H&V FL3 Center

Sunday, March 17th, 2024

D/ HH Family-to-Family Support and Leadership: The Blueprint for Success

National EHDI Conference Denver, Colorado



d Human Services (HHS) as part of an award, 2 UJ1MC30748 an endorsement, by HRSA, HHS or the US Government.

Welcome!

Agenda for today

- We will take a break!
- Interactive get ready to participate
- Introduction of presentation team
- Introduction of participants

HRSA's Blueprint for Change

– Impact on Family-to- Family
Support and EHDI

- Equity
- Accessto Services
- Finances
- Quality of Life

Q and A

Opening Questions



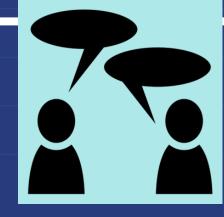
By a show of hands:

- •Have you ever heard of the HRSA Blueprint for Change?
- Have there been any conversations about this at state EHDI stakeholder meetings?
 Among parent groups (FBO's)?
 Other spaces?

Discussion:

- What do you hope to get out of today's conversations?
- Handout for your use
 - WWDWBW?



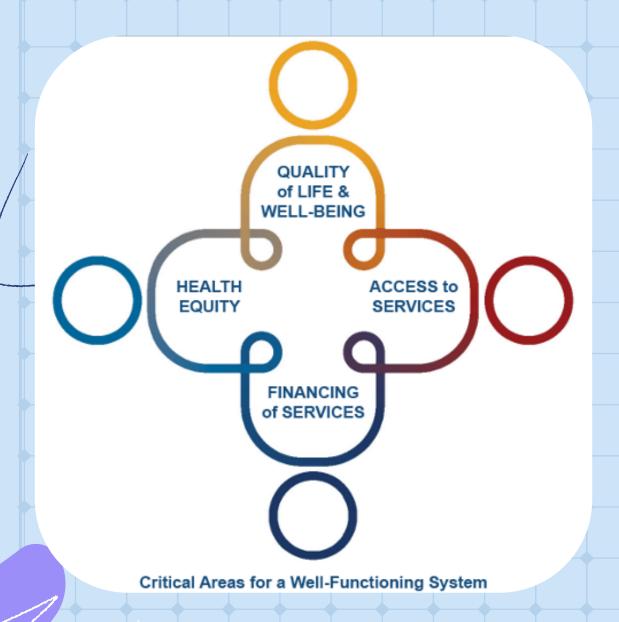


Introducing



A National Framework for a System of Services for Children and Youth with Special Health Care Needs

Vision



Through the Blueprint, we envision that every child and youth with special health care needs:

- Enjoys a full life, from childhood through adulthood
- Thrives in systems that
 - Support their families and their social, health, and emotional needs
 - Ensure dignity, autonomy, independence, and active participation in their communities

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

ARTICLES

Introducing the Blueprint for Change: A National Framework for a System of Services for Children and Youth With Special Health Care Needs Treeby W. Brown et al

A Blueprint for Change: Guiding Principles for a System of Services for Children and Youth With Special Health Care Needs and Their Families Sarah E. McLellan et al

Children and Youth With Special Health Care Needs: A Profile Reem M. Ghandour et al

Progress, Persistence, and Hope: Building a System of Services for CYSHCN and Their Families Michael D. Warren et al

Health Equity for Children and Youth With Special Health Care Needs: A Vision for the Future Amy Houtrow et al

Quality of Life and Well-Being for Children and Youth With Special Health

Care Needs and their Families: A Vision for the Future Cara L. Coleman et al

Access to Services for Children and Youth With Special Health Care Needs and Their Families: Concepts and Considerations for an Integrated Systems Redesign Dennis Z. Kuo et al

Financing Care for CYSHCN in the Next Decade: Reducing Burden, Advancing Equity, and Transforming Systems Jeff Schiff et al

https://publications.aap.org/pediatrics/issue/149/Supplement%207



HRSA Maternal & Child Health

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PEDIATRICS

JUNE 2022 - VOLUME 149 - SUPPLEMENT www.pediatrics.org

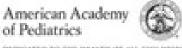
A SUPPLEMENT TO PEDIATRICS

Blueprint for Change. A National Framework for a System of Services for Children and Youth with Special Health Care Needs

