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MCH Innovations Database Practice Summary & Implementation Guidance

Virtual programming to provide treatment, support mental health and facilitate family engagement for CYSHCN

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Location

New Jersey



Topic Area

Family/Youth Engagement



Setting

Urban



Population Focus

CYSHCN



NPM

NPM 11: Medical Home



Date Added

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Contact Information

Pamela Martorana, Manager, Clinical Programs
St. Joseph's Children's Hospital
703 Main St. Paterson, NJ 07503
973-754-4302
MartoraP@sjhmc.org



Section 1: Practice Summary

PRACTICE DESCRIPTION

Due to the pandemic, all CYSHCN service providers dramatically increased their use of telehealth services. New Jersey was among the first states to impose a lock-down (mid-March) due to our COVID-19 infection rate, proximity to New York City, and to our dense population. As a result of these strict measures, our State and various healthcare facilities had to respond quickly to this new environment. The baseline goal of the program is to support CYSHCN and their families. The pandemic driven goal has been to continue to provide individual, group, and family services. In response to the new challenges connected to COVID-19, the program needed to shift to a virtual platform. The AMCHP telehealth grant allowed NJ DOH and St. Joseph's Children's Hospital to collaborate on this front to enhance offerings.

When the COVID pandemic hit, social workers and BAC team started making "wellness calls," simply calling families to ask "how are you doing, what do you need, how can we help?" The staff listened and provided emotional support and connected families to community resources when needed. As a result of these calls, we began to identify the needs of the families. The consensus was feelings of isolation and loneliness due to missing staff and group activities.

The BAC Staff started to provide parent education over the phone, by being supportive and helping parents develop strategies for virtual learning. We piloted small groups with the learners; attendance was high so we started to layer in more groups, such as, yoga, cooking, and science. The groups were similar to what they had participated in before the pandemic but now provided a virtual platform was added. To provide therapeutic groups, we had about 6 kids in each group. We set expectations about virtual groups, they learned the rules and the experience improved. To ensure families have the necessary supplies for art, science, or cooking group, the BAC team prepares weekly supply bags for families to pick up; these bags have all the necessary tools for a week of programming. Last April to celebrate Autism Awareness month, we had "Tuesdays with Temple," We virtually interviewed Temple Grandin and our BAC families had an opportunity to ask her questions at the end. For Autism Awareness 2021, author Cindy Gelormini, shared her experience as a parent of a child with autism. This powerful presentation was well-received.

Patients from the inner city of Paterson are treated in the Pediatric Subspecialty areas of St. Joseph's Children's Hospital. Patient treatment plans and services are developed and designed to meet the needs of the identified patient and his/her family. Typically the patient's education needs are established, and patients are then connected to academic support in the school setting. There is a need for social skill development for the patient and overall support for the family unit.

Each time a provider refers a patient to Binder Autism Center, (BAC), the parent receives a personal phone call from a team member to begin the relationship. This initial phone call introduces the parent/caregiver to the services provided by the Binder Autism Center. Each new patient referred receives an intake to assess the strength and need areas of the patient, this information is then used to determine which groups and services are appropriate for the patient. The initial phone call informs parents of the variety of parent workshops, support groups, and social activities available to them. Our social activities for families are all about facilitating parent to parent contact.



Our program is based on parallel programming, the group for children and group for parents occur simultaneously. Parents need to know and understand what their child is learning in group and how to reinforce the learning in the home setting. The BAC offers individual sessions and group sessions such as art, movement, yoga, and social skills development. In effort to provide parent respite, we offer parent cooking classes and yoga. We also provide sibling support through groups and family events.

Parent education is paramount, it is important for them to know their rights. Additionally, the BAC brings in special guest speakers to give parents information on a variety of topics, such as, guardianship, transition, sexuality etc. Autism Speaks is very supportive of the BAC. We have earned grants for some of our special programs, such as, swimming and summer camp. BAC also offers field trips at the end of each summer, day trips for families, and is working towards offering overnight activities for families. This allows families to have a “fun Filled” day with other families who understand them and their child. We organize and run the trips, taking the pressure off the parent. Services run across all disciplines, including but not limited to, OT, PT, Speech, etc. and are based on the need of the patient. Telehealth services were introduced across pediatric subspecialty areas, such as, diabetes, cystic fibrosis and include individual and group sessions.

