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MCH Innovations Database Practice Summary & Implementation Guidance



Early Intervention Caregiver and Provides Support Services (EI CAPSS)

EI CAPSS works within the state's existing Part C system to provide caregiver and provider coaching around evidence-based intervention practices for young children with autism, increasing access to high-quality services for children in rural and under-served populations or areas.



Location

Nashville, TN



Topic Area

Family/Youth Engagement;
Telehealth/Emergency
Preparedness; Service
Coordination/Integration



Setting

Community



Population Focus

CYSHCN;
Families/Consumers



NPM

Not applicable.



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Section 1: Practice Summary

PRACTICE DESCRIPTION

As the prevalence of autism spectrum disorders (ASD) has continued to rise, Part C systems have seen an increasing demand for autism-focused diagnostic and early intervention services. However, numerous barriers impact families' access to care, even for those families actively engaged in their Part C system. Due to the limited availability of diagnostic providers outside of larger cities or communities, access to these specialty evaluations often requires significant travel and/or time spent on a waitlist for an appointment. Furthermore, therapies recommended for most children at the time of ASD diagnosis (i.e., Applied Behavior Analysis (ABA) provided under the direction of a board certified and licensed behavior analyst) are similarly difficult to obtain due to provider availability. Addressing these barriers requires creative approaches that leverage both existing service systems and novel tools for reaching families.

Our Early Intervention Caregiver and Provider Support Services (EI CAPSS) were developed through a partnership between the Vanderbilt Kennedy Center's Treatment and Research Institute for Autism Spectrum Disorders (VKC TRIAD) and the Tennessee Early Intervention System (TEIS), Tennessee's Part C system. This partnership, begun in 2014, has resulted in innovative programming that provides families access to tele-diagnostic evaluations for ASD and brief, focused education and support opportunities. Families engaged in EI CAPSS are referred for a traditional or tele-diagnostic evaluation by their Part C service coordinator. Following the diagnostic appointment, eligible families are offered 6 follow-up education and support sessions with a TRIAD behavioral consultant to debrief the outcome of the diagnostic evaluation and support caregiver-identified goals for the child and family. These goals are generally related to communication development, behavioral support needs, social play skills, toilet training, or sleep challenges and are guided by TRIAD developed curriculum modules. These modules were developed to address frequent concerns of caregivers, emphasize family-centered and routines-based intervention strategies, and facilitate individualization of supports to the unique needs of each child and caregiver.

In addition to caregiver education and support opportunities, EI CAPSS aims to support Part C providers already providing services (e.g., developmental therapy) to participating families. TRIAD consultants collaborate with these providers throughout the delivery of the 6 follow-up visits and are available for ongoing coaching and consultation. EI CAPSS also offers professional learning communities to providers throughout each year. Online curriculum modules have also facilitated the dissemination of evidence-based practices to families and service providers across the entire state.

EI CAPSS prioritizes use of telemedicine practices to extend services to families living in geographically rural and under-resourced communities. Telemedicine applications have facilitated TRIAD psychologists and behavioral consultants in serving a higher volume of families and providers



in their most natural environment. Furthermore, telemedicine has helped to eliminate geographical barriers for families that may otherwise be unable to access such specialized services.

CORE COMPONENTS & PRACTICE ACTIVITIES

The goal of our program is to improve access to early diagnostic evaluations for autism and specialized behavioral intervention services. We have done this by developing a telemedicine model for diagnostic evaluations and caregiver education and support services while partnering with our state’s Part C system to implement, evaluate and refine these services to best meet the needs of families across diverse communities. Core components of this program include a telediagnostic evaluation model that utilizes the caregiver-mediated TELE-ASD-PEDS (TAP) and a 6-visit caregiver education and support service (EI-CAPSS) that can be delivered in person or via telemedicine. Additional core components include topic-focused curriculum modules available in both print and online, interactive course formats.

A second goal of our program is to increase capacity of Part C developmental therapists to support families of children with ASD or related developmental concerns. Core components of this sector of the program include collaborative delivery of the 6-visit caregiver education and support series, availability of behavioral consultants for ongoing consultation with Part C providers, the curriculum modules detailed in the paragraph above, and opportunities to engage in professional development.

