



innovation hub

AMCHP | *Explore. Build. Share.*



MCH Innovations Database Practice Summary & Implementation Guidance

Parents as Collaborative Leaders: Improving Outcomes for Children with Disabilities

Parents as Collaborative Leaders: Improving Outcomes for Children with Disabilities is a practice focused on building the capacity of parents and direct caregivers to become leaders that advocate for systems change and positive outcomes for children and youth with special healthcare needs (CYSHCN) using a nationally recognized, research-based curriculum.



Location

North Carolina



Topic Area

Family/Youth Engagement, Health Promotion and Communication, Safe and Connected Communities



Setting

Community



Population Focus

Families & Caregivers



NPM

NPM 11: Medical Home



Date Added

October 2023

Contact Information

Mahala Turner, Division of Child and Family Well Being, Whole Child Health Section, (919-707-5634, Mahala.turner@dhhs.nc.gov)

Section 1: Practice Summary

PRACTICE DESCRIPTION

Parents as Collaborative Leaders: Improving Outcomes for Children with Disabilities is an initiative developed by the Whole Child Health Section within the NC Division of Child and Family Wellbeing. The practice focuses on building the capacity of parents and direct caregivers to become leaders that advocate for systems change and positive outcomes for children and youth with special healthcare needs (CYSHCN). The Parents as Collaborative Leaders curriculum is a nationally recognized, research-based curriculum. It was initially developed in 2008 by the University of Vermont and the PACER (Parent Advocacy Coalition for Educational Rights) Center. Since 2015, the Whole Child Health Section has presented training to over 1770 parents and caregivers of CYSHCN to develop advocacy skills and promote family-professional partnerships.

Parent/caregiver leadership occurs when parents and direct caregivers gain the knowledge and skills they need to function in meaningful leadership roles and represent the “parent voice” to help shape the direction and outcomes of programs, policies, and laws that affect CYSHCN. The Whole Child Health Section employs a full-time Family Liaison Specialist who oversees this initiative. She works to identify and engage parents and caregivers of CYSHCN to become trained facilitators. Upon completion of a Train the Trainer workshop, the facilitators deliver training to local communities across the state and receive stipends for their work. Ten training modules were developed using materials provided by the PACER Center. These training modules are selectable to fit the group’s needs and available in English and Spanish at no cost to parents and caregivers. The Family Liaison Specialist promotes parent leadership training to parent leader groups and schedules training upon request.

Health care providers and policy makers understand the value of incorporating families’ lived experience in systems-level activities. Unfortunately, there are few opportunities and supports available to assist families and professionals with the process of engaging with one another. Parents are historically strong advocates for their own children with special healthcare needs, and with parent leadership training parents are given even more opportunities to play significant roles in making systems level change that represents a larger community. Often parents don’t feel qualified or welcome at the table. They haven’t had an opportunity to gain the necessary skills to get involved at a local or state level on equal footing. This is particularly a barrier for parents experiencing poverty or from diverse cultural backgrounds, or parents whose first language is not English. In recent years the CYSHCN Blueprint elevates implementing strategies that support families of CYSHCN to be active in their communities.

The overall goal of the Parents as Collaborative Leaders (PACL) peer to peer training initiative is to improve the system of care for CYSHCN by building the leadership skills of their parents/caregivers.

CORE COMPONENTS & PRACTICE ACTIVITIES

PACL Leaders training empowers family leaders among rightsholders in the systems that represent CYSHCN across the state. The core components of this program include a nationally recognized curriculum, trained facilitators with lived experience, multiple modules with flexible scheduling options, and evaluation opportunities for each participant to provide feedback.



