



Supporting Meaningful Youth & Family Engagement within Children's Special Health Care Services to Impact Programs and Policy

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Objectives



- Recognize how youth and family partners are engaged with statewide stakeholders to improve programs and policies.
- Understand strategies providers and other health professionals can use to engage with youth and family partners.

Children's Special Health Care Services (CSHCS)

Children's Special Health Care Services



Children's Special Health Care Services (CSHCS) is a program within the **Michigan Department of Health and Human Services**. It is for children and some adults with special health care needs and their families.

- Medical care, treatment and other supports
- 2700+ qualifying conditions
- Eligibility → Severity, chronicity and the need for treatment by a specialist
- Fee to join – fee is waived if the client has Medicaid
- Local Health Departments support CSHCS clients
- Average monthly enrollment is 52,400

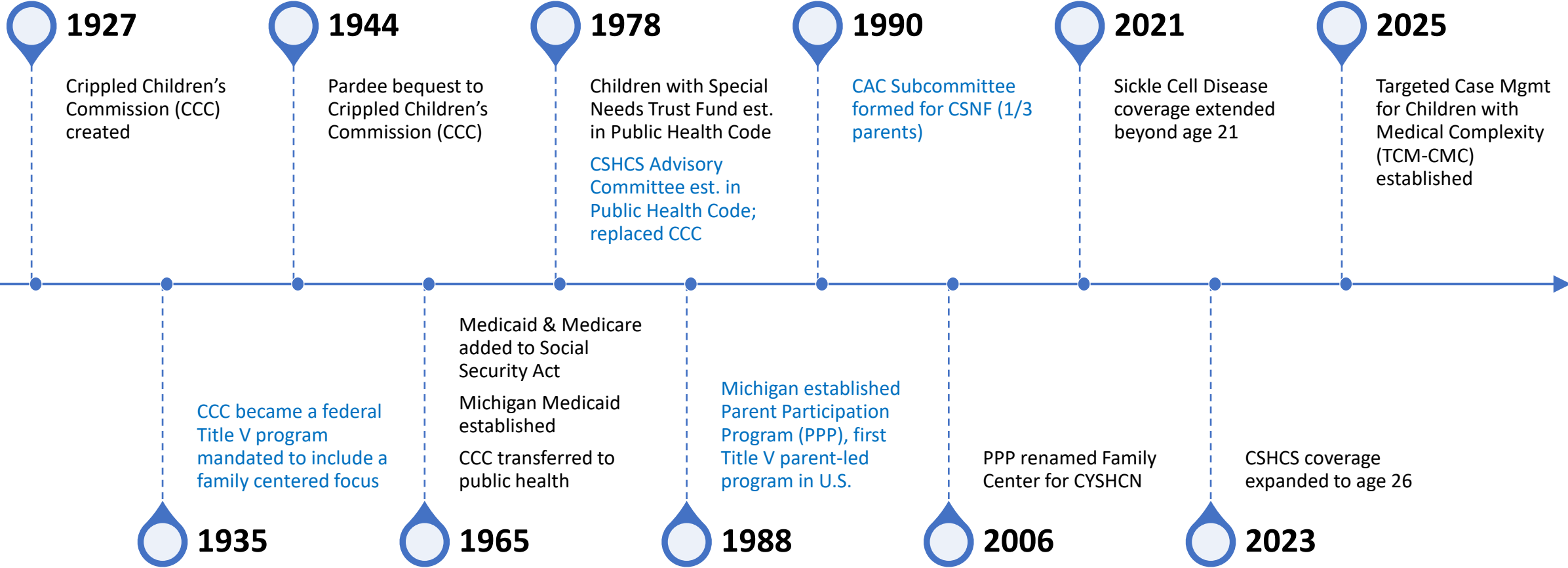
For more information about CSHCS: Visit our website at www.michigan.gov/mdhhs/assistance-programs/cshcs

Or call the **Family Phone Line** at 1-800-359-3722 or email us at cshcsfc@michigan.gov

Youth and Family Engagement: Our Goal



Children's Special Health Care Services (CSHCS) Milestones



Prioritizing the Youth & Family Perspective within CSHCS



Policy & Practice

- Advisory committees
- LHD Accreditation
- Development/review of CSHCS policies
- CSHCS program & resource development
- Strategic Plan

Prioritizing the Youth & Family Perspective within CSHCS



Programs

- Grant writing, development, implementation
- MCHB Title V Needs Assessment
- Bullying Prevention Initiative
- Children with Medical Complexity Targeted Case Management (CMC TCM)
- Professional presentations

Family Center for Children and Youth with Special Health Care Needs

The Family Center for Children and Youth with Special Health Care Needs (Family Center)



The Family Center for Children and Youth with Special Health Care Needs (Family Center) is the statewide, parent-directed center within Children's Special Health Care Services (CSHCS).