Core Components & Practice Activities		
Core Component	Activities	Operational Details
Telediagnostic Evaluation	Telemedicine-based screening and evaluation for ASD	Connects psychologists to caregivers and young children through use of video-conferencing technology. Utilizes the caregiver-mediated TAP to evaluate for ASD. Medical background and other screeners are collected in advance of the visit. At the conclusion of the appointment, families are provided with a diagnostic outcome or, for a small percentage of families, referred for a full diagnostic evaluation.
Caregiver Education and Support Services	6-visit caregiver education and support series provided in person or via telemedicine	Connects behavioral consultants (i.e., experts in early childhood development, special education, speech language pathology, and/or behavior analysis) to caregivers and their young children recently evaluated for ASD. Visits are guided by



		caregiver priorities and utilize topic-focused curriculum modules to facilitate sharing of information and individualization to the unique needs of the caregiver and child.
Provider Collaboration	Collaborative delivery of caregiver education and support services.	Connects behavioral consultants to Part C providers to collaborate throughout the delivery of EI CAPSS to build the capacity of Part C providers and facilitate continuity of services for each family as the 6-visit series is completed.
Provider Education and Support Services	Virtual professional learning communities (VPLC)	Connects Part C providers to virtual professional learning communities (VPLCs) that combine small group learning with coaching and consultation.
Early Intervention Curriculum Modules	Topic-focused curriculum modules intended to support caregivers and providers in learning and applying evidence-based strategies to address areas of concern.	Curriculum modules are developed to be general enough that the information is applicable across a wide range of children but also easily individualized to meet each learners' unique needs. Modules are available in print or interactive, online-course formats. Current topic areas include communication development, behavioral support needs, social play skills, toilet training or sleep challenges. Brief modules are available on additional topics (e.g., transition from Part C to Part B) as well.

HEALTH EQUITY

The EI CAPSS model has increased timely access to care for families, most of whom come from rural and under-resourced communities where specialty care can be difficult to obtain. The use of novel teleradiologic technology has alleviated significant geographic, financial, and time barriers associated with tertiary diagnostic referrals. Families whose access to care otherwise would have been limited by prohibitive distance, transportation difficulties, time constraints, and/or safety concerns have been able to connect with diagnostic services within the comfort of their homes or other familiar spaces.

Furthermore, this model of service delivery has significantly shortened wait times, ensuring that families truly obtain access to care, and not simply a waitlist/queue; prior analyses showed that our use of telehealth reduced the time between initial referral and evaluation by up to a year (Stainbrook et al., 2019). Similarly, the EI CAPSS model has allowed families to access education and support



related to evidence-based intervention strategies, which can be exceedingly difficult to find and access especially in rural and under-resourced communities.

A key cornerstone of our model is our unique partnership with TEIS, Tennessee's statewide Part C system. By collaborating with this state system and prioritizing capacity building among Part C providers, we are able to provide and strengthen support for families outside of the constraints of traditional healthcare reimbursement models. Rather than placing the burden on families to find and connect with providers or navigate complicated referral systems and coverage limits, our program provides families with specialty care as part of their existing Part C service plans. Furthermore, our focus on situating and delivering care in the context of established relationships (e.g., actively involving Part C providers in the tediagnostic evaluation and caregiver education and support visits) allows us to build on existing trust rather than requiring families to seek services from unfamiliar providers or a healthcare system that has not earned their confidence. Recognizing the longstanding structural and systemic inequities in healthcare, positioning care within the framework of Part C services provides a more just opportunity for families to access support regardless of their location, income, insurance status, level of education or health literacy, or cultural background.

Our model also maintains a family-centered approach. Since primarily shifting to direct-to-patient telehealth services, EI CAPSS diagnostic and intervention services have centered around caregiver-mediated activities in a child's natural environment. Clinical observations and follow-up support/caregiver coaching occur within the context of a family's typical routines, with trained consultants coaching families to embed specific observation and intervention strategies within. This approach shows respect for families' own culture, values, and traditions and affirms their important role in decision making and care. Telehealth interpreter services and bilingual staff are also crucial in ensuring services are culturally effective for families who primarily speak languages other than English. Finally, through a focus on both child and caregiver goals (with an emphasis on skill acquisition and building rather than simply highlighting challenges), EI CAPSS services aim to provide families with compassionate care built around families' unique values and priorities.