Treeby W Brown, MA, Sarah E MoLellan, MPH, Marie Y, Mann, MD, MPH, FAAP, and Joan A. Scott, MS, CGC, Guest Editors

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DEDICATED TO THE HEACTH OF ALL CHILDREN'S

BLUEPRINT IN PRACTICE: FUNDING to Support the Blueprint Implementation

- Children and Youth with Special Health Care Needs <u>Research</u> Network (CYSHCNet)—University of Colorado
 - Blueprint focus
 - ✓ Identifying and defining measures of wellbeing and QoL for CYSHCN and caregivers
 - ✓ Defining and measuring family partnership at the systems level
 - ✓ Understanding integration of models of care
- <u>Family</u> Engagement and Leadership in Systems of Care—Family Voices
 - Blueprint focus
 - ✓ Promoting shared definitions and metrics for family engagement across systems
 - ✓ Achieving health equity for CYSHCN through engaging diverse families in systems of care

- National Center for a System of Services for <u>CYSHCN</u> (Blueprint Center)—AAP
 - AAP (prime) with consortium of partners including Catalyst Center, Family Voices, and Got Transition
 - Center responsible to implement the Blueprint nationally across state Title V programs and other key partners
- Enhancing Systems of Care for Children with Medical Complexity <u>CMC</u>—Academy Health
 - Blueprint Focus
 - ✓ Supporting approaches addressing the elevated social needs and risks of CMC so children and families can thrive
 - ✓ Measuring patient/family experience of care



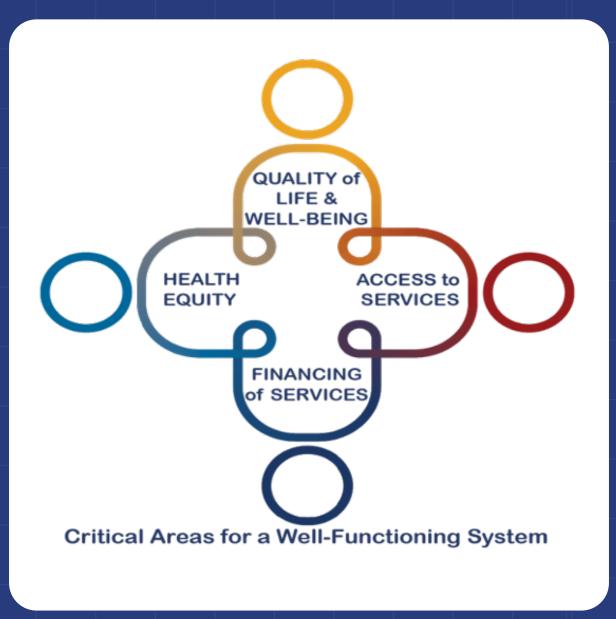
The Blueprint for Change

Ensures that:

- * Families are partners in decision-making at all levels
- * Families receive coordinated, ongoing, comprehensive care within a medical home
- * Families have adequate private and/ or public insurance
- Children are screened early and continuously for special health care needs
- ❖ Services are organized so families can use them easily and are satisfied with the services they receive
- ❖ Children receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence

4 Critical Areas of inequities needed to improve:

- Health Equity
- Access to services
- Financing to Services
- Quality of Life & Well-Being
 - Family AND Child



MCHB Blueprint for Change:

HEALTH EQUITY

Rosabel Agbayani and Ana Brooks

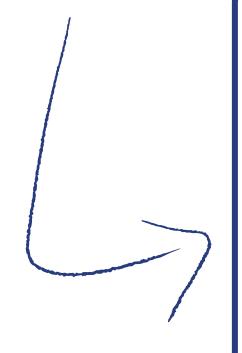
Health Equity for Deaf and Hard of

Hearing Children: A vision for the future

- Empower Parents to help their children develop and realize their potential
- Providing Family Centered Care to satisfy their needs
- Giving skills to parents to allow their DHH child to develop capacities allowing them to interact successfully with their biological, physical, and social environments



Health Equity Concepts



- Discrimination
- Health Disparities
- Health Equity
- Intersectional Identities
- Social Determinants of Health



Question:

What are ways families may experience unequal treatment and discrimination in systems serving Deaf/ Hard of Hearing Children?