Core Components & Practice Activities

Core Component	Activities	Operational Details
PACER Curriculum	10 modules	<p>The PACER Center enhances the quality of life and expands opportunities for CYSHCN and their families. This curriculum is a nationally recognized training resource developed in cooperation between the University of Vermont and the PACER Center to provide the foundation of key knowledge and skills needed to become an effective leader within one’s community. Curriculum modules are available in both English and Spanish.</p>
Training of Trainers	Train the Trainer workshop	<p>The Family Liaison Specialist facilitates Train the Trainer workshops. A request for applications is shared throughout the state inviting family partners to become trained facilitators. At the workshop, participants learn about curriculum content and best practices for implementing the training. Trained facilitators are English and Spanish speakers.</p>
10 Module Delivery	Ten 90-minute modules	<p>Over the ten modules of the Parent Leadership Training, parents/caregivers learn how to:</p> <ul style="list-style-type: none"> • define leadership roles • create action plans • collaborate effectively <p>• recognize the stages of group development</p> <ul style="list-style-type: none"> • lead effective meetings • ask clarifying questions • understand conflict • reframe agendas <p>• solve problems in groups</p> <ul style="list-style-type: none"> • understand diversity <p>The activities contained in these modules are designed to help parent leaders articulate their views, consider their personal stories in</p>



		relation to leadership, and use this information to think about ways to extend their experiences as leaders.
Evaluation	Survey opportunity for each participant at the completion of each module	At the close of each module, participants are asked to complete a survey that provides feedback to the Family Liaison Specialist. This survey is available in both English and Spanish.

HEALTH EQUITY

According to HRSA’s National Survey of Children’s Health, CYSHCN are more likely to live in poverty, be non-Hispanic Black, and have public insurance than non-CYSHCN. Consequently, health equity is a key pillar in supporting children and youth with special health care needs. PACL training modules prepare and empower parents/caregivers of CYSHCN to participate in decision-making at all levels of care, from direct care to the organizations that serve them. Our practice is committed to equitable access by partnering with trusted messengers in the community to promote our training/practice that can be tailored to a community’s language(s), literacy levels, and cultures. The facilitators are all parents/caregivers of CYSHCN from diverse communities from across the state. PACL trainings use clear, easy-to-read, and transparent information that is culturally relevant in terms of language, messaging, tone, images, and format. The information presented is suitable for diverse audiences including people with disabilities, limited English proficiency, or people who face other challenges accessing information.

EVIDENCE OF EFFECTIVENESS

The Whole Child Health Section implements Key Performance Indicators (KPIs) using PACL training data. Parents/Caregivers of CYSHCN Education is measured by the number of trainings provided to parents/caregivers of CYSHCN, the percentage of participants reporting an increase in knowledge and confidence to work on issues related to CYSHCN, and the percentage of participants who agree/strongly agree that the workshop met expectations. Spreadsheets and surveys are used to track data which is reported annually to the Senior Leadership Team.

Feedback from trainers and agencies (that host training) is informally collected via email and meetings, particularly if a challenge arose, to discuss opportunities for improvement. Feedback from participants about the learning environment, pace of instruction, and presenter preparedness is collected via evaluation survey and shared with trainers.

This Table shows PACL training data used to measure Key Performance Indicators from 2020 – 2022.



	Number of trainings provided to parents/caregivers of CYSHCN	Percentage of trainings presented in Spanish	Percentage of participants reporting an increase in knowledge and confidence to work on issues related to CYSHCN	Percentage of participants who agree/strongly agree that the workshop met expectations
2020	36	28%	99% English 99% Spanish	100% English 86% Spanish
2021	39	18%	96% English 95% Spanish	92% English 90% Spanish
2022	19	47%	100% English 98% Spanish	100% English 91% Spanish

In response to feedback from our key collaborators, in 2020 we began offering the trainings in Spanish (requested by community-based organizations who serve families of CYSHCN). The numbers of training provided trend positively (with a dip in 2022 due to staffing shortages) and we are on track to exceed the previous year’s numbers in 2023. From 2020-2022, 26 training modules were presented to 329 Spanish speaking parents/caregivers of CYSHCN. The parent leadership trainings are offered in Spanish to address health inequities and systemic oppression that impact families of the CYSHCN population.

During our Train-the-Trainer workshop, staff noted some trainers seemed to be more experienced presenters. There were hesitations about assigning them to the schedule even though they had completed all facilitator requirements. However, after trainers were given the opportunity to facilitate training it was evident (based on participant feedback) that all trained facilitators bring a richness of diverse life experiences and backgrounds. These varying perspectives and insights can resonate with diverse audiences within a community. A facilitator with shared lived experiences and/or shared cultural background possesses the ability to empathize, relate, and communicate in ways that connect with the audience. This creates an inclusive atmosphere for all involved and facilitators are well received by the participants from their respective communities.

