



Family Involvement and Leadership: Pathways to Success for Families with Children who are Deaf and Hard of Hearing

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Universal Newborn Hearing Screening Program
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Workshop Goals

- Define Family Engagement
- Provide examples of family engagement
- Discuss leadership development

AMCHP Definition

“The intentional practice of working with families for the ultimate goal of positive outcomes in all areas through the life course. Family Engagement reflects a belief in the value of the family leadership at all levels for the individual, community and policy level.”

Massachusetts Title V Division for Children & Youth with Special Health Needs



VISION

Optimal health and quality of life for children and youth with special health needs and their families.

MISSION

Assuming a leadership role in assuring a comprehensive service system for children and youth with special health needs by working in partnership with families, providers and other stakeholders. We do this by: assessing needs, strengthening infrastructure, assuring access, enhancing expertise and knowledge, and engaging in continuous quality improvement.

Core Outcomes

Families & YSHN **partner** with us in **decision making** at all levels about services received.

Infants, children & youth are **screened** early & continuously for SHN.

CYSHN receive ongoing care within a **medical home**.

Community-based service systems are organized in ways that families can use them easily.

YSHN receive the services necessary to make successful **adult health transitions**.

Families of CYSHN have **adequate private / public insurance** to pay for services needed.

Values-based Methods

We partner with families in everything we do.

We promote a comprehensive service system that is family-centered, culturally competent, coordinated, inclusive & community-based.

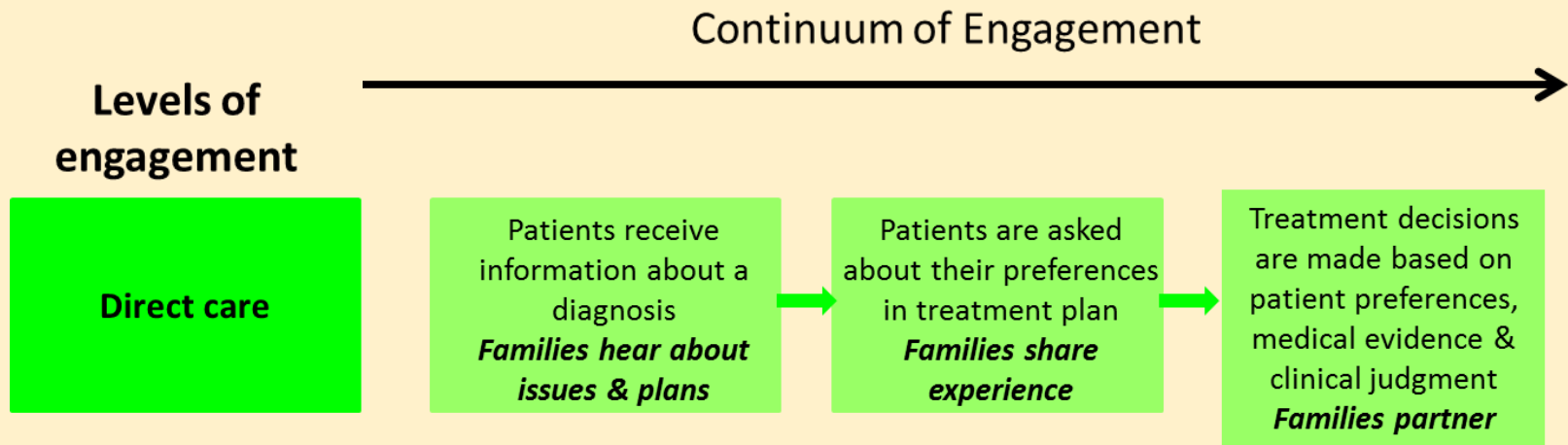
We promote healthy equity by applying best practices for racial justice and cultural & linguistic competence to our work.

We partner with youth with special health needs to improve health transition and promote self-advocacy.

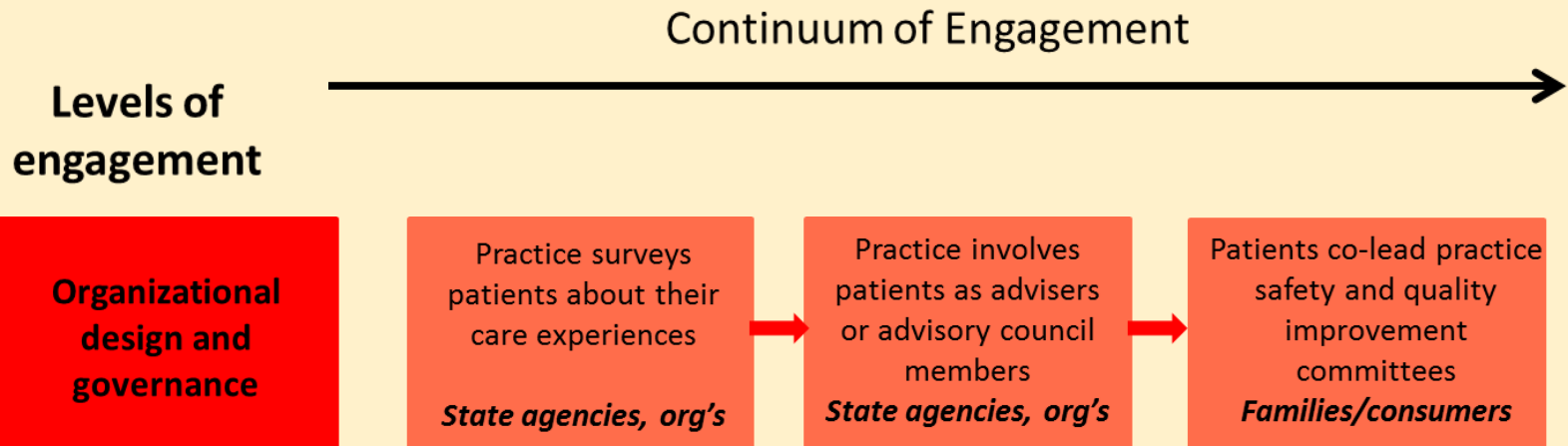
We collect, analyze, share and report data to inform program needs, monitor policies and programs, and evaluate and research outcomes.