EVIDENCE OF EFFECTIVENESS

We collect data across the core components of our program including tediagnostic evaluations, caregiver and provider support services (child outcomes and caregiver satisfaction), and module usage.

Telediagnostic Evaluations

Previously, we have assessed several aspects of our tediagnostic evaluation model, including diagnostic accuracy and validity, feasibility of implementation, psychologist and caregiver satisfaction, clinical value, and service system outcomes (e.g., impact on regional referrals, families' abilities to access care). These evaluations have demonstrated that:

- Telediagnostic evaluation can be used to accurately identify a significant proportion of young children with ASD (78.9% of children who ultimately received ASD diagnoses based on blinded full diagnostic evaluations) with no children inaccurately classified as having ASD.



- Most families participating in our feasibility studies (91%) provided anonymous ratings indicating very high levels of satisfaction with the telediagnostic evaluation model. In addition, they reported saving an average of 3.92 hours ($SD = 1.59$, range = 1-7 hours) of travel time.
- A considerable increase in referrals for ASD evaluations following introduction of our telediagnostic evaluation model (56.76% total increase from the previous year). At the same time, we noted a 64.86% decrease in referrals to tertiary ASD clinics.
- Introduction of our telediagnostic evaluation model also resulted in significantly decreased waits for families, making a difference of up to a year in the time between referral and evaluation, and significantly increased show rates.

Most generally, the implementation of telediagnostic evaluation services has resulted in decreased wait times for families, increased access within their own communities, and high levels of satisfaction from both caregivers and service providers. Additional details can be found in the References section (see below) under *“Telediagnostic Evaluation Publications”*.

Caregiver and Provider Support Services

Since the initiation of the program in April 2014, EI CAPSS has served over 1000 families. We assess several aspects of our caregiver and provider education and support programs, including treatment fidelity, consultant and caregiver satisfaction, child outcomes, and modality effectiveness/satisfaction. An outline of these measures and some basic outcomes is provided below. Additional information can be found in the resources section.

Treatment fidelity

Treatment fidelity is assessed using a checklist outlining skills introduced in each curriculum module. Generally, each session includes three to five objectives. Objectives are related to specific strategies and caregiver implementation of strategies with their child (e.g., “identify how your child is communicating,” “identify next steps for communication”). Caregivers frequently reach high levels of treatment fidelity within targeted curriculum modules.

Caregiver, EIP, and consultant satisfaction surveys

An internally developed 14-item questionnaire assesses caregiver and EIP satisfaction with the service model and consultant, as well as perceived impact on self and child (e.g., “The consultant was knowledgeable about interventions”). Caregivers generally report high levels of satisfaction with the consultant, the information learned, and the program.

Child outcomes

Caregivers and TRIAD Consultants were asked to complete several rating scales at the beginning and conclusion of services. Measures included Clinician Global Impression scales tailored to this program, and published measures such as the Communication and Symbolic Behavior Scale-Developmental Profile (CSBS-DP) (Wetherby & Prizant, 2003) and the Macarthur-Bates Communicative Development Inventory (MCDI)- Short Form (Fenson et al., 1993).

On a Clinician Global Impressions scale measuring child outcomes caregivers and TRIAD consultants reported improvements in children’s functioning across seven areas where families of children often experience challenges (e.g., behavior, communication).



Across all groups, caregivers reported specific improvements in child communication development, as measured by the MCDI and CSBS-DP. Caregivers reported statistically significant increases across all composite scores on the CSBS-DP from pre- to post-intervention. (See Graph 1 & Graph 2 in Appendix)

Provider outcomes

We evaluate Part C system acceptance through the administration of satisfaction surveys to Early Intervention Providers (EIPs). EIPs consistently reported high levels of satisfaction across a variety of areas, such as the utility of recommendations provided, consultant expertise, improvement in child skills, and service outcomes.

Early intervention providers participating in the professional development component of this program were asked about their satisfaction with programming following the completion of the trainings. These providers also reported high levels of satisfaction with the training model and content of the trainings.