Who We Are:

- Each Family Center team member is the parent of a child with special health care needs.
- We are a resource that families can turn to for support and encouragement.
- We seek to empower families through education and connection to their communities.

Who We Serve:

- The Family Center serves all families with children who have--or are at increased risk for--physical, behavioral, developmental, and emotional conditions.
- Families do not have to be enrolled in Children's Special Health Care Services to receive Family Center Services and Support.

For more information about the Family Center: Visit our website at www.michigan.gov/familycenter

Our Mission



To support and connect Michigan families of children and youth with special health care needs, provide family-centered leadership throughout Michigan's health care settings, and partner in decision making within the systems of care for children and youth with special health care needs.

Elevating Youth & Family Voices

Research has consistently shown that when families are engaged and included as decision-makers in the programs that impact them:

- Children have better outcomes
- Programs and policies are more effective because parents bring a level of expertise and lived experience that professionals do not have
- Programs are more responsive and reflect the needs of communities

Michigan has a rich history of youth and family engagement and elevating this perspective, so families have a seat at the table where the decisions that impact their families are being made



Family Centered Leadership

Family Center Manager participates on the CSHCS management team to ensure the family perspective is considered in all aspects of program and policy development.

The Family Center team provides family-centered leadership by elevating the family voice and perspective on other decision-making bodies within CSHCS, MDHHS, and other statewide initiatives.



Continuum of Parent Voice and Leadership

MICHIGAN'S PARENT VOICE AND LEADERSHIP CONTINUUM

How Parent Leaders Become Change Agents to Impact Decisions

INVOLVEMENT	ENGAGEMENT	EMPOWERMENT	LEADERSHIP
Parents are enrolled and participate	Parent voice informs	Parent partners collaborate in planning and implementation	Parent leaders are integral decision-makers
The system designs all policies, programs and evaluation tools for parent participants	The system learns from parent voice through surveys, focus groups and interviews	The system changes approach with parent partners	The system designs policies, programs and evaluation tools with parent leaders

Advisory Boards and Committees



CSHCS
Advisory
Committee

CSN Fund
Advisory
Committee

Family
Leadership
Network

Youth & Family Engagement Opportunities

- Planning Committee for National Bullying Prevention Month activities
- Developing and presenting trainings for families and providers
- Grant reviewers
- Reviewing materials and resources to ensure they are family-friendly
- Contributing news articles and resources for the Michigan Family Connections Newsletter
- Participating on Title V needs assessment workgroups
- Focus Studies to plan new peer support program
- Providing peer support through Parent to Parent USA
- Serving on panel discussions for conferences and other meetings



Strategies to Increase Engagement

- Establish a Reimbursement Policy – childcare, mileage, etc.
- Assign meaningful work – match people to their interests and talents
- Define roles and have clear expectations – signed agreement to serve
- Orientation/preparation – level the playing field
- Consider developing a **Stakeholder Engagement Plan** to operationalize your engagement strategy

Local Health Department Family/Youth Engagement Grant Program



The purpose of the CSHCS Family/Youth Engagement program is to assist local CSHCS programs in creating opportunities for families and youth to participate in local CSHCS activities as well as be supported in leadership development and decision-making roles. Involving parents and youth in decision making, providing them with a voice, and including them on committees and workgroups promotes leadership development. Parents and youth can and should be involved in the planning, review, evaluation, and improvement of programs that impact their families.

Local Health Departments are eligible to apply for up to **\$10,000** each fiscal year (October 1 – September 30) to implement activities.