CORE COMPONENTS & PRACTICE ACTIVITIES

The goal of the program was to provide telehealth services to the Binder Autism Center, endocrinology and Cystic Fibrosis patients and their families. Throughout the pandemic, we offered virtual services to the patients and the families of St. Joseph’s Children’s Hospital. We achieved this goal by facilitating virtual, social skill development groups, cooking, yoga, and karate classes, open parent support groups, parent workshops etc. The framework was in place, the BAC always offered individual, group, and parent services. The transition from in person treatment to the virtual platform was challenging but definitely possible as we have

Core Components & Practice Activities		
Core Component	Activities	Operational Details
BAC Team: ABA, RBTs, BCBA	Facilitate group & individual sessions, parent workshops, parent events etc.	Plan group curriculum based on the treatment goals of the learners. Facilitate sessions, take attendance, track data, and provide feedback to caregivers.
Outside Facilitators	Facilitate karate, yoga and cooking classes.	Special Dragons facilitates karate for learners diagnosed with ASD. Yoga instructor trained to work with special needs population. Cooking instructor/chef is a special education teacher. All outside facilitators



		experienced to work with special needs population.
BAC Families	Participate and buy-in to new virtual programming	Parents/caregivers trusted the BAC team to join virtual programming. Families worked with SPAN for technical support for telemedicine appointments and group preparedness. Families showed up for services, promptness for activities improved as programming progressed. Families learned to ensure their IT was in place prior to session.

HEALTH EQUITY

The low-income, Hispanic/Latino communities around Saint Joseph’s Children’s Hospital are continually identified as in need of services and will benefit most from this project. St. Joseph’s Children’s Hospital is located in Paterson, New Jersey, in Passaic County. Passaic County, located in northern New Jersey, includes 192 square miles and reports a population of 512,607 (2017). Of this population, more than 10% are African-American, over 40% are Hispanic/Latino, and over 23% are under the age of 18. The median household income in Passaic County is \$62,016, and approximately 30% of the population is living below the poverty level. St. Joseph’s Children’s Hospital has a long history of having a strong community presence. In collaboration with SPAN Statewide Parent Advocacy Network, the communities will be engaged in taking advantage of the services provided and by having the opportunity to partner with SPAN in the role of parent leaders to share their lived experiences. SPAN provides telehealth support for the families in English and Spanish.

The identified population will benefit by having expanded options for accessing mental health services and expanded options for virtual programming via telehealth. The opportunities are designed to promote health and wellness for CYSHCN and their families.

EVIDENCE OF EFFECTIVENESS

We track attendance for all classes. We see consistency across all patient and parent classes. Typically, we cap groups at 6-8 patients and 90% of our groups are filled to capacity. Originally the plan included increasing the hours of a psychologist but this was not meeting the needs of the family during the pandemic. The group classes were very popular, so they were pivoted to incorporate the social worker and therapist into the classes to provide similar support in a less formal, less intimidating way. We learned from our parents that they needed virtual, meaningful services, for their learners to prevent learner regression and to help occupy their learner.

Topic	January	February	March	Total
Social Skills	# of classes: 2 Total Learners: 4	# of classes:4 Total Learners:6	# of classes: 5 Total Learners:6	# of classes: 11 Total Learners:16
Individual Art	# of classes: 6	# of classes: 12	# of classes: 9	# of classes: 27 Total Learners: 27
Karate	# of classes: 8	# of classes: 12	# of classes: 15	# of classes: 35



	Total Learners: 96	Total Learners: 118	Total Learners: 115	Total Learners: 329
Teen Cooking (2 Levels/Classes)	# of classes: 2 Total Learners: 8	# of classes: 6 Total Learners: 24	# of classes: 10 Total Learners: 40	# of classes: 17 Total Learners: 69
Caregiver Yoga	# of classes: 2 Total Learners: 25	# of classes: 4 Total Learners: 23	# of classes: 5 Total Learners: 36	# of classes: 11 Total Learners: 84
Open Support	# of classes: 1 Total Learners: 6	# of classes: 2 Total Learners: 15	# of classes: 2 Total Learners: 13	# of classes: 5 Total Learners: 34
Little Art		# of classes: 4 Total Learners: 32	# of classes: 8 Total Learners: 60	# of classes: 12 Total Learners: 82
Parent Cooking	# of classes: 2 Total Learners: 20	# of classes: 4 Total Learners: 40	# of classes: 4 Total Learners: 38	# of classes: 10 Total Learners: 98
Little Yoga		# of classes: 1 Total Learners: 5	# of classes: 4 Total Learners: 23	# of classes: 5 Total Learners: 28
Teen Movement		# of classes: 1 Total Learners: 11	# of classes: 4 Total Learners: 39	# of classes: 5 Total Learners: 50
Little Movement	# of classes: 3 Total Learners: 12	# of classes: 3 Total Learners: 15		# of classes: 6 Total Learners: 27
Teen Yoga	# of classes: 2 Total Learners: 27	# of classes: 3 Total Learners: 27		# of classes: 5 Total Learners: 54
Girls Yoga		# of classes: 4 Total Learners: 14		# of classes: 4 Total Learners: 14

