the in-person course. The virtual

course - that uses sign language - includes participant's socio-demographic information, pre-test, course topics, post-test, evaluation, and an open-ended question to share experience. A certificate is sent via online or post office to persons that complete the course.

When asked about the virtual prenatal course, the HEs - while recognizing its quality in form and content - expressed some concerns : 1) it does not cover indepth the topics discussed in the in-person prenatal course; 2) the participants do not interact virtually with facilitators as other online courses do; 3) participants' questions and doubts are left unanswered.

The HEs made suggestions to handle the limitations they see in the prenatal digital course. These are: 1) create a mechanism whereby participants can contact a CHW or an HE to ask questions and more information about topics covered in the course; 2) offer the course through the government TV channel; 3) create stand-alone videos on each topic presented in the virtual course that a participant can watch, if interested.

#### <u>Staff Strengths</u>

Disposition, knowledge, commitment, teamwork, perseverance, mutual support, and open communication were mentioned as main strengths that made possible to face the challenges brought on by the pandemic. A HE echoing others said:

"The Division never stopped working. Contrary to other programs that literally were paralyzed, it remained active. And that shows that the Division have a human resource full of interest, willpower, disposition to work and to move forward despite the adversities of the pandemic."

#### <u>Staff Needs</u>

- 1) Better internet connection and signal in the regional offices
- 2) Open DOH email accounts for the CHWs so they can access online webinars and trainings.
- 3) Trainings on a variety of topics and digital building skills.

#### Pediatric Consultant

Under the leadership of the pediatric consultant, the PR chapter of the American Academy of Pediatricians (PR AAP) was instrumental in addressing emergent needs. This partner has plenty of experience and a YouTube channel to inform and educate its members, other professionals, the public, and families.

Among the actions undertaken by the pediatric consultant several stand out. One action was the creation of webinars and chat groups targeted at the medical professionals to learn and discuss COVID-19 related health topics. Another type of action was the creation of policy recommendations (in collaboration with a group of neonatologists and Obstetric /gynecologists) for the management of the health of women and newborns in hospitals including breastfeeding. Very importantly, webinars and videos related to Title V objectives and strategies were produced and/or disseminated through the PR AAP virtual platform. These included safe sleep, infant nutrition, and infant/child development, among others. These webinars were attended by the staff from head start, early head start, childcare centers as well as parents and are available in the PR AAP website. In addition, short video clips were created with messages for parents encouraging preventive pediatric care, immunization and breastfeeding during the pandemic and measures to prevent infection, and transmission of COVID-19. She also collaborated in the creation of the video on safe sleep.

When asked about staff strengths, she emphasized strong collaborative networks and ability to do teamwork as major assets. In her view, the staff did their best under duress.

She identified stress management as a major need among the staff to prevent burnout.

#### HNA Researchers' Comments on the HPCO

- Stopping the parental and prenatal courses left families without an important source of knowledge. For example, in FY 2018-2019, there was increased knowledge of participants as shown in the pre-and post-test scores. Pregnant women in prenatal course (95% post-test score vs 70% pre-test); parents in 0-5 y/o course ( 94% posttest vs 78.6% pre-test); parents in 6-11 y/o (96% post-test vs 80% pre-test).
- The electoral ban adversely affected the multimedia campaign on pregnancy health as it was stopped for several months in 2020 waiting for authorization. The campaign was finally run from October thru December 2020.
- The virtual prenatal course does a service to pregnant women unable to attend inperson courses. Nevertheless, it will be necessary to consider the recommendations of the HEs regarding the identified limitations.
- The staff learned to use the virtual platforms through basic official training and/or self-training.
- As a non-government organization, the PR AAP was free from the barriers imposed by the PR electoral ban to promptly respond to the crisis.
- The Pediatric consultant had the advantage of having developed technological skills prior to the pandemic that allowed her to act immediately.

#### PROGRAM: Comprehensive Adolescent Health Program (CAHP)

HEALTH DOMAINS: Adolescent

Promotes adolescence health and wellbeing – based on the Positive Youth Development Model. The CAHP is staffed by an Associate Director, a Youth Health Promoter Center Coordinator (YHPC-C), a Healthy Youth Development System Coordinator (HYDS-C) and 6 Regional Coordinators (CAHP-C). The CAHP-Cs implement the Youth Health Promoters Project (YHPP) composed of voluntary students that promote healthy lifestyles among their peers in participating schools. The Youth Advisory Council (YAC), led by the HYDS-C, is composed of adolescents that help the DOH identify and implement strategies to improve youth health.

