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MCH Innovations Database Practice Summary & Implementation Guidance

Autism Diagnostic Clinic

Easterseals Autism Diagnostic Clinic increases efficiency, reduces wait time and eliminates geographic barriers by bringing together developmental specialists and clinicians using a virtual healthcare model to evaluate children 18 months to 3-years old in the comfort of their homes.

Cutting-Edge

Emerging

Promising

Best



Location

Pennsylvania



Topic Area

Health Screening/Promotion



Setting

Home-based



Population Focus

CYSHCN, Health Care Providers



NPM

NPM 6: Developmental Screening
NPM 11 Medical Home and NPM
15 Adequate Insurance



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Section 1: Practice Summary

PRACTICE DESCRIPTION

In 2018, the Autism Diagnostic Clinic (ADC) was a pilot program conducted as a hybrid telehealth model. Caregivers and their toddler arrived in-person at our clinic in Reading, PA where a trained examiner administered a play-based assessment called the ADOS (Autism Diagnostic Observation Schedule). Offsite, using an advanced camera system, a developmental nurse practitioner and a developmental pediatrician observed child and clinician interactions as well as caregiver and child interactions. Clinicians then discussed the intricate scoring based on each other's shared conclusions. This model reduced cost and travel time and created an easily accessible alternative to our community. In 2020, the COVID-19 pandemic interrupted services and necessitated the implementation of a fully virtual model, which resulted in a dramatic improvement in delivery and effectiveness. It is now our preferred method of operation.

Easterseals Eastern Pennsylvania primarily serves families with lower incomes and provides its specialty medical clinics at no cost. We partner with six different county Birth to Three Early Intervention systems to provide early autism identification. Toddlers in the Early Intervention system have already been identified with a developmental delay or disability. The child is further assessed using the M-CHAT autism screening tool to determine his/her risk factor for Autism Spectrum Disorder. Children who score 8 or higher are referred to Easterseals Autism Diagnostic Clinic (ADC) for an evaluation. The ADC provides a virtual, home-based model so that families do not have to travel for services, the child is evaluated in familiar surroundings, and geographic barriers are eliminated. The wait time for an evaluation with Easterseals ADC is less than nine months while wait time through other clinics and hospitals is over one year. The average age of children diagnosed through Easterseals is age 2, while the national average is age 4.

Easterseals contracts with diagnosticians from Children's Hospital of Pennsylvania (CHOP) and St. Christopher's Hospital for Children to conduct the evaluation virtually in partnership with its clinicians. Both the St. Christopher's psychologist and Easterseals autism program manager are bilingual in Spanish. This allows us to effectively reach a wider audience of people who are underserved. The psychologist provides an educational classification, reducing the need for an additional evaluation through the local intermediate unit (ages 3-5 Early Intervention). A written order for behavioral health services is also provided, reducing the need for an additional evaluation through the behavioral health system. As appropriate, we can conduct the Vineland Adaptive Behavioral Scale, sometimes required for IDD (Intellectual and Developmental Disabilities) case management services.

We did some preliminary observation with the CATCH TEAM Chester Intermediate Unit. They had a solid program using a multidisciplinary model to evaluate children for Autism. Referrals came through the Birth to Three Early Intervention unit. Our model of evaluating the child in their natural setting aligns with the PA EI guidelines. We also have a framework for clinics that dates back to the early 1990's with a long standing relationship with St. Christopher's Hospital for Children. Our fully virtual practice also came out of COVID pandemic necessity



CORE COMPONENTS & PRACTICE ACTIVITES

The goals of the ADC are to provide early and high-quality diagnostic services to young children at risk of autism spectrum disorder, and to address many of the barriers to accessing this service (ie. long wait times, no local providers, cost). Furthermore, this program relies on a culturally and linguistically responsive model and incorporates a multidisciplinary referral process. The accurate and early diagnosis of neurodevelopmental disorders is a critical element to identifying comprehensive and evidence based treatment protocols. The ADC strives to achieve these goals by relying on the following core components:

1. Establishing partnerships with local early intervention agencies, the department of health and Medicaid system to ensure an efficient, supportive and seamless referral process that does not impose socioeconomic/insurance based barriers or leave referral or treatment gaps on either end of the process.
2. The use of standardized diagnostic tools and telehealth processes administered by qualified professionals skilled in the assessment of neurodevelopmental disorders.
3. The incorporation of a program manager to provide technical and administrative assistance prior to and following the evaluation to decrease attrition, increase follow-through, and ensure reliable data collection.