In 2020 the practice faced the challenge of shifting the training from in person to a virtual platform. For staff and trainers, this shift required additional training and learning new skills. Shortly after we began offering virtual training opportunities, staff realized that we were able to reach more families. The shift to virtual training removed barriers such as transportation, travel time, and childcare so that training opportunities were more accessible to families. Even though we are once again offering training in person, we continue to use a virtual platform. An unexpected outcome is that our virtual training modules continue to be the most popular and well attended training modules.

The Family Liaison Specialist often shares participant evaluation results with trained facilitators by email or phone to discuss strengths and opportunities. In turn, the Family Liaison Specialist also uses feedback gathered from the trained facilitators to discuss ways to improve the overall practice. Most often the changes to presentation characteristics were particular to the facilitator. For example, one facilitator received feedback that the pace of the training was too fast. The facilitator and Family Liaison Specialist discussed strategies to build in more time to each module such as “check-in” time every 3-5 slides to allow for clarification, questions, comments, and group discussion amongst participants. This course of action worked well for future training sessions.



At the close of each year the Family Liaison Specialist sends a brief questionnaire to each facilitator to take inventory of who is interested in continuing as a trainer throughout the next year. This gives facilitators an opportunity to opt out if needed. Providing permission for trained facilitators to step away as needed ensures continuous quality of the practice.



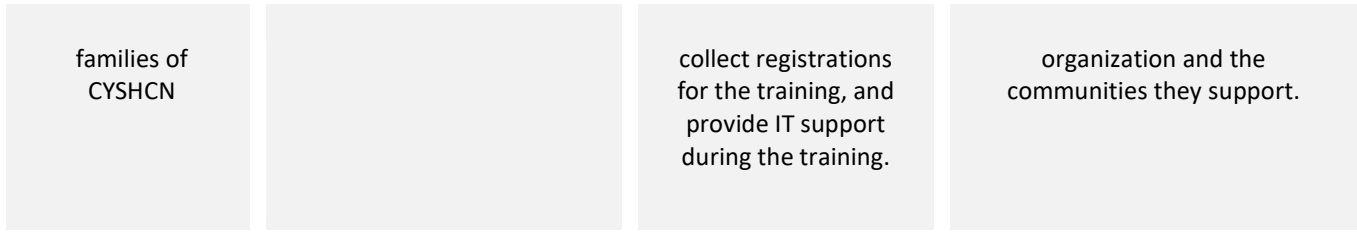
Section 2: Implementation Guidance

COLLABORATORS AND PARTNERS

The North Carolina Department of Health and Human Services (NCDHHS) Whole Child Health Section partners with community-based organizations who serve families of CYSHCN across the state to deliver parent leadership training to parents and caregivers of CYSHCN. All training is provided by trained facilitators who are also parents/caregivers of CYSHCN. The Whole Child Health Section values feedback provided by training participants to improve future training opportunities.

Practice Collaborators and Partners			
Partner/ Collaborator	How are they involved in decision-making throughout practice processes?	How are you partnering with this group?	Does this stakeholder have lived experience/come from a community impacted by the practice?
NCDHHS Whole Child Health Section	The Section elevates family engagement as a priority and developed Key Performance Indicators (KPIs) around PACL data.	KPI data is reported annually to the senior leadership team to monitor meeting these goals.	No, but the NCDHHS Whole Child Health Section programs serve CYSHCN and their families.
Parents/caregivers of CYSHCN	Parent/caregiver training participants give feedback about their training experiences.	Participant feedback is shared with training facilitators to collaborate on strategies that improve the training as well as how to navigate difficult questions that arise during training.	Yes, parents/caregivers are the primary care providers for the children receiving services from the program.
Community based organizations who serve	Local organizations host PACL training and inform decisions about scheduling needs and virtual platform preference.	Local organizations recognize the need in their community, schedule and advertise training,	Yes, parents/caregivers of CYSHCN often work for the community-based organizations and provide a bridge between the





REPLICATION

A specific parent leadership training using the same PACL curriculum has not been replicated. However, the PACL peer-to-peer training model has been used as the framework to develop a new parent/caregiver three module training, “Teaching Children with Disabilities about Sexual Health”. The new addition to the parent training cadre will be launched by the Whole Child Health section in 2024 using the same collaborators and partners, health equity efforts, and effectiveness surveys.