**Dialogue Participants:** 9 staff – Central Level CAHP Associate Director, YHPP-C, HYDS-C, and the Regional CAHP-Cs.

#### Facing the Effects

YHPP

The YHPP was severely impacted by the pandemic crisis. Being a school-based project, it ceased operations completely in 2020 leaving out 949 youth health promoters in 51 participating schools.

The most immediate reaction among the CAHP-Cs was uncertainty, fear of job loss, and anxiety. As one said:

"Honestly, the first concern I had was if I was going to be left without a job...a big feeling invaded me for not knowing what was going to be the future of our program because we know that our program is based on our approach to the schools and work with our youths in the schools'

For the CAHP-Cs, stopping the YHPP has been hard to bear. As they explained, the YHPP meetings had begun several weeks prior to the lockdown in Mid-March 2020 due to the January earthquakes that kept many schools closed. Therefore, the time spent with the Youth Health Promoters (YHPs) was extremely short in 2020. They reported feeling sad because they were not able to say goodbye to the youth, particularly the ones in their last year of participation.

The CAHP-Cs reported they stayed in contact – via telephone calls or text messages – with liaisons from participating schools. The CAHP-Cs provided COVID-19 information and stress management support to the school liaisons. Some liaisons passed the information on to the YHPs and/or their parents. The liaisons told the CAHP-Cs they were experiencing difficulties with online platforms as schools were not as ready as it was expected.

In the meantime, the CAHP staff engaged in workforce development activities (e.g., webinars, online trainings, book reviews, in-house training) to enhance their knowledge and skills. They also engaged in the evaluation of the YHPP.

Encouraged by the YHPC-C, the CAHP-Cs shifted gears and took on the task of adapting the YHPP curriculum in-person sessions to virtual ones. The staff commented that this a very challenging process as the YHPP is a 3-phase project whereby the promoters get involved for 3 consecutive years which makes it difficult to quickly turn the in-person sessions into digital sessions. They said the process is highly strenuous, time consuming, and drains energy.

While digitalization is important, the staff expressed concerns about virtual sessions: confidentiality and privacy; youth capacity to use digital platforms; internet access; having the right equipment.

The use of virtual platforms for internal communication and teamwork also posed a big challenge for the staff, especially those "who are not technological"

that had to learn "*new processes*". The CAHP staff used their own economic resources to buy or upgrade existing equipment. The technological challenge continued after they returned to in-office work as the desktop computers have no microphone or cameras. What some staff have done is to buy cameras with microphones to be able to use the office computers for virtual meetings.

The CAHP-Cs also spoke about anxiety and frustrations they experienced in fulfilling their duties under the new circumstances. As one described:

"I had my own personal equipment but sometimes it did not function well for what it was needed. And that creates a lot of anxiety since you cannot meet what is being demanded from you. To be able to fulfill all of that created anxiety and there were nights that I could not sleep."

Despite these challenges, the staff spoke of gains resulting from doing remote teamwork. First, acquisition of at least basic technological skills to enhance capacity to develop the virtual sessions. Second, blending their varied capacities, strengths, and skills (technological, artistic, writing, and logistics). Third, to know one another in different ways both personally and professionally (togetherness and sense of family).

### YAC

YAC members continued meeting and working together through the virtual modality but in reduced hours compared to the in-person meetings that normally lasted all day. The YAC created educational COVID-related videos to share with peers through social networks (washing hands, how they have handled physical distancing or what they did as young people during the pandemic). Their main concerns as reported to the HYDS-C were family obligations (e.g., shopping, banking, and childcare, helping younger siblings with school tasks) and academic duties, all of which cause stress.

In 2020, the members were due to end their 2-year participation in the YAC but decided to continue participating until new advisors are selected in 2021. This can be seen as a sign of duty and commitment to the Council.