Think about these as you answer your question:

- Could they be perceived as ableist/audist?
- How does disability get framed?
- How does cultural responsiveness intersect?
- Are there any indicators of inferiority towards medical diagnosis/treatment?



The Blueprint for Change Values:

"All children should be equally valued; resources to promote health should be distributed fairly; commitment to health equity represents justice in health; progress is measured by a reduction in health disparities".

[•] Amy Houtrow, Alison J. Martin, Debbi Harris, Diana Cejas, Rachel Hutson, Yasmin Mazloomdoost, Rishi K. Agrawal; Health Equity for Children and Youth With Special Health Care Needs: A Vision for the Future. Pediatrics June 2022; 149 (Supplement 7): e2021056150F. 10.1542/peds.2021-056150F

Question:

What are some examples of policies and laws that are designed to sustain unequal treatment?



- American with Disabilities Act 1973
- The Rehabilitation Act of 1964
- IDEA 2004 principle of Free
- Appropriate public education in the least restrictive environment

Medical Home Systems and its

im p lic it b ia s

- Disparities in medical home access
- Coordination not adequate for equitably delivered or paid for
- Practices might choose to care for children who tend to be more
 economically advantaged (typically White, Non-Hispanic) because they
 are less likely to be poor and without a disability.
- The need for cultural model and family centered care vs. medical home



- American Rescue Plan Act 2021
- Early Periodic Screening Diagnostic
 and Treatment (EPSDT) 2014

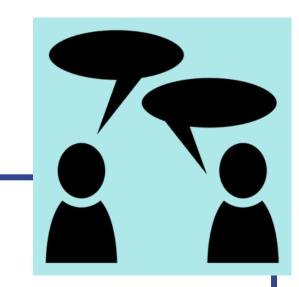
Research & Practice

- · Knowledge of persistent disparities advance equity
- Collaborating with minoritized communities aid efforts to obtain true data of the minoritized community needs
- Provide evidence-driven solutions to reduce disparities
- Ensure equitable dissemination of surveying methods
- Collaborate and coordinate to meet the multiple needs of Deaf and Hard of Hearing (DHH) children and their families
- EHDI System needs to provide culturally-responsive care
- Reduce burden and risk of re-traumatization
- · Authentic engagement from individuals and families of children who are DHH

Discussion: How to implement the principles and strategies

• What are the barriers you have experienced serving diverse families in EHDI?

• What are your expectations, perceptions and how does that become a barrier?



Think about:

- How do we create space "at the table" for underserved populations?
- Are we creating financial reserves to provide culturally appropriate care?
- How do we empower and educate families how to:
 - Provide parent to parent support
 - Hold positions of leadership to influence system

MCHB Blueprint for Change:

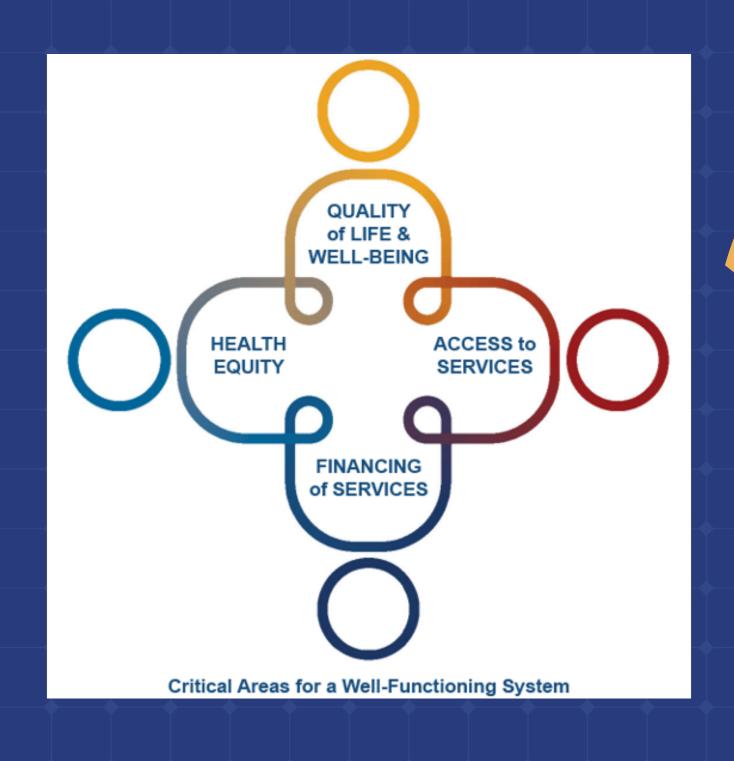
Access to Services

Terri Patterson and Sara Kennedy

H&V HQ/ FL3 Center

Access to Services:

What FBOs can Do



Shift in Access

Prior: Diagnosis-Driven

- Coverage
- Services
- •Timeliness
- Capability of workforce
- System

Goal: Meeting unique needs of the family

- When, where, and how
- Inequities addressed
- Continuity
- Improved quality of life and well-being

*For D/HH families this begins at 13-6

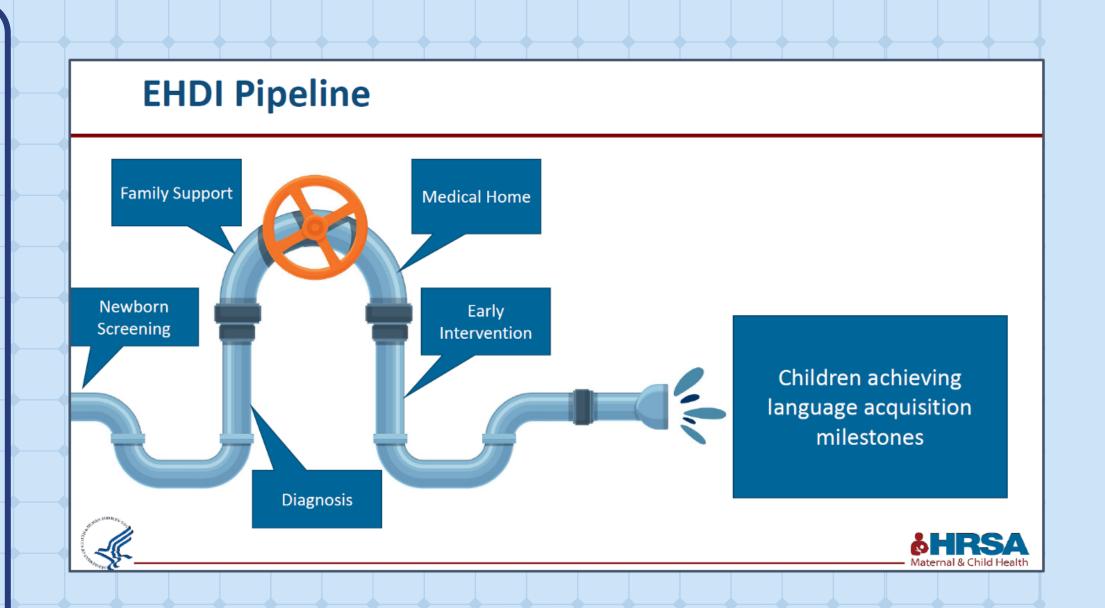


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The 3 Blueprint Principles on Access

What can FBOs do to improve:

- Ease and availability of services for families
- Access to a prepared
 workforce for D/HH/DHH+
 needs
- Streamlining administrative issues



"The system doesn't work for us."

- Service deserts
- Border issues
- Lack of skilled providers in all fields
- Families are told that they should move,
 can't use that method/ language/
 technology



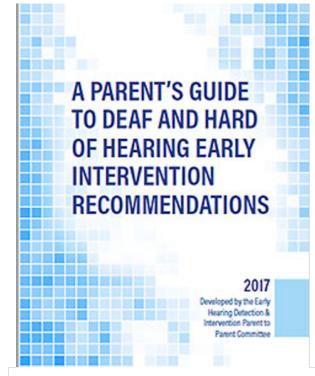
"How do I know what I need?"