INTERNAL CAPACITY

The Whole Child Health Section employs a full-time Family Liaison Specialist who leads this initiative. She works to identify and engage parents/caregivers of CYSHCN to become trained facilitators and oversees the Train the Trainer workshops. The Family Liaison Specialist promotes parent/caregiver leadership training to parent leader groups, secures trainers, and schedules training upon request. She is also responsible for submitting reimbursement requests from trainers upon completion of each training activity. An additional Whole Child Health Section staff member, the CYSHCN Access to Care Specialist, supports the Family Liaison Specialist’s oversight of the practice by providing consultation, monitoring evaluation plans to measure the impact of PACL series, and ensuring adequate and timely reimbursement strategies.

PRACTICE TIMELINE

The table reflects an estimated timeline for the parent leadership training practice.

Phase: Planning/Pre-Implementation		
Activity Description	Time Needed	Responsible Party
Recruit trainers (parents/caregivers of CYSHCN) via application process.	5 hours	Family Liaison Specialist



Train the Trainer Workshop: Plan workshop curriculum and develop materials. Facilitate the workshop.	10 hours	Family Liaison Specialist
Develop promotional materials.	3 hours	Family Liaison Specialist
Build relationships among community-based organizations serving families of CYSHCN. Promote the training.	Ongoing (1 -2 hours per week)	Family Liaison Specialist
Plan and secure reimbursement strategy for trained facilitators.	3 hours	CYSHCN Access to Care Specialist
Prepare evaluation survey and data tracking methods.	3 hours	CYSHCN Access to Care Specialist

Phase: Implementation

Activity Description	Time Needed	Responsible Party
Partner with community-based organizations to host training modules. Plan training details (date, time, platform). Secure available facilitator.	3 hours per training module	Family Liaison Specialist
Prepare for and deliver training module.	2.5 hours per training module	Trained Facilitator
Be available to assist with unexpected issues (such as trainer unavailability or IT issues).	As needed	Family Liaison Specialist



Collect attendance/ participants' email addresses and send to Family Liaison Specialist. Disseminate and encourage completion of evaluation survey.	1 hour per training module	Community Based Organization Representative (Host)
Monitor evaluation results from participants and feedback from host organizations for acute needs. Communicate with facilitators and adjust strategies as needed.	1 hour per month	Family Liaison Specialist
Input training details, number of participants, and email addresses into data tracker. Report training data at quarterly Whole Child Health Section Family Partner Engagement and Leadership Committee meeting.	0.5 hour per training module	Family Liaison Specialist
Complete process to reimburse facilitator. Maintain records regarding reimbursements.	3 hours per month	CYSHCN Access to Care Specialist

Phase: Sustainability

Activity Description	Time Needed	Responsible Party
Maintain ongoing and effective communication and partnering with community-based organizations serving CYSHCN and their families.	5 hours per week	Family Liaison Specialist
Compile and analyze evaluation survey results and feedback from hosts. Review with trained	12 hours per year	Family Liaison Specialist



facilitators. Consider strategies to improve the practice.		
Take inventory of continued facilitator interest.	1 hour per year	Family Liaison Specialist
Compile and report training data that informs KPIs to the Senior Leadership Team.	3 hours per year	CYSHCN Access to Care Specialist

PRACTICE COST

The PACL training is offered at no cost to participants.

Oversight of the practice by the Family Liaison Specialist and support from the CYSHCN Access to Care Specialist are embedded in their job responsibilities.

Reimbursement to the parents/caregivers for their time to be trained as PACL facilitators and conduct PACL trainings is provided through Title V Grant funding. An estimate of costs reimbursed to parent/caregiver facilitators is outlined below using data from the initial year of the practice as an example.