#### <u>Staff Strengths</u>

The staff mentioned desire to learn and to improve themselves, commitment, teamwork, human quality, mutual support, capacity to adapt to novel situations, perseverance, and creativity as key strengths in the CHAP. This comment best expresses staff feelings:

"The greatest strength that we have is the human resource. We have it, teamwork, independently from the technological limitations that we have. That is our main strength. And the way that we are resilient and do not get down on our knees."

#### <u>Staff Needs</u>

1) Computers equipped with cameras, microphones and programs needed to work online.

2) Training on the use of digital platforms.

#### HNA Researchers' Comments on CAHP

- A ripple effect of the YHPP discontinuity during 2020 has been that other students in participating schools could not receive correct health information from the youth health promoters.
- The staff clarified that the YHPP in-person sessions serve to develop teamwork among youth and in the process conflicts do occur. The CAHP-Cs as social workers help them handle and resolve conflicts. Teamwork development and conflict resolution are big challenges to be considered in conducting virtual sessions.
- The staff learned to use the virtual platforms through basic official training and/or self-training.
- The staff as well as the members of YAC received support from the mental health consultant of the MCAHP.
- The HNA Research Team suggests: 1) to explore the possibility of creating short videos or a virtual campaign on bullying to reach out to youth across PR; 2) to keep electronic lists of the YHPs to enable direct contact with them and their families (names, parents names, address, email, telephone); 3) to explore the feasibility of creating a YHPP webpage.

#### STAFF CATEGORY: Health Care Providers

HEALTH DOMAIN: Children with Special Health Care Needs

Type of Professionals: Physicians; audiologists; speech and language pathologists; physical, occupational and speech therapists and assistants; nurses; nutritionists; psychologists.

Percent Staff Survey Respondents: 43 %

Health care providers described some of their feelings when they started offering remote services: anxiety, doubts, fear, hesitation, and disorientation. A speech and language pathologist expressed that she said to herself:

"But how am I going to do this? I have never given a therapy other than with the patient in front of me! ".

Most providers reported being grateful for a variety of reasons: having the opportunity to continue working, staying in contact with their CSHCN and families, staying safe at home with their family while working, having a sense of usefulness and stability, earning a salary. Some providers stated that they auto-trained in health virtual modality through webinars, literature review and reading. For example, an occupational therapist expressed:

"I took the time to prepare myself, studied the tele-health law, and I took webinars from the United States...and I accepted the challenge. At the beginning I felt a little anxious, but then I was satisfied to see the results and the benefits that this modality has brought to families and children."

Eighty three percent (82.5%) of health care providers reported the need of developmental capacity in addition to those offered information system work team. Frequent examples are: how to offer effective physical and occupational therapies virtually, carrying out virtual evaluations and screenings, making families feel safe with telemedicine, working with severe cases, psychological evaluation and intervention processes and regulations of teleworking practice for each discipline.

STAFF CATEGORY:

HEALTH DOMAIN: Children with Special Health Care Needs

Top and middle management

Type of Professionals: Medical directors; administrators; program managers; supervisors.

Percent Staff Survey Respondents : 9 %

The greatest challenge reported by the top/middle management was the urgent implementation of a telework system which was different to the one planned previous to the pandemic. An administrator, for example, expressed:

"There were many doubts about how to perform the functions (implement) since there was no precedent...in this modality."

They also reported that some providers adapted rapidly while others showed difficulty in the use of electronic equipment and virtual communication platforms. They stated that team work was key for remote services success, and that the number of families served has increased due to professionals reaching-out to those families that were not complying with the in-person appointments.

Eighty eight percent (87.5%) of top/middle management reported the need for developmental capacity. Some of the needs are: virtual service monitoring/supervision techniques, virtual service billing, insurance coverage, empowering families on tele-practice, encrypting documents, protected health information, handling documents in digital form, how to create a remote workspace, and techniques to preserve emotional and physical health. STAFF CATEGORY: Enabling Care Providers HEALTH DOMAIN: Children with Special Health Care Needs

Type of Professional: Social workers; service coordinators; family representative; FESAs.