Section 2: Implementation Guidance

STAKEHOLDER EMPOWERMENT & COLLABORATION

The partnership between DOH and St. Joseph's is a very dynamic and true partnership. St. Joseph's is fortunate to have additional support from SPAN who connects with parents and prepares parents for telehealth appointments. SPAN helps our families engage in telehealth services. SPAN has assisted families from the BAC, diabetes, and Cystic Fibrosis. SPAN calls to make sure the telehealth connection is secure; the app is working, and families understand how to get on the call. SPAN works hard to provide parent support during the day, but we identified the biggest challenge is that during the day families are focused on school and work, so to pull away and attend something at lunch is difficult. As the programs evolve, all partners continue to collaborate and share what they learn to improve programming and to better support parent involvement.

REPLICATION

Within BAC, this practice has been replicated to include new class types and sessions. To replicate this program externally, it begins with having a dedicated team. The BAC team was willing to learn the necessary IT to facilitate virtual programming; we learned the difference between WebEx, Zoom and FaceTime real fast. The team became savvy controlling the virtual room, muting everyone so it was not chaos as we were setting up the activity for example. Families needed patience and support so the BAC team would email out directions for logging into virtual sessions, screen shots of what they should expect to see as they followed the directions. We must acknowledge that the success of the program is directly correlated to the relationship the BAC team has



with the BAC families. A trusting relationship is at the core of our success, our families trust us with their children, their time and their feelings. Our families were unsure if their child would do well learning and participating virtually but they hung in there with us and together we were successful. The BAC team learned to open the rooms 15 minutes ahead of the session so they could take attendance parents could work out IT issues and the learners could say hello and talk with their peers. For parent presentations and workshops opening the room up earlier allowed for parent to connect, support one another and network. Preparing for virtual services takes great coordination, parents had to pick up weekly supplies for each and every activity their child or themselves was going to participate in that week. The BAC team did an amazing job organizing supplies and pick up times so everyone was prepared for weekly individual and group sessions. Parent pickup allowed for the team to “see” the parent and have a quick conversation and check in. As always if we had a larger team, more staff it would be easier and we could treat more learners and their families.

INTERNAL CAPACITY

“It takes a village” is the best way to describe the personnel needed to support this program. The Program Coordinator, Kathleen Moran, ABA, team Social Worker, Carmen Valentin, MSW, team Registered Behavior Technician, Hillary Clemente represent the core of the BAC team. In addition to the core we have a per diem art therapist and another ABA therapist who facilitate individual and group sessions. Our outside facilitators are all a great match for our populations, the trained chef who leads cooking is a Special Education teacher, our Yoga instructor has a certificate in working with special needs children and our karate school specializes in teaching karate to autistic children. It took everyone one of these dedicated, talented staff to make our program a success. Each team member is gifted at establishing a therapeutic relationship with the learner and his/her family. The BAC had full support from Executive Leadership at St. Joseph’s Health, we had laptops and IT support as needed to launch our virtual program. The department secretaries were instrumental in registering the families and making sure the patient was in the virtual room for their medical appointments with providers. Our virtual program is comprehensive and all services are directed toward meeting the therapeutic goals of the learner and family.

PRACTICE TIMELINE

The table may not accurately reflect that every activity was planned with a therapeutic goal, all activities are purposeful. Each session takes time for planning, writing a curriculum, organizing supplies and parent pick up, registering the participants and assessing if they are appropriate for the activity, facilitating the event and documenting the event in the learner’s EMR. It is a very parallel process as we are in the middle of a group cycle we are already planning for the next cycle of groups, it is continuous. The skill level of the learner is always taken into account to ensure we are mapping the learner to the appropriate services. Data and feedback for groups is necessary to help plan for the next round of programming for the learner.