- Family-friendly guidance and introduction to the vision.
 - from the 2013 Supplement to the JCIH 2007 Position Statement

For each recommendation from JCIH

- What this means to me/my family
- Things to think about/explore in El
- What I have a right to expect:

*Key: DHH expert(s) a vailable on team





**https://publications.aap.org/pediatrics/article/131/4/e1324/31903/Supplement

to-the-JCIH2007 -Position-Statement

"How do I know what I don't know?"

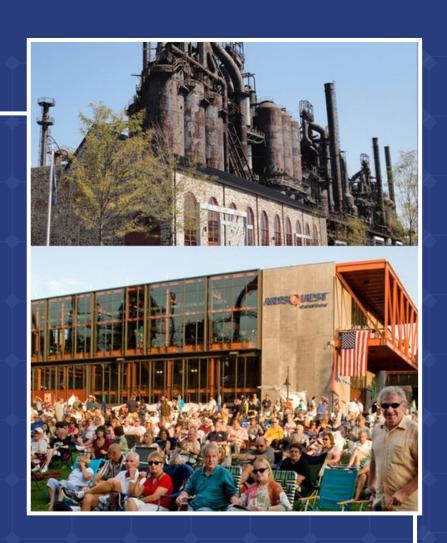
- Connect with trained parent-to-parent support
- Ask providers
- Do your "homework"
- Connect with diverse DHH leaders with lived experience
- Seek better access
- In your home language
- With respect to your culture

This takes courage! (Systems need to flex)



"How do I get that?"

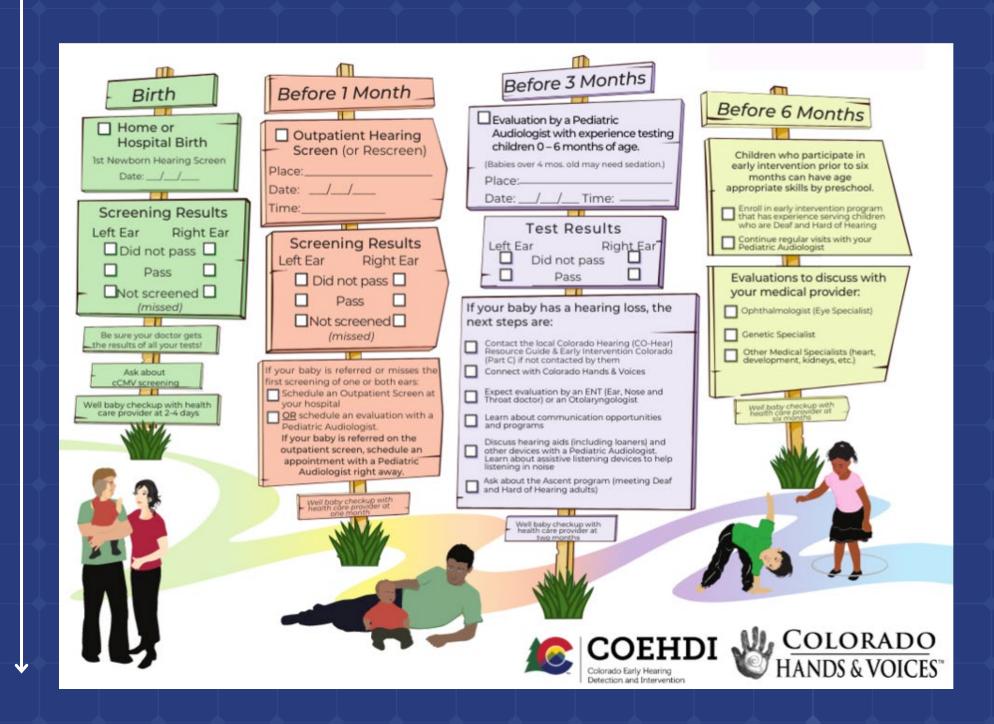
- Single point of entry (no wrong door)
 - Coordinated data system
 - Georgia Pathway to Language and Literacy
 - Direct referrals: Illinois, Minnesota, others
- Integrated and proactive
 - Audiology-ElFamily SupportDHH Leaders
 - Relationships!
 - Advocating for the need for more training/recruitment/telehealth
 - Family-friendly Roadmaps (next slide)