Core Components & Practice Activities		
Core Component	Activities	Operational Details
Establish community partnerships	Develop efficient and streamlined referral systems both before and after engagement with the ADC	<p>Pre-Evaluation Phase: Establish referral processes with community providers that includes pre-screening/identification of need to ensure accurate referral.</p> <p>Post-Evaluation Phase: Facilitate re-engagement with intervention system during “warm hand off” back to therapy teams (both through early intervention and community behavioral health systems).</p>
Utilize standardized tools and best practices	Introduce telehealth model using evidence-based telehealth diagnostic tools and processes	Accurately assess neurodevelopment using best practice in telehealth processes and standardized tools (e.g., TELE-ASD-PEDS: Corona et al., 2020), thus eliminating geographic obstacles or barriers to accessing highly trained specialists (also see Stainbrook et al., 2019; Juarez et al., 2018).
Incorporation of key program manager role	Provide technical and administrative assistance to families prior to and following evaluation	Provide support and facilitate access to technology for telehealth assessment during pre-evaluation consult (eliminating technology barriers) and ensure pre-data collection and administrative activities are completed (consents). Facilitate re-



connection and communication of recommendation/results with intervention/treatment team in post-evaluation phase.

HEALTH EQUITY

To address health inequities experienced by our primary target audience, we pay close attention to the barriers present in our community and across the region. We partner with the Birth to Three Early Intervention system to intentionally identify children under the age of three who may be at risk of Autism Spectrum Disorder. With a virtual service delivery model, transportation challenges and traveling long distances are avoided. Utilizing Title V funding, we are able to provide services at no cost to the family. Our bicultural, bilingual staff engender tolerance, acceptance and adaptability, and are better able to meet the unique cultural needs of the people we serve (many Spanish speaking families). We maintain a simple referral process with care coordinators guiding patients and their families through each step. This includes a carefully executed prep meeting that takes place a couple of days prior to the evaluation. This meeting creates shared understanding, anticipatory guidance and enhances parent engagement. Our marketing materials, referral forms and flyers are produced in both English and Spanish. In addition, the recommendations section of the written evaluation shared with the family includes a list of autism resources available in Spanish.

Beginning Fall 2022 we will be working with an organization called The Color of Autism and UCLA's Center for Autism Research & Treatment. The Color of Autism is an advocacy group focused on empowering African-American families with information on autism so that they can serve as their children's first and greatest advocates. They provide education, advocacy, and support lessening the stigma associated with autism spectrum disorders and reducing the feelings of isolation and intimidation that many African-American families confront when seeking services for their children. UCLA Center for Autism Research and Treatment is dedicated to improving the lives of all children and adults with autism, and their families, through its research, patient care, and training of the next generation of researchers and clinical practitioners. They are conducting an NIH study, Autism Genetics & Human Diversity Project, aimed at better understanding autism spectrum disorders within African-American families.

EVIDENCE OF EFFECTIVENESS

The summative evaluation plan includes a non-experimental evaluation design with a pre- and post-assessment and qualitative data analysis. Data collection methods include surveys, direct observation of diagnostic evaluations, and 1:1 interviews with parents to gather testimonials on how the program is addressing participants' needs. Surveys will be administered both before and after participation in the diagnostic clinic to determine the degree to which the program is helpful to participants. Through the support of the PA Dept. of Health, we have secured AJ Drexel Autism Institute to conduct a thorough program evaluation for future sustainability and replicability of the ADC.

Process Evaluation

- Did the program deliver a diagnostic evaluation for parents seeking a medical diagnosis for their child under the age of three?
- Did the program deliver a diagnostic evaluation in a timely manner (9 months or less)?



- Were parents/guardians comfortable with the evaluation being virtual?
- Were program participants comfortable with clinicians during the evaluation? language spoken, credentials of diagnostician
- Did the preparatory meeting prior to the diagnostic evaluation create greater confidence and competence/provide anticipatory guidance for the caregiver?
- What helps and hinders implementation of the ADC program?