Early Intervention Curriculum Module Usage

To date, TRIAD's Early Intervention team has developed 30 basic online training sessions. The majority of these are embedded within curriculum series that focus on common challenges faced by caregivers and providers for children with autism spectrum disorder or related developmental disorders.

During the 2020-21 fiscal year, these modules were viewed and completed 2396 times by 521 unique users. Modules can be accessed by creating a free account at www.triad.vkclearning.org.

PRACTICE COLLABORATORS AND PARTNERS

TRIAD has had a lengthy partnership with TEIS focused on supporting young children with ASD, their families, and their services providers. We attribute much of the success of the EI CAPSS model to our ability to embed within this existing system of care for infants and toddlers with developmental delays and disabilities. Our partnership was initiated in 2014 from a shared interest in increasing access to early identification and intervention services for young children demonstrating characteristics of ASD. Early on, we met extensively with Part C leadership as well as service coordinators and early intervention providers within our community to develop a model that would best meet the needs of children and their families. Initially, these support opportunities were limited in accessibility to those living closest to Vanderbilt University Medical Center or in other highly resourced communities. We began with a small geographic region surrounding our medical center home with the intention of scaling up as soon as we were able to demonstrate optimal outcomes with the established model.



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?
Part C Leadership	<p>We meet with our state’s Part C leadership representative(s) every quarter to share data on service reach and outcomes. We collaboratively use this data to inform needs for modification and new service line development.</p>	<p>Yes, Part C Leadership oversees family access to early intervention services across the entire state and supports Part C services providers. They are responsible for monitoring and addressing quality in the delivery of services.</p>
Part C Service Providers	<p>Service Coordinators (i.e., case managers) and Developmental Therapists (i.e., early intervention providers that provide general developmental therapy services) are sent needs assessment and feedback surveys at least 1 time each year. Developmental therapists also have opportunities to complete satisfaction surveys each time they engage in services with TRIAD. When beginning our program, we sought feedback from providers about the needs of the families they serve through stakeholder meetings.</p>	<p>Yes, Service Coordinators and Developmental Therapists engage directly with the families and children seeking diagnostic evaluation and specialty intervention services. These providers are typically engaged with families from point of entry until the child turns 3 years of age.</p> <p>We have made several changes to our program (e.g., developing curriculum modules for common areas of concern, and increased options for provider education) based on feedback from this group.</p>
Caregivers	<p>Caregivers are asked to complete a series of feedback surveys at the completion of services. Surveys address caregiver perceptions of child growth, caregiver confidence and competence implementing supports introduced through services, and general satisfaction</p>	<p>Yes, caregivers are the primary care providers for the children receiving services from the program.</p> <p>Feedback from caregivers suggested the expansion and acceptability of increased telehealth service provision.</p>



	with the service models and providers.	
TRIAD Psychologists	We meet regularly with lead psychologists within our organization to discuss items such as waitlists, referral and scheduling needs, satisfaction with the diagnostic process for both providers and caregivers, and potential next steps.	Yes, our psychologists provide diagnostic evaluations for families of children demonstrating characteristics of autism.
TRIAD Behavioral Consultants	TRIAD Behavioral Consultants meet bimonthly to discuss family and provider support needs. They also complete pre and post data related to caregiver and child outcomes with each family served. Data is shared with the team on a regular basis to inform needs for modification and other next steps.	Yes, our behavioral consultants engage directly with the families and children following diagnostic evaluation autism.
TRIAD advisory council	The TRIAD advisory council is made up of stakeholders with lived experience related to autism. This group meets regularly to consider practice questions, material development, and provide advice on best practices.	Yes, all council members have lived experience with autism.

REPLICATION

While this model has not been replicated outside of the TN, we have had multiple opportunities to replicate and evaluate the model within our own state. EI CAPSS was initially only available to families and service providers in the middle region of our state. Following 2 years of successful implementation, we extended and replicated the model to much of the western region of our state with some adjustments specific to the needs of that community. Since 2020, we have begun replication in the eastern region of our state. Each replication has yielded comparable outcomes.