Local Health Department Family/Youth Engagement Grant Program (con't)



Objectives

Grants will be awarded based on the extent to which applicants meet the following grant objectives:

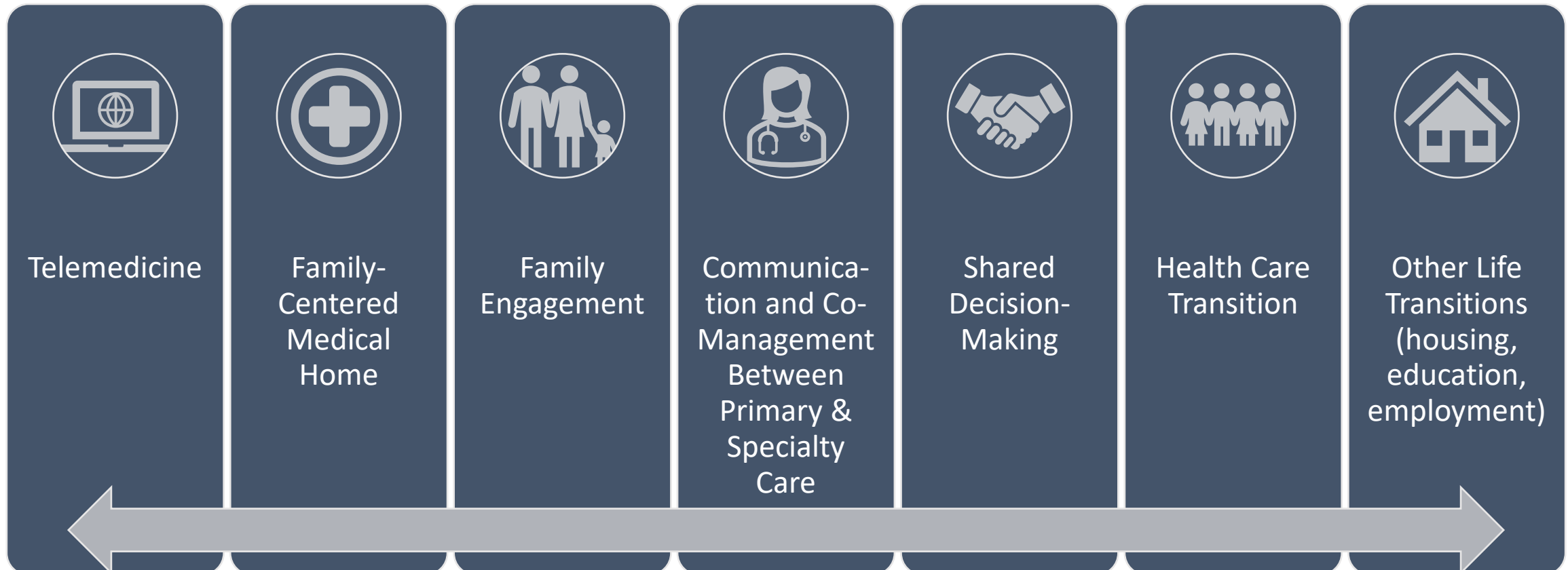
1. Remove barriers for families/youth to participate in networking, peer support, and/or educational events.
2. Support the development of knowledge, leadership, and advocacy skills among CSHCS families and youth.
3. Elevate the voice of families and youth in the development, planning, and implementation of local CSHCS policies, programming, and activities.
4. Support the engagement of families and youth in leadership and decision-making roles at the local level.

For more information, contact the Family Phone Line at 800-359-3722

Michigan Pediatric Epilepsy Projects

Pediatric Epilepsy Grants (2010-2029)

The project aims to improve health outcomes among Michigan's children and youth with epilepsy (CYE), especially those in rural and underserved areas by promoting best practices in the following areas:



Project Clinic Partners

PRIMARY CARE CLINICS

- ✦ Alcona Health Center – Alpena, Cheboygan, Harbor Springs
- ✦ MSU CHM Child Health Clinic
- ✦ MSU COM Pediatric Clinic

PEDIATRIC EPILEPSY SPECIALTY CLINICS

- Beaumont Children’s (Corewell)
- Children’s Hospital of MI
- DeVos Children’s Hospital (Corewell)
- Marquette General Hospital
- MSU Neurology Clinic

ADULT EPILEPSY SPECIALTY CLINICS

- Detroit Medical Center
- Trinity Health



MSU Neurology

DeVos Children's Hospital

Trinity Health

Marquette General Hospital

Beaumont Children's

Children's Hosp. of Michigan and Detroit Medical Center

Michigan Youth with Epilepsy Transition (MiYET)