Phase: Planning/Pre-Implementation

Activity Description	Time Needed	Responsible Party
Wellness calls to families- checking in how families were doing March 2020	Hours each day, phone calls, making notes, comparing what we learned	BAC team and manager
Planning-using feedback from families to decide what is next	Weekly meetings to plan, assess, edit, secure resources, shop etc.	BAC team, everyone facilitated sessions

Phase: Implementation

Activity Description	Time Needed	Responsible Party
Individual session- session, planning, documentation etc.	For each session, 2 hours.	ABA, RBT, MSW etc.
Group session- planning, shopping, parent pick up session, documenting etc. Cooking, Art. Social skills, etc.	For each group 3 hours	BAC team and outside facilitators
Parent support services- planning documenting	Open support 2 hr. per week Each event 2-3 hours	BAC team



Phase: Sustainability

Activity Description	Time Needed	Responsible Party
Planning & assessing & tracking	Ongoing	BAC team
Billing- all BAC team members credentialed and will be billing for services	Ongoing	BAC team, medical secretary and billing department
Nurturing & maintaining relationship with program donor and DOH	Ongoing- keeping everyone informed	Manager

PRACTICE COST

The practice cost varies based on the services being offered at the time, for example offering cooking group is costly due to the cost of art supplies needed for weekly projects but social skill group is not as costly since it is more focused on personal engagement with conversation, board games etc. Also, the cost of outside facilitators, for example, Special Dragons karate is \$1000 per month for classes three times a week for 15-18 learners per class. Family bingo nights for example we purchase the bingo supplies and prizes it could be \$500 for 30 families to participate. To start a yoga program we had to purchase yoga mats and blocks for each learner and pay an outside trained facilitator. The cost depends directly on the service being offered, and allows the organization to be flexible in rolling out virtually programs that meets and adjusts to budgetary and family needs.

Budget

Activity/Item	Brief Description	Quantity	Total
Cooking class	Weekly supplies for cooking class- all food items needed to make the recipe	8-10 learners per group x \$20 per week per learner	\$200 x 8 = \$1,600 per week



Karate class	Contract with Special Dragons to provide lessons virtually	15-18 learners, three sessions per week	\$1,000.00 per week
Family BINGO night	Purchase supplies and surprises for virtual BINGO	30 families	\$500 per event
Total Amount:			Varied

LESSONS LEARNED

The original plan had been to provide more traditional mental health services, but the classes were the most popular and has expanded how we think about mental health supports. For example, during a parent baking class, as the pies are baking, parents are talking in a group with a therapist. The parents and caregivers need respite and this is achieved during parent cooking, baking and yoga classes. All classes are dedicated to supporting and connecting with the parent. All virtual programming has a therapeutic value (they are not drop-in classes); all provide support to families and provide activities for the learners. We learned that cooking is better when the learner is in the home environment. Learners can generalize what they learn in the cooking lesson more effectively if they learn and practice in their home kitchen.

NEXT STEPS

We have learned that virtual programming is effective and we will continue this throughout our summer camp in July. Summer camp is typically in-person, but our space is limited in effort to keep everyone safe and we will continue virtually in July and offer half day sessions of summer camp. Learners will have a variety of modules, life skills, social skills, movement etc. In August, we will transition to a hybrid model maintaining some virtual and bringing some components back in-person. We want to support the learners as they prepare to return to school in the fall and summer camp provides an opportunity for them to practice in-person learning once again.

RESOURCES PROVIDED

References

Cutler, E. (2004). A thorn in my pocket: Temple Grandin's mother tells the family story. Future Horizons.

Gelormini, C. (2021). Robbie's world: And his spectrum of adventures! Book 1.

Gelormini, C. (2021). Robbie's world and his spectrum of adventures! Book 2.

Gelormini, C. (2021). Robbie's world and his spectrum of adventures! Book 3. Xulon Press.

Grandin, T., & Panek, R. (2014). The autistic brain. Ebury Press.



Martin, N. (2009). Art as an early intervention tool for children with autism. Jessica Kingsley Publishers.

APPENDIX