INTERNAL CAPACITY

Our EI CAPSS team is led by two Early Intervention (EI) Associate Directors with expertise in behavior analysis, early childhood development, and caregiver and provider coaching. These two individuals also have experience with program development and supervision of teams. Together, the (EI) Associate Directors provide oversight to the day-to-day operations of the program, support team members in implementation of services, manage communication between our program and all relevant stakeholders, and facilitate data collection and review activities. The Associate Directors are supported by one of TRIAD's Co-Directors who has experience in systems level work and development and implementation of sustainable programming.

Our team also includes 8 educational consultants with backgrounds in speech language therapy, behavior analysis, and early childhood development. EI CAPSS consultants have significant experience working directly with young children with autism and related developmental disabilities, coaching caregivers in homes and via telemedicine, collaborating with other service providers and delivering high quality professional development opportunities through both in person and remote modalities. This team gathers weekly to promote internal capacity building.

Our organization is embedded within the Vanderbilt Kennedy's Center's (VKC) TRIAD which includes a number of programs focused on improving assessment and treatment service for children with autism and their families while advancing knowledge and training. Embedded within the larger infrastructure of TRIAD, the EI CAPSS program can access support from program managers and administrative assistants that can help with tasks like data system development, data entry, materials creation, ordering supplies, and mailing resources to families. TRIAD also has an online content development team that can assist with the development of online learning modules and data collection related to usage. EI CAPSS personnel also have access to behavior analysts, psychologists, educators, and speech language pathologist working across variety of programs that serve families, students, and teachers across the lifespan.

TRIAD is one of four main pillars of the Vanderbilt Kennedy Center (VKC). The VKC offers logistical and IT support as well as financial oversight. The VKC is part of the Vanderbilt University Medical Center which provides contract management resources, access to interpreter services and many professional development opportunities for our staff.

PRACTICE TIMELINE

The following tables offer an ideal timeline for developing an EI-CAPSS program. The timeline addresses three main phases: Planning/Pre-Implementation, Implementation, and Sustainability. Timelines may vary significantly depending on the existing relationship with a potential funding source (e.g., Part C system) and the scale of the program. When possible, we recommend starting with a smaller program and scaling the program as quality is demonstrated. Responsible parties include Treatment and Research Institute for Autism Spectrum Disorder (TRIAD), Tennessee Early Intervention System (TEIS), and Vanderbilt University Medical Center (VUMC).



Phase: Planning/Pre-Implementation

Activity Description	Time Needed	Responsible Party
Establish relationship between Part C and TRIAD	1-2 months	TRIAD
Attend local and state meetings to gather information on needs and existing resources	2-4 months	TRIAD and TEIS
Develop service proposal and budget	2 weeks	TRIAD
Review service proposal and budget	2-4 weeks	TEIS
Contract negotiations	TBD	VUMC and TEIS
Materials development (e.g., data collection tools, caregiver resources)	1-3 months	TRIAD

Phase: Implementation

Activity Description	Time Needed	Responsible Party
Hiring and training new hires	1-3 months	TRIAD
Introduction of services to community agencies and providers	1-2 months	TRIAD and TEIS



Enroll families and providers in service options	Ongoing/rolling	TRIAD
Data collection and documentation of service delivery	Ongoing	TRIAD
Meet to review outcomes and next steps	2 hours quarterly	TRIAD and TEIS

Phase: Sustainability

Activity Description	Time Needed	Responsible Party
Review of data	Quarterly	TRIAD
Submit annual reports	Yearly	TRIAD
Training and support for internal staff	Weekly	TRIAD
Disseminate outcome data locally and nationally	TBD	TRIAD and TEIS

PRACTICE COST

The greatest cost within the EI CAPSS model is personnel. We estimate 1 FTE can see approximately 36 families via a combination of in person and telepractice service delivery each year. We estimate that .4 FTE can support 30 hours of group professional development for EIPS each year, with that FTE including direct time with participants in group meetings and planning, content development, and discussion board monitoring. We estimate that an additional 240 hours of EIP coaching can be provided with .6 FTE, with that FTE including time for planning and preparation for direct coaching contacts.



Additional personnel costs are from support staff personnel including program leadership, administrative assistants, and IT support.

Other costs include equipment/supplies and travel. The cost breakdown below includes the personnel, equipment/supplies and travel costs to see 170 families per year and provide 270 hours of professional development to EIPs.