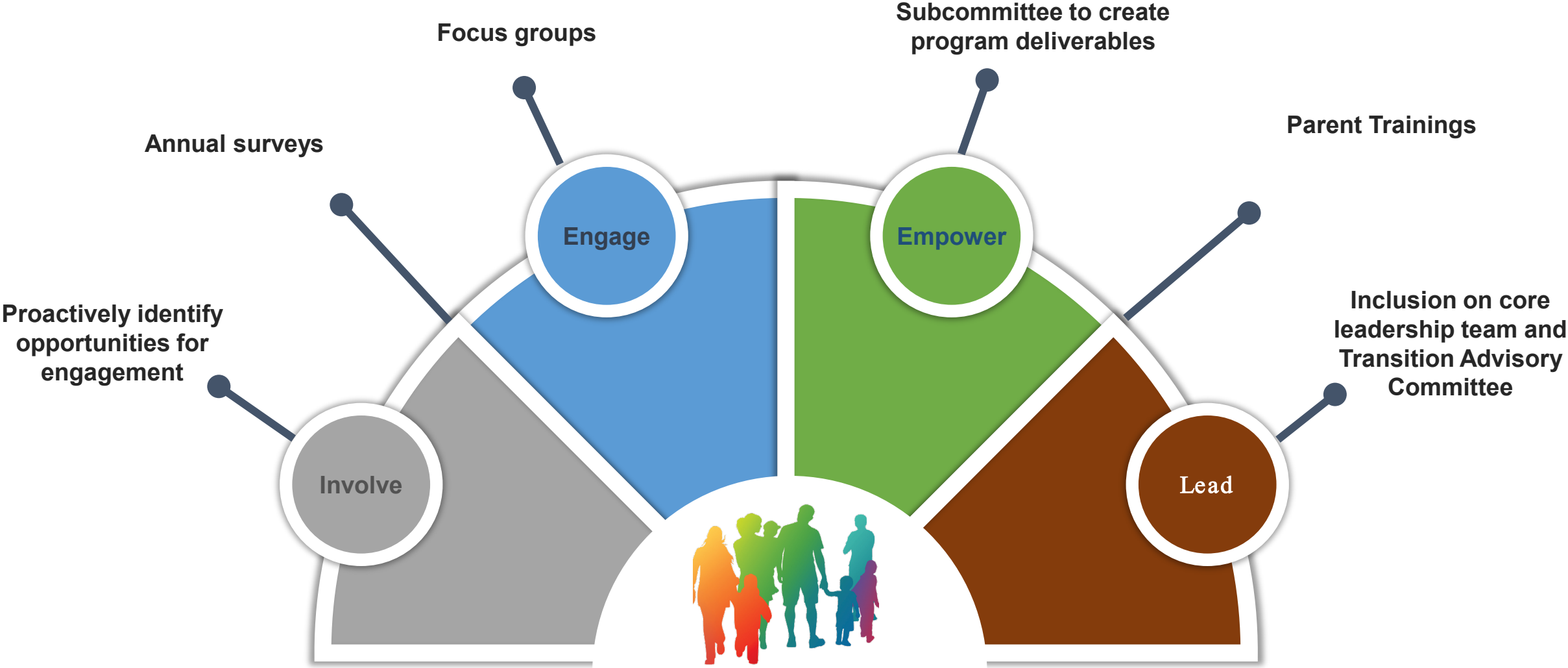
Project Goal: Improve the quality of life and well-being among Michigan's Youth with Epilepsy requiring Supports (YES), ages 13-26, transitioning from a child to an adult health care model and improving self-efficacy for their families/caregivers.