Percent Staff Survey Respondents : 32.6 %

The great majority of the enabling providers group stated they felt grateful and satisfied when the remote modality started because they could maintain contact with families, including those that had not visited the centers for some time, and support them during this crisis. Few participants reported feelings of doubts, most of them regarding to the lack of electronic skills. A FESA expressed:

"I do not know how to handle all the situations that we are going through (referring to the pandemic), and my role with the parents is to be able to project security, knowledge, and be a figure of support and optimism, which I cannot project in these moments."

A social worker expressed:

"...There were therapeutic approaches that I was using with some families in person that cannot be applied through teleworking."

Eighty four percent (83.6%) of this group reported the need of capacity development. Some of the needs include: working with parents of ASD children; documenting virtual services in the medical record; virtual activities for children with attention, visual or sensory deficits; techniques of virtual services focused on young people in transition to adult life; time management during a tele-consultation and managing stress in parents.

STAFF CATEGORY: Public Health

HEALTH DOMAIN: Children with Special Health Care Needs

Type of Professionals: Epidemiologists, Evaluators, Health Educators; Program Coordinators; Community Coordinators.

Percent Staff Survey Respondents: 7.5%

The public health group did not expressed concerns or doubts in relation to telework. On the contrary, they expressed satisfaction and gratification. Forty three percent (42.9%) reported development capacity needs such as accessing and using applications where documents can be uploaded such as Sharepoint and Google Docs; education about programs like google meets, google forms, operation and functionality of the cloud.

#### HNA Researchers' Comments

- Findings related to support staff (accountants; data collectors; clinical clerks; information systems team which represents 9% of respondents) are not reported on the CSHCN HNA Update Summary.
- The reported staff perceptions on barriers and strengths of the telework implementation are:

**Strengths:** Staff reported an excellent communication with leaders, senior management, and work team. They reported on how virtual meetings and communication maintained the work cohesion and described communication as "continuous", "effective", "good" and "excellent". Other reported strengths were the availability and disposition of leaders and co-workers, support, EHR work team accessibility, continuity of follow-up to families, flexibility and adaptability.

**Barriers**: because staff was working from their homes, some barriers reported were: intermittent internet, unstable signal, unsupported operating systems, power outages, inaccessibility to the paper clinical records. Other barriers reported are difficult coordination with some families, service difficulty with families with multiple children, and working from home in shared places.

Lastly, 72.7% of staff reported they prefer the combination of face-to-face and virtual modalities, while 18.2% indicated they prefer only the face-to-face modality and 9.1% the virtual modality alone.

#### **CSCHN FAMILIES**

HEALTH DOMAIN: Children with Special Health Care Needs

Families who participated in the survey received virtual services from the seven RPCs and the Metro Autism Center. Their CSHCN's ages ranged from 0 to 11 years of which 70.3% were aged 2 and 3. Most of families (95%) referred they have technological equipment always available at home.

Number of Survey Participating Families: 387

Fifteen percent of families (15%) reported they had some technical difficulty during the remote services. Of this group, 53.4% expressed having received the technical support they needed, of which 70.7% indicated the situation was resolved quickly. Seventy four percent (73.6%) of families reported their child managed remote sessions well.

Ninety eight percent of families (97.5%) reported having received clear instructions on the remote services, and 87.6% reported that the Consent Form was provided. The Consent Form explains in simple terms the different communication alternatives of distance services, with whom the information will be shared (multidisciplinary team), definition of protected health information (PHI) and how it is protected when interacting through electronic means. Ninety five percent (94.6%) of families expressed receiving guidance about the service they would be receiving.

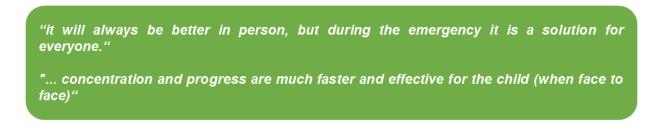
Ninety seven percent (96.5%) of the families reported that educational material provided during virtual interventions has been useful; 53.7% reported having obtained services from FESAs; of this group, 90% agreed this was very supportive.

Regarding the quality of communication with providers, more than 95% of the families expressed that there is good communication with the two groups of providers that represent health and enabling services.