Table 1

Activity	Variable	Measurement	Frequency
Virtual Autism Diagnostic Evaluation; referrals come through 0-3 Early Intervention system	<ol style="list-style-type: none"> 1. Virtual or in person (Caregivers have a choice to attend an in-person eval through another provider or choose the ADC) 2. Age at time of referral 3. Wait times vary, parents have a choice of setting for eval 	survey/interviews wait time (from date of referral to actual evaluation day)	One session per child
Preparatory Meeting	Perceived anticipatory guidance	survey, focus group, affinity group, 1:1 interview regarding confidence in upcoming evaluation	One session per child, prior to evaluation day
Post-Evaluation Follow-Up	Participation	Interview	Once, after the diagnostic evaluation
Currently funded through PA Dept. of Health	funding limited and not sustainable	Cost to execute vs Insurance reimbursement	Time limited through 2023

Impact/Outcome Evaluation

- What percentage of participants diagnosed with ASD accept offer to attend ABA Parent Coaching program?
- What percentage of children referred to ADC were under the age of three by the time they received the diagnostic evaluation?
- Did participants report satisfaction with the tele-health/virtual diagnostic evaluation?
- Did the preparatory meeting provide sufficient anticipatory guidance to feel prepared for the upcoming diagnostic evaluation?



Table 2: INSERT VALID TOOLS FOR COLUMN 4

Activity	Variable	Operationalization (sample question)	Instrument (citation)
Diagnostic Evaluation	Perceived Stress	“In the last month, how often have you dealt successfully with irritating life hassles?”	Cohen S, Kamarck T, Mermelstein R. Perceived stress scale. <i>Measuring Stress: A Guide for Health and Social Scientists</i> . 1994;10(2):1–2. *known to have particularly good psychometrics for caregivers of children with autism
Preparatory Meeting	Satisfaction	“My general feeling about this service’s ability to respond to my child’s needs is: ___” *5-point scale (1=very dissatisfied, 5=very satisfied)	Adapted from Therapy Attitude Inventory. Eyberg, S. (1993). Consumer satisfaction measures for assessing parent training programs. In L. VandeCreek, S. Knapp, & T. L. Jackson (Eds.), <i>Innovations in clinical practice: A source book</i> , Vol. 12, pp. 377–382).
Preparatory Meeting + Diagnostic Evaluation	Telehealth Satisfaction	Did the evaluator obtain an accurate picture of your child through the virtual platform?	**adapt from known source

Counties we do not serve have contacted this writer to find out how they too could have access to the ADC for their 0-3 program. Surveys are filled with positive responses from families on several key indicators. Our wait time remains less than local options. We expanded into several other counties during the COVID pandemic and did so with relative ease. The referrals we receive are ‘good’ referrals, the majority of patients who scored high on the MCHAT also were diagnosed with ASD. County administrators are pleased to have this clinic as an option for the families in their community.



Section 2: Implementation Guidance

COLLABORATORS AND PARTNERS

ESEP collaborates with hospital systems and county Service Coordination units to provide virtual Autism evaluations. Their clinical staff have the expertise and experience while the Early Intervention system provides us with our main population, toddlers at-risk of ASD.

Practice Collaborators and Partners		
Partner/Collaborator	How are they involved in decision-making throughout practice processes?	Does this stakeholder have lived experience/come from a community impacted by the practice?
Children’s Hospital of Philadelphia and their Autism Integrated Care program	CHOP demonstrated an interest in use of telehealth and was very willing to participate. They have extensive experience with ASD and have partnered with local intermediate units to provide a multidisciplinary approach to ASD diagnosis. The staff at CHOP introduced the use of the tool, TELE-ASD-PEDS (TAP). This assessment is still undergoing psychometric analysis and is used along with the CARS and the DSM-V. CHOP determines the schedule of evaluations and the appointment times, as well as the duration of the evaluation and follow up session.	Yes, CHOP has focused research on autism and works directly with toddlers and preschoolers with autism spectrum disorder.
St. Christopher’s Hospital for Children and their Center for Children and Youth with Special Healthcare Needs	When we had the opportunity to expand geographically, CHOP was not able to provide services any farther than Berks County at the time. St. Christopher’s was available and enthusiastic about contracting to expand our services to the Lehigh Valley. They have expertise in autism and other behavioral health conditions. The staff at St. Christopher’s also introduced the use of the tool, TELE-ASD-PEDS (TAP) and support the work being done by	Yes, St. Christopher’s has an expanding footprint in the Behavioral Health field and seeks to affect change across the northeast region



	Vanderbilt Kennedy Center to obtain robust validity and reliability.	
Service Access & Management, Inc. (SAM) Lehigh County, Northampton County, and Carbon/Monroe/Pike County Early Intervention	We have a relationship with these organizations through our Early Intervention contracts. In order to provide optimal support during and after the ADC evaluation process, service coordinators from SAM attend the appointment and often remain an integral part of the patient's care coordination. The service coordinators are the main point of contact and ensure the MCHAT scores, IFSP/ER and authorizations for release of information are collected. The service coordinators are rich in their knowledge of resources and focus on ways to provide care coordination and case management. We rely on their capacity to assist the families they refer to us with community resources and follow up activities after an ASD diagnosis.	Yes, SAM is Berks County's Service Coordination Unit and Early Intervention Unit. It is advantageous for the county to have a local autism clinic as this engenders trust from the community and provides a local resource for their case managers to share with families. The children they serve are 0-3, diagnosed with a developmental delay and already receiving services which address language, behaviors and other activities of daily living. Service Coordinators often have social work, infant mental health, and autism knowledge and resources.