Budget			
Activity/Item	Brief Description	Quantity	Total
Initial Train the Trainer Workshop	Potential trainers are reimbursed for participation in a workshop to learn about curriculum content and best practices for implementing the training, including practicing their skills.	\$20/hour x 6 hours. This is an initial (one time) cost but may be required again if new trainers are added to the trainer roster.	\$120.00 x number of trainers plus roundtrip mileage. For example, 10 trainers were trained in the initial year of the practice and were reimbursed \$1000** in mileage. $\begin{array}{r} \$120.00 \times 10 = \$1200.00 \\ + \$1000.00 \\ \hline \$2200.00 \end{array}$
Ongoing Trainer training	Trainers are reimbursed for participation in annual reviews, updates, and as needed	\$20/hour x 3 hours.	\$60.00 x number of trainers. For example, $\$60.00 \times 10 = \600.00



	communications with the Family Liaison Specialist.		
Ongoing Reimbursement to Trainers for facilitating modules	Trainers are reimbursed for 1 hour of prep time and 1.5 hours of presentation time for facilitating a training module.	\$20/hour x 2.5 hours.	<p>\$50.00 x number of modules plus, roundtrip mileage. For example, PACL trainers facilitated 16* modules in the initial year of the practice and were reimbursed \$600** in mileage.</p> <p>\$50.00 x 16 = \$800.00 + \$600.00 (annually) \$1400.00</p>
Total Amount:			\$4200.00

*The practice has grown since the initial year to an average of 35 modules (\$50.00 x 35 modules = \$1750.00) annually. However, due to training being virtual, mileage costs in recent years have been \$0.00**

LESSONS LEARNED

It benefits the practice as well as the facilitators to emphasize to facilitators that it is okay to decline an opportunity to facilitate a training. As parents of CYSHCN, they often do not have a choice but to keep pressing forward even when maybe they have a lot going on and cannot be “present”. We are also learning to look for more structured and frequent ways to incorporate improvements based on feedback from the evaluations.

It is necessary to have a backup plan approach for each scheduled training module. Keep in mind that facilitators are parents/caregivers of CYSHCN and can have unexpected personal or family demands necessitating sudden unavailability. Our back-up plan includes identified facilitators that often have last-minute availability if needed. The Family Liaison Specialist can also step in as a facilitator as a last resort when no other options are available.

Consistent and open communication with the host prior to the training regarding registration/attendance and incorporating plans to address concerns is also important. For example, if the attendance numbers are low, then the Family Liaison Specialist and host community-based organization partner to brainstorm strategies to boost registrations (i.e., personal invites, email blasts, social media, etc.). If attendance numbers continue to be low and the training is imminent, the Family Liaison Specialist and host community-based organization consider rescheduling or cancelling the training. The ideal attendance is six or more participants so that the training can be truly interactive with a variety of perspectives contributing to group discussions.

An additional lesson learned is to prepare the facilitators to keep the training on track and avoid going off course due to comments containing personal beliefs that tend to be divisive or offensive. For example, training facilitators to communicate expectations that honor all participants’ time by sharing information relevant to the group and resist making religious/political references.



NEXT STEPS

We will consider additional Train the Trainer workshops to adapt to community needs, ensure that the skills of facilitators are being maintained over time, and maintain fidelity across facilitators. In 2020 we held a workshop to bring on new facilitators, train all facilitators to present the modules virtually, urge adherence to the provided curriculum, and discuss strategies to overcome any emerging challenges. We aim to ensure our trainer supply (and their skills) match training demand and quality expectations. Expanding our facilitator pool to include more facilitators from diverse lived experiences, racial, and cultural backgrounds, and being able to present in various settings, will enable our practice to reach and empower more future family leaders. For example, one way to consider expanding our facilitator pool is to recruit individuals who can present in additional languages beyond our current English and Spanish offerings, such as American Sign Language.

Plans to collect longitudinal data are underway. An evaluation survey to measure the impact of the PACL series is under development. Information about types of leadership roles in which our participants have been involved, and how the skills and strategies they gained during the parent leadership training helped to navigate their path into new leadership roles will be gathered. We will incorporate the data collected from the evaluation survey to validate, strengthen and extend current training practices.

RESOURCES PROVIDED

Parent Leadership Training flyer: <https://www.ncdhhs.gov/parent-leadership-training-flyer/download?attachment>

Spanish Parent Leadership Training flyer: <https://www.ncdhhs.gov/parent-leadership-training-flyer-spanish/download?attachment>

APPENDIX

<https://mchb.hrsa.gov/programs-impact/focus-areas/children-youth-special-health-care-needs-cyshcn>