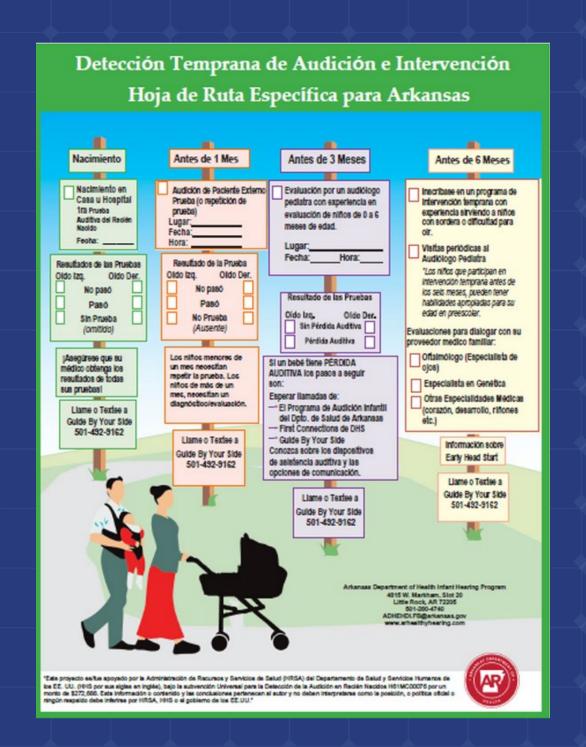




EHDI Roadmap Examples: CO and AR

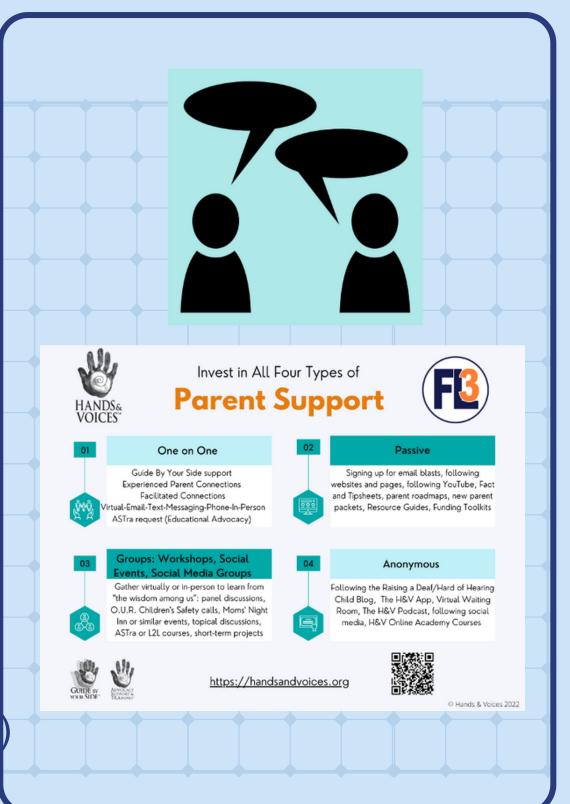
*Where am I on the roadmap?"





What can FBOs do?

- Offer consistent support to all families
 - Who are your underserved families and how do we reach them?
 - How do we engage families in leadership?
 - How do we build safety nets?
 - How do we get services in service deserts?
- FBOs can help programs anticipate needs and barriers
 - Making that work: Illinois story
 - Being a voice for parents (MI EHDI Storytellers, Virtual Site Visits, EHDI Advisory Meetings, EHDI systems map review)



Call to Action: Where Can Access be

Increased?

- All families are unique
- They can be complex
- They all need access to services
- Will we wait and hope/blame the system

Or make a plan... together?

insured-underinsured-uninsured island- frontier - rural- service desert - suburban - urban early id, later onset, late id, Deaf family



English speaking, multilingual, monolingual

MCHB Blueprint for Change:

Financing of Services

Janet DesGeorges

Financing of Services

From the Blueprint:

- Accessible
- Affordable
- Comprehensive
- Continuous
- Prioritizes the wellbeing of families
- Ensuring benefit adequacy
- Addresses racial disparities



Finances and the Impact on Family Dynamics

- Avoiding changing jobs
- Reduced employment
- Difficulty paying medical bills
- Emotional stress
- Impact on spousal relationship

Financing of Services

From your vantage point in the system, what specific areas do you think funding is a challenge for families moving through EHDI 1-3-6?