REPLICATION

The Autism Diagnostic Clinic began in Berks County through a partnership with Children's Hospital of Philadelphia (CHOP). When additional funding was received, we were able to expand to Lehigh County, then into Northampton County and then to Carbon/Monroe/Pike (county joiner). These counties are served through Easterseals' partnership with St. Christopher's Hospital for Children. As much as possible, we replicated the program and process used with CHOP to the areas served by St. Christopher's. It was necessary to modify the intake paperwork and evaluation templates. The recommendations, which also include community resources, are tailored to the county in which the child is served.

When we began the ADC, we made assumptions about EI Service Coordination (SC) capacity based on Berks County's SC unit. Their model of case management has high productivity standards meant to maintain revenue flow but also with the intent to spend time with and support consumers as much as possible. Keeping this in mind, ESEP initially relied on the case manager to provide anticipatory guidance, participation during the evaluation itself, support during the review of results and the key person to provide additional follow up, community resources, referrals and transition information. In light of the county differences, the SC may not be able to provide as much support as originally anticipated. This compels us to ensure our Autism Program Manager and our clinicians provide robust support before the evaluation and during the evaluation. It would be ideal for us to provide on going support and /or follow up, however this is not fixed in our budget at this time. We do, however, offer caregivers the opportunity to attend our ABA Parent Coaching program. CHOP does



offer follow up at the Philadelphia location; however this is challenging due to the transportation challenges many of our consumers face.

Replication and expansion of the ADC will require funding innovations, securing billing specialists, support from managed care organizations and private insurance companies. Through the professional program evaluation we also believe there will be enough substantive evidence of success to justify replication.

INTERNAL CAPACITY

The Pennsylvania Department of Health appoints a Program Coordinator to manage the administrative aspects of our AMCHP grant. The Program Coordinator was instrumental in the development and launch of the Autism Diagnostic Clinic. The role of the Program Coordinator is to foster relationships between the medical practitioners, the Early Intervention Coordinators, and any other personnel involved in creating contracts. Relationships were established between Children's Hospital of Philadelphia and Easterseals Eastern PA and a new partnership was formed with St. Christopher's Hospital for Children when the program expanded. To achieve the goal of identifying children at risk of autism as early as possible, referrals come from the Birth-3 Early Intervention system. This allows for a streamlined process of referrals coming from only one entity.

Grant funding supports the salary for an Autism Program Manager, who coordinates referrals, team participation, and the physicians' schedules. The Autism Program Manager is a full-time position, with the majority of time spent preparing for evaluations, attending evaluations, and ensuring proper follow up. A critical component to the success of the virtual model is the time the Autism Program Manager devotes to preparing the family for the evaluation day. The Autism Program Manager needs to be highly organized and articulate as well as comfortable with different computer programs and software. Having a bilingual Autism Program Manager is a tremendous advantage in the counties we serve.

Personnel from the hospitals who complete the evaluations are developmental nurse practitioners supervised by developmental pediatricians. At St. Christopher's, a school psychologist completes the evaluation process and provides an educational classification in addition to the medical diagnosis of ASD. Diagnostic tools used during the evaluation are the following: the TAP (Tele-ASD-Peds), the DSM V (Diagnostic & Statistical Manual) and the CARS (Child Autism Rating Scale) Though practitioners are trained and experienced using these tools, soliciting feedback from the caregiver along with practitioner observation are also vital to the process.