The family survey included an open question for families to provide additional comments. Eighty-three (83) families commented in this section. Twenty-seven (27) families rated the service as: "excellent", "very good", "super-good", and "good". Fifteen (15) families described the staff as: "very professional", "very humane",

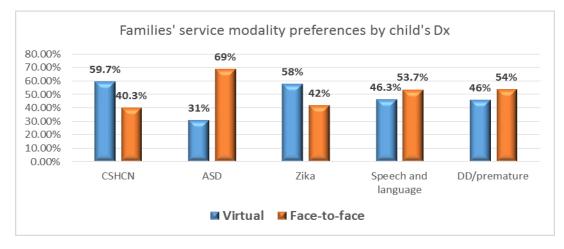
"caring", "kind", "responsible", "committed", "willing", "patient", and "available". Five (5) families described the service as: "organized", "good management", "good follow-up", and excellent work team".

Thirteen (13) families reported they prefer the face-to-face modality, but some expressed they prefer to wait until Covid-19 pandemic ends. Some families with children with complex conditions stated that they prefer the face to face services right away.



A family recommended to: "...receive children (visits) for evaluations... following health and safety protocols; and to "evaluate who are candidates for the face-to-face (modality)".

Based on the survey results, families with children with ASD, speech/language delay and developmental delay tend to prefer face-to-face services. The graphic below shows the percentage distribution of modality preferences per child's Dx. Results may vary out of pandemic



Changes in organization structure and leadership:

In January 2021, the new elected Governor of PR, Pedro Pierluisi, appointed Carlos Mellado, MD as the Secretary of Health. Therefore, the PRDOH is currently undergoing re-organization in its structure and top management.

Title V Partnerships, Collaboration, and Coordination:

MCAHP/ CSHCNP enhance health promotion and leadership through formal agreements - committees, task forces, and alliances, coalitions, cross coordination, resource and data sharing – with other federal, state and local agencies.

A major focus of MCAHP/CSHCNP is to strengthen family partnerships. For details see Section III.E.2.b.ii.

MCAH/CSHCN Programs continue partnering with agencies described in the 5YR HNA. Following is an updated list

#### Title V Program Partnerships, Collaboration, and Coordination

Other MCH Investments	
SSDI	
MIECHV	
Other federal investments	
WIC Program	Personal Responsibility Education Program
FEMA	CDC (PRAMS & HIV/STDs Prevention Division)
Immunization Program	Centers for Medicare and Medical Services
Early Intervention Program	CMS Zika Health Care Services Program
Sexual Risk Avoidance Education Program	-
Other HRSA programs	
HRSA Funded Health Centers	
Ryan White HIV/STD Program	
Zika Maternal and Child Health Service Program	
State and local MCH programs	
MCAHP regional offices	
Regional pediatric centers	
Autism centers	
Other programs within the State Department of Health	
Chronic Disease and Health Prevention Programs	Medicaid Program
Administration of Mental Health and Anti-Addiction Services	Office of Regulation and Certification of Health Professionals
Office of Informatics and Advanced Technology	Emergency Medical Services for Children
Demographic Registry Office	Office of Public Health Preparedness and Response
Other governmental agencies	
Insurance Commissioner Office	Family Department
PR Health Insurance Administration	Head Start and Early Head Start Programs
Education Department	PR Institute of Statistics
PR has no tribes, Tribal Organizations, and/or Urban Indian Org	anizations
Public health and health professional educational programs and universities	
UPR University – Agricultural Extension	PR Family to Family Health Information Center
Health and Justice Center, San Juan Bautista School of Medicine	Medical Science Campus, University of PR
Institute on Developmental Disabilities, UPR Medical Science Campus	PR-Neonatal Screening Laboratory
Other state and local public and private organizations that serve the state's MCH population	
United Way	Quality Office of La Fortaleza
March of Dimes	Women and Patient Procurator
Hospital Association	Institute for Youth Development
AAP Puerto Rico Chapter	PR Boys and Girls Club
PR Pediatric Society	Pro Familia (Planned Parenthood)
Association of Primary Health Care of PR	PR-ACOG
Highway Safety Commission	PR Society of Pediatric Dentistry
Oral Health Alliance	Proyecto Nacer
La Leche League PR	Maternal Fetal Medicine Specialist
Proyecto Lacta	APNI
PR Breastfeeding Coalition	SER de PR
Promani	MAVI
ASI	