Budget			
Activity/Item	Brief Description	Quantity	Total
Direct Service Personnel	Staff to provide caregiver and provider support services Includes cost of fringe benefits	170 families 200 hours of PD	\$900,000
Support Staff	Staff to support logistics and IT	TBD	\$100,000
Equipment, Supplies and Meeting Expenses	Computers, printers, and software to support telepractice sessions and materials development. iPads and hot spots to support telepractice	1 computer/staff person 2 printers 1 Boardmaker online license/staff member 1 iPad/staff member 2 to 3 hot spots	\$30,000
Travel to homes, meetings and conferences	Mileage reimbursement for traveling to families' homes as needed	TBD	\$30,000
Total Amount:			\$1,060,000.00

LESSONS LEARNED



Highlights: Our program has established that a 6-week caregiver training program can significantly impact a child’s developmental progress and can teach caregivers valuable skills. Furthermore, providers gain valuable information from professional development and collaboration opportunities that can expand their own knowledge base and improve services for all families in the community.

TRIAD’s ongoing partnership with TEIS has been the key to our success. Because of the number of families served by TEIS, we have been able to reach many families and expand our services several times to meet additional needs. Our collaboration has also allowed us to support TEIS in thinking about novel ways to serve families, including supporting the rapid transition to telehealth services at the start of the covid-19 pandemic. During the transition, we conducted an 8-part webinar series “Telehealth for EI Providers.” This series had average weekly viewership between 250-350 participants and the archived sessions were viewed over 2000 times.

Challenges: Similar to other professionals working with children with developmental disabilities and their families, we have often had long waitlists for diagnostic evaluations and have not always been able to meet the demand for intervention. In 2014, we began with a small service area as we felt it was important to establish an effective program before expanding. As our capacity has increased, we have gradually increased the geographic area that we serve and our capacity within those areas. We have partnered with other providers in other regions of the state to help us understand the needs of each region. Our professional development model has also focused extensively on increasing the capacity of local providers to support families independently using resources created by TRIAD. Over time, this has allowed us to shift into a role that focuses on coaching providers instead of solely focusing on direct support to families.

Additionally, access to a reliable internet connection and an appropriate device pose a significant barrier for some families. While access to broadband internet has improved significantly in recent years, there are many areas where a Wi-Fi connection is not available to families and cellular service is not accessible or the cost of wi-fi or a compatible device may be prohibitive for some families. We have partnered with our part-C to provide a variety of solutions to increase access to services.

NEXT STEPS

Our programming continues to be driven by a shared mission to facilitate quick access to high quality early assessment and intervention services. As such, we will continue to work with our Part C system to expand services to additional families across the state of TN.

Increase access to caregiver education and support opportunities:

The renewal of a contract between our organization and TEIS has allowed us to formally extend our caregiver follow-up and support opportunities to the eastern region of our state.

We are piloting implementation of an additional service model that aims to provide focused, brief follow-up to families that might not need or want our 6-visit caregiver education and support service.



Expand provider education and support opportunities:

To meet the professional development and coaching needs of early intervention providers serving young children with ASD and related developmental delays/disabilities and their families, we have initiated a multi-tiered approach to training. Each tier focuses on supporting providers in gaining increasingly advanced levels of knowledge and skills for best practices in teaching young children and working with caregivers.

Engage developmental therapists in telediagnostic evaluations:

Currently, we are piloting a telediagnostic service model that actively engages caregivers and their early intervention provider in the evaluation process. Early results of this pilot work have been overwhelmingly positive.

Develop toolkits, online modules and training opportunities on neurodiversity and self-determination:

We are in the early stages of developing printable toolkits, online modules, and live training opportunities to address neurodiversity and self-determination in the early intervention population.

RESOURCES PROVIDED

- [Early Intervention modules](#)
- [TRIAD Early Intervention website](#)
- Please reach out to Alacia Stainbrook at alacia.stainbrook@vumc.org for additional information including measure templates, expanded outcome data, and additional analyses.

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APPENDIX

- Module access directions (see supplemental PDF attached on Innovation Hub)
- Internally developed measures (see supplemental PDF attached on Innovation Hub)
- Graphs (see supplemental PDF attached on landing page)