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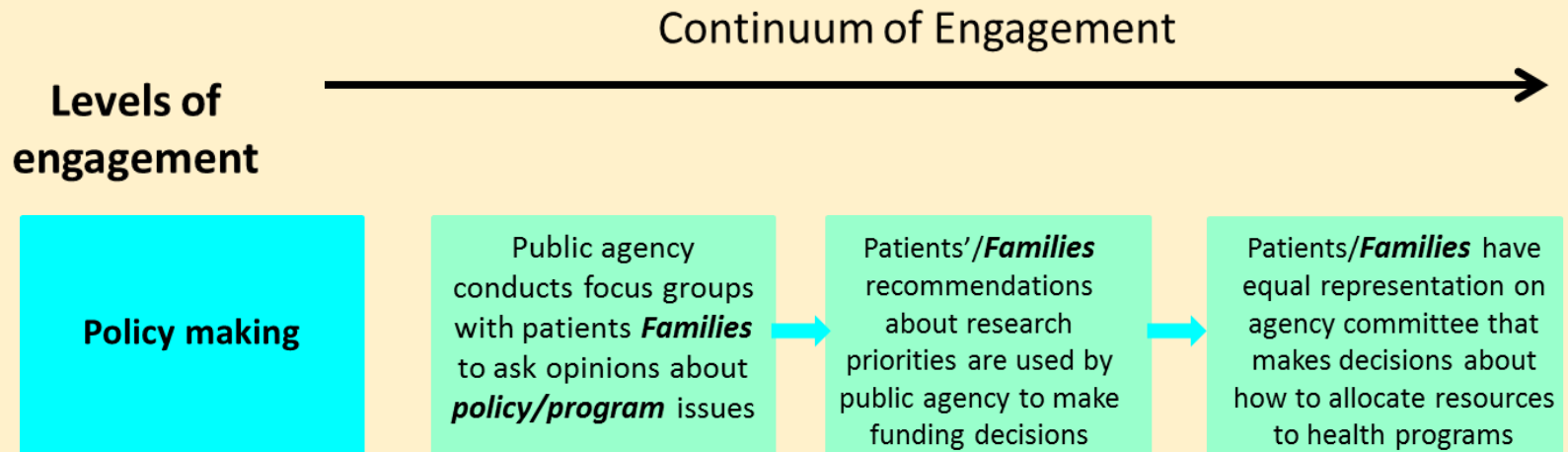
Direct Care Engagement



Organizational Engagement



Policy Engagement



Continuum of Engagement



Levels of engagement

Consultation

Involvement

Partnership & shared leadership

Direct care

Patients receive information about a diagnosis
Families hear about issues & plans

Patients are asked about their preferences in treatment plan
Families share experience

Treatment decisions are made based on patient preferences, medical evidence & clinical judgment
Families partner

Organizational design and governance

Practice surveys patients about their care experiences
State agencies, org's

Practice involves patients as advisers or advisory council members
State agencies, org's

Patients co-lead practice safety and quality improvement committees
Families/consumers

Policy making

Public agency conducts focus groups with patients *Families* to ask opinions about *policy/program* issues

Patients' *Families* recommendations about research priorities are used by public agency to make funding decisions

Patients/*Families* have equal representation on agency committee that makes decisions about how to allocate resources to health programs

Factors influencing engagement:

Patient (beliefs about patient role, health literacy, education) ; **Organization** (policies and practices, culture); **Society** (social norms, regulations, policy)

UNHSP paid staff positions



UNHSP Staff 2017

- HRSA funding 2000 for part-time family outreach specialist
 - Parent on staff from program start
- HRSA funding 2017 for part-time parent special projects coordinator
- Both positions include benefits

Advisory Committee



Advisory Committee Meeting
May 2017

- 14 member committee
 - 2 Parents mandated
 - 2 Consumers mandated
- Chair is parent of child with reduced hearing
- Stipends cover transportation/parking in Boston
- Committee approves all policy documents

Parents Present



Jackie Gomez, Parent Forum 2017

- Parent Forum
 - Stipends provided
 - Content influenced by parents and consumers
- Digital stories and vignettes for website

Funded Family Events



Cooking Event, August 2017

- Legoland
- Indoor play spaces
- Literacy events
- Baseball games
- Cooking event
- Art events
- Children's museums

Family Leadership in Action

- Parent advocacy leads to Legislative change -- H52 Children's Hearing Aid Law
 - Lisa Adams awarded 1st annual EHDI Family Leadership Award
- Parent to lead Shared Reading Saturday southeast
 - Funded by UNHSP
- UNHSP partners with Decibels Foundation to expand parent support groups
 - Calendar of events developed
- Families contribute to projects nationally
 - EHDI-PALS

Identify family leaders



Panel photo, Parent Forum 2015

- Develop Email List
 - Foster communication
 - Solicit input
- Create Facebook presence
 - Advertise events
- Develop personal relationships
 - Parent Forum, Family Events, and Conferences

Developing individual leaders



Family Leadership Training Institute

- Provide EHDI family sponsorships
 - 5 parents 2018
 - Supplement NCHAM scholarship
- Fund families to attend MA conferences
- Train parents as Family TIES mentors
- Partner with MA DPH Family Leadership Training Institute

Contact Us!

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<https://www.mass.gov/universal-newborn-hearing-screening-program>

www.facebook.com/MassNewbornHearingScreening