Timeline: 9/1/2024 to 8/30/2029

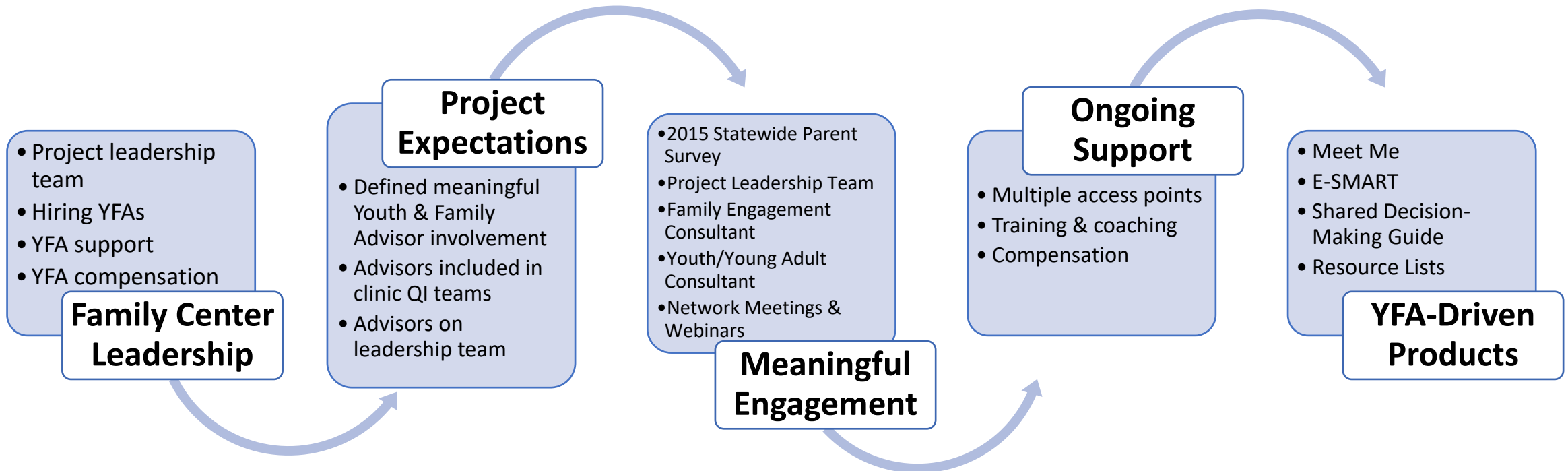
Strategies:

- Partner with pediatric and adult epileptologists to integrate family navigation into the transition services, provide education to providers and staff, and develop connections across transition domains (education, employment, independent living, guardianship and alternatives, etc.).
- Develop a Michigan Transition Framework that will help clinics; youth, young adults, and families; and agencies with successful transitions.
- Bridge gaps between agencies, community-based organizations, local health departments, and clinics through education, training, and collaboration.

Youth & Family Engagement Strategies



Youth & Family Advisors



Growth Assessment Tool

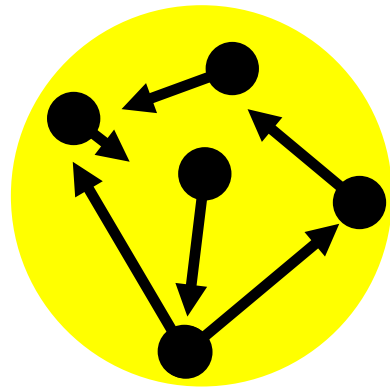
Patient And Family Engagement, CYE, Quality Improvement Project Assessment Tool					
1. Practice utilizes the Patient and Family Advisory (PFA) mechanism within the CSHCS CYE Learning Collaborative Project					
	Never	Occasionally	Usually	Always	N/A
a) Practice has identified one or more patients, or patient family member to work as a collaborative team member on CYE grant activities					
b) Practice includes a CYE Patient & Family Advisor in QI project planning meetings					
c) Practice shares project documents or plans with a PFA for feedback on proposed QI plans.					
d) Practice utilizes the expertise of a practice PFA in implementing QI activities					
e) PFE is a standing agenda item in leadership and quality improvement team meetings.					
Practice-Level Patient and Family Engagement Assessment Tool					
2. Practice can demonstrate that it encourages patients and families to collaborate in goal setting, decision making, and self-management.					
	Never	Occasionally	Usually	Always	N/A
a) Practice has/utilizes tools for shared decision-making (gathering patient/family insights, observations, concerns).					
b) Patient identified goals are documented in the patient chart.					
c) Patients have ready access to their medical record (i.e. <u>Open Notes</u>)					
d) Practice staff participates in periodic PFE training, or other educational opportunities.					
e) Staff in the organization demonstrate through words and actions, the value of patient & family engagement.					
f) Staff practice of PFE is periodically measured and reported in the aggregate.					
3. Practice has a formal approach to obtaining patient and family feedback and incorporating this into the QI system, as well as the strategic and operational decisions made by the practice.					
	Never	Occasionally	Usually	Always	N/A
a) Leaders demonstrate through words and actions, support of PFE.					