Covered, not covered, partially covered...it depends

- Screening costs (hospital, home birth)
- Medical home (well baby visits, typical health needs)
- Diagnostics (audiology, ENT, additional recommended testing i.e. genetics)
- DHH+ Specialists
- Technology (Cochlear Implants, Hearing Aids)
 - Warranty
- Appropriate intervention (Part C, private)

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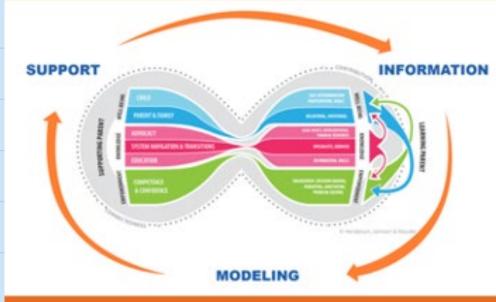
The Role of Family

-to-Family Support and

talking about money

- Know your Resources
- Basic knowledge of private, public, and other insurance
 - issues
- DHH+ considerations
- Responding to the emotional toll it takes on families

HANDS & VOICES FAMILY SUPPORT ACTIVITIES GUIDE



A guide that includes family support activities developed from an evidence-based parent-to-parent support framework for families with children who are Deaf or Hard of Hearing.

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You'll hear more about this in a minute!

Component 3 - Financial Resources

Financial assistance, insurance, government funding, entitlements and not-for-profit or voluntary sector supplements.

TOPIC	FAMILY SUPPORT ACTIVITIES
Insurance Coverage	Knowing what is included in an insurance policy and who can help when families have questions regarding coverage for a D/HH child is important.
Activity:	Explore the EHDI-PALS website. Here you can locate Pediatric Audiologists/Facilities searched by state/territory that include information about what insurance is accepted. https://ehdi-pals.org/SmartTool/EP_SmartTool.aspx#gsc.tab=0 Also in Spanish
Activity:	View the resources listed within this article from Verywell Health to learn about potential financial aid assistance for hearing technology. https://www.verywellhealth.com/financial-aid-for-hearing-aids-and-cochlear-im-plants-1046604
Activity:	Learn how to appeal a decision made by an insurance company if you disagree. https://www.healthcare.gov/appeal-insurance-company-decision/appeals/ Also in https://www.healthcare.gov/appeals/ Also in https://www
Activity:	Review the following list of State Insurance Mandates for Hearing Aids from the American Speech-Language-Hearing Association (ASHA). https://www.asha.org/advocacy/state/issues/ha_reimbursement/
Managing Healthcare Expenses	Being aware of state specific Insurance Programs, Health Savings Accounts, Care Credit and other available resources for managing healthcare related expenses can reduce the financial stress for families.
Activity:	Review the following resources with information about managing healthcare related expenses. https://www.carecredit.com/ https://www.healthcare.gov/glossary/health-savings-account-hsa/ Also in Spanish https://www.healthcare.gov/medicaid-chip/getting-medicaid-chip/ Also in Spanish
Activity:	Find resources for childcare, health and social services, financial assistance, support for children with special needs, and more from various states/territories. https://www.childcareaware.org/resources/map/ Also in Spanish
Activity:	Learn about Supplemental Security Income (SSI) for children with disabilities and to review eligibility requirements. https://www.ssa.gov/pubs/EN-05-10026.pdf Also in Spanish, Arabic, Chinese, Farsi, French, Greek, Italian, Korean, Polish, Portuguese, Russian and Vietnamese

Systems improvements

Reducing Burden, Advancing Equity, and Transforming Systems

- Hearing Aid and C.I. Legislation (state-by-state)
- Funding for Sign Language programs for families
- Expanding Family-to-Family funding mechanisms
- Larger systems transformation and EHDI/ Parent representation —
- Do we have a place at the table -
 - Medicare/Medicaid expansion
 - CHIP
 - Care coordination adequately funded
- Have you invited experts in these areas to 'your' table? i.e. state EHDI Advisory committees