PRACTICE TIMELINE

Phase: Planning/Pre-Implementation

Activity Description	Time Needed	Responsible Party
Locate hospital system(s) or other health care entity interested in community outreach and open to telehealth. Create relationships with leaders in the county Early Intervention system for seamless referral process	2 months	Program Coordinator
Hire Autism Program Manager to coordinate day to day operations	2 months	Program Coordinator

Phase: Implementation

Activity Description	Time Needed	Responsible Party
Negotiate rates, number of evaluations per day, coordinate schedules between practitioner and Autism Diagnostic Clinic. Determine which diagnostic tools will be used to evaluate child, adopt mutually agreed upon template for the evaluation	1 month	Program Coordinator, Autism Program Manager, Hospital System Administrator
Discuss referral process, intake process and optimal ways to ensure seamless process between county service coordination units and ADC;	1 month	Program Coordinator, Autism Program Manager, EI County Coordinator



<p>Create power point to assist in training county personnel and Early Intervention provider network. Create survey to determine caregiver satisfaction.</p>	<p>1 month</p>	<p>Program Coordinator, Autism Program Manager, EI County Coordinator</p>
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Phase: Sustainability

Activity Description	Time Needed	Responsible Party
<p>Review processes and protocols for greatest efficiency and shared understanding. Create survey to determine caregiver satisfaction with program</p>	<p>Semi-annually</p>	<p>Hospital partners, Autism Program Manager, Program Coordinator and other stakeholders</p>
<p>The ADC is currently fully grant funded. For sustainability, we need to have the program professionally evaluated for its replicability and seek avenues to bill insurance (both private and public) in order to decrease reliance on grant funds.</p>	<p>Program Evaluation takes approximately one year.</p>	<p>A.J. Drexel Autism Institute, PA Dept. of Health, Easterseals Eastern PA (specifically senior leadership). Managed Care organizations</p>
<p>Demonstrate program effectiveness, positive outcomes, community impact, integrate the ADC into established systems (behavioral health, medical, educational perhaps)</p>	<p>6 months – one year</p>	<p>Research associates from A.J. Drexel Autism Institute, PA Dept. of Health</p>



PRACTICE COST

Budget			
Activity/Item	Brief Description	Quantity	Total
Salary & Wages	Autism Program Manager (full time position; manages two Autism programs at ESEP)	1 full time program manager	\$60K/year
	Program Coordinator (position supervises multiple programs; % of salary allocated to this budget)	1 part time program coordinator	\$25K/year
Contracted Services	Hospital/health care partners	One year, 12 evaluations per month @\$1,000 per evaluation	\$120K/year
Total Amount:			\$205,000/year

LESSONS LEARNED

The role of the Autism Program Manager is key to the success of this program. This person must know the culture of the community, be well versed in the Early Intervention system, and if applicable, speak two languages. What we would do differently, however, would be to hire a program manager who was licensed as a BCBA or LSW possibly. If we had this, we could have used more interns and provided the local universities with field work experiences. This would elevate the investment we've made to include additional community impact. We currently contract with two different hospital systems. We recommend locating one contractual agent to avoid the cumbrances associated with two separate contracts, staffing changes, reimbursement rates, processes, etc.

The biggest challenge is finding a partnering physician group that can work within the means we have as a non-profit agency. We are tight with our budget, our staffing, and are beholden to the Birth to Three entity that provides us with the referrals. We started with one hospital system and did not contract with another one until we had a smooth process established with the first. Negotiating was simpler than we had anticipated, especially because the leaders we worked with were highly invested in similar outcomes...."to ensure children are identified with ASD prior to age 3".



When we began this enterprise, we had a very short window of time to plan and were under strict timelines to utilize funding. We began with a budget and planned the practice out accordingly. Working backwards has always felt like we were chasing our proverbial tails. It is much better to complete the foundational work necessary and build the budget around the known factors.

As mentioned prior, county differences need to be taken into account during the implementation phase. How each county executes their Birth to Three EI program, Service Coordination expectations, caseload size, and other factors that influence the user experience.

NEXT STEPS

Working closely with the PA Department of Health, they have now secured a master contract with AJ Drexel Autism Institute for a professional program evaluation of the ADC. As we continue to serve our community using DOH funding, we also want to find long-term, sustainable options for funding. This may include using medicaid dollars and private insurance in conjunction with grant funding. We also hope to find the means to bill insurance for the work being done and then expand the ADC to other counties within our catchment area. The DOH has plans to expand the ADC throughout the Commonwealth, utilizing Easterseals Eastern PA as a hub for training.

We hope to be a resource to the families with children ages 3-5 and provide them, too, with a virtual diagnostic option. Billing insurance while utilizing some DOH funding could allow us continuity in practice along with the staffing expense of a program manager. Survey creation, analysis, and feedback loop needs to be honed and monitored more closely.

RESOURCES PROVIDED

<https://mchatscreen.com>

Diagnostic & Statistical Manual of Mental Disorders (DSM 5-TR)

<https://vkc.vumc.org/vkc/triad/tele-asd-peds>



APPENDIX

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