Opportunities for Youth and Family Involvement

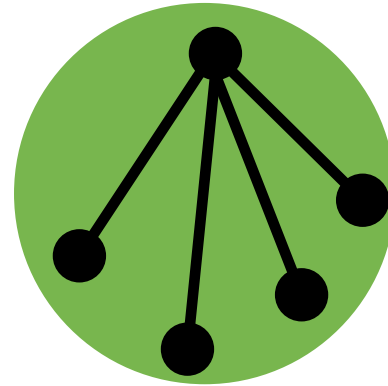
It's a process, not an end point



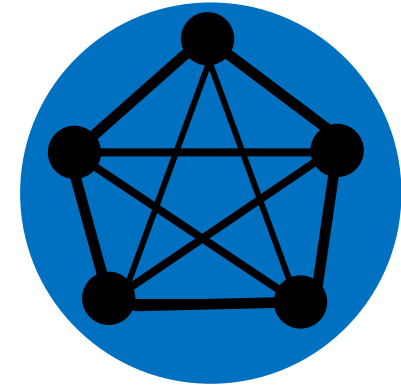
Forming



Storming



Norming



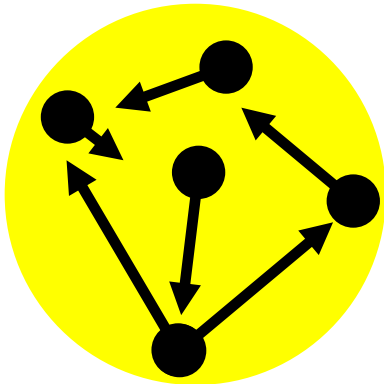
Performing

Forming & Storming



Forming

- Seek informal feedback from youth & family members on quality improvement ideas
- Ask your team to recommend youth & family members who may be interested in sharing their feedback
- Share your ideas and seek input from youth & family members
- Schedule Zoom meetings to connect with youth & family members on particular topics



Storming

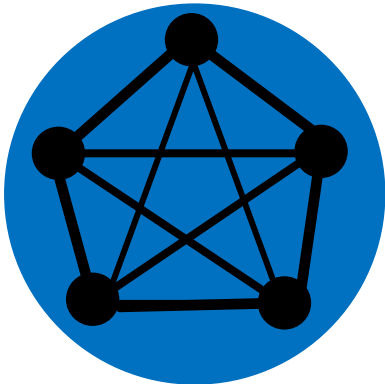
- Distribute simple feedback forms to youth & families at appointments for a defined period of time
- Conduct focus groups with a group of youth & families regarding your QI ideas
- Seek out a family engagement expert to brainstorm ways to identify and engage youth & family members
- Identify one or more youth & family members.

Norming & Performing



Norming

- Routinely ask youth & families for feedback on suggested improvements
- Include youth & families in:
 - Identifying and planning the QI project
 - Implementing the QI project
 - Evaluating the successes, strengths and opportunities discovered in the QI project
 - Making recommendations for next steps



Performing

- Establish a Youth & Family Advisory Council (YFAC) with regular meetings attended by staff leaders
- Hire a youth/family member as a member of your QI team, full or part time.

Strategies to Support Youth & Family Engagement



Orientation for staff

Orientation and support for Youth & Family Partners (YFP)

Be intentional about diversity

Provide stipends and support

Provide “safe space” for YFPs to discuss their experiences

Example: Annual In-Person Meeting Youth & Family Panels



- Each panel was organized around a theme (transition, seizure action plans, etc.)
- Family Engagement Consultant prepped the parents in advance
- Youth and parents shared their stories, including challenges they faced
- Providers listened & asked questions
- Youth & family member perspectives were validated
- Providers rated this an extremely valuable part of the meeting

Youth Involvement

Representation of various viewpoints

- Youth have a very different perspective than parents, so working directly with them is helpful.

Opportunity for test runs and feedback

- Making changes and adjustments is easier with the assistance of youth.
- Things that seem obvious to youth might not even be considered by adults and vice versa.



Tips for Youth Involvement



DO's

- Provide multiple routes for participation
- Create a sense of value and equality
- Consider their background, interests, and experiences
- Build benefits for the youth
- Give credit for involvement
- Communicate results of efforts



DON'Ts

- Place youth in situations where they feel alone
- Ask for participation and not utilize it
- Leave youth to work alone, without support

YFP-Developed Products

A Patient and Family Guide to Shared Decision Making

Taking care of special health care needs – for yourself or for a child – is a big job. For many patients and family members, it can feel new and overwhelming. You may feel very alone.

It doesn't have to be that way. Research has shown that the best health care outcomes happen when patients, their family members, and their providers work together to understand a patient's needs, consider what works best for each family situation, and make decisions together about treatment plans. This is called Shared Decision Making.



S Seek participation

H Help to compare treatment options

A Assess your values and preferences

R Reach a decision

The Agency for Healthcare Research and Quality created the **SHARE approach** to describe the provider role in Shared Decision Making. A group of parents and family members who have faced challenges dealing with special health care needs have modified the **SHARE approach** to describe the role that patients and families play in Shared Decision Making.

The patients and family members who helped create this document want you to know that you don't need to have all of the answers right now; you just need to know how to find the answers. Shared Decision Making means that health care providers,



My Health

Type(s) of seizures I have:

How long I have had seizures:

How I manage my seizures (medications, sleep, diet, exercise, etc.):

Meet Me

Shared Decision Making relies on mutual trust and understanding. The Patient and Family Advisors to Michigan's Pediatric Epilepsy Project recommend patients and families set the stage for partnership *before* the first visit by sharing key information with your health care provider. This tool can be used with pediatric or adult patients.

All about me

My school or work:

I feel most confident about:

I'm really proud of:

My goals for the future:

I am concerned about:

Questions I have about my future:

I would like more information about:

Youth/Family Partner-Developed Products

E-SMART

Epilepsy Self-Management, Advocacy, & Resilience for Teens






Teens with epilepsy, ages 13 – 17, are encouraged to sign up for this free, six-week, Zoom-based self-management program. Sessions focus on understanding epilepsy, developing self-management, self-advocacy skills, building resilience, and transition.

Space is Limited,
Apply Now!

Summer Session:
June 21 - July 26h
Wednesdays 2-3:30pm



Beneficial Apps for Children and Youth with Epilepsy

- | | |
|--|---|
| <p>1. HealthUnlocked: a social network service based upon health information. There are over 700 different communities for various conditions, and the service connects you with other people in similar health situations or sharing specific topics of interest. When creating a profile, you can add health conditions, including epilepsy, to make it easier to join communities and connect with other people. If you have health-related topics that you would like to explore this is also an option. (iPhone app)</p> |  |
| <p>2. Seizure Log: a resource for making seizure activity easier to manage by logging and keeping track of information such as description, length, possible triggers, and type of seizure. The app allows you or your family members to record the seizures and share them privately over YouTube with whomever would be helpful. After a video of a seizure is taken, the information will be added to a seizure log you can access whenever necessary. (iPhone and Android app)</p> |  |
| <p>3. Seizure First Aide: app with information on how to react to all types of seizures in real time and the appropriate first aid for seizures. The app allows you or those around you to track the time and length of a seizure, determine the type, and provides a resource for understanding how to respond to seizures. There also are direct links to seizure hotlines or 911 if necessary for a seizure. (iPhone and Android app)</p> |  |
| <p>4. Snug Safety: a check-in service that makes it safer to live alone with medical conditions. The app checks in with you every day to make sure everything is alright, and if you do not check in, it will alert your emergency contacts. If you experience serious seizures but still want to be independent, it is beneficial to have a resource to help ensure your safety and that can also respond to problems you encounter. (iPhone app)</p> |  |
| <p>5: ICE Medical Standard: an app for emergency contact information. You enter the information of your emergency contacts into the app, which then appears on the lock screen of your phone. This allows first responders or other medical personnel to access these emergency contacts in case of an accident by looking at your phone, making it easier for your contacts to receive notice of your status. Also, you can include information on your health conditions and medications you are taking. (iPhone and Android app)</p> |  |

Thank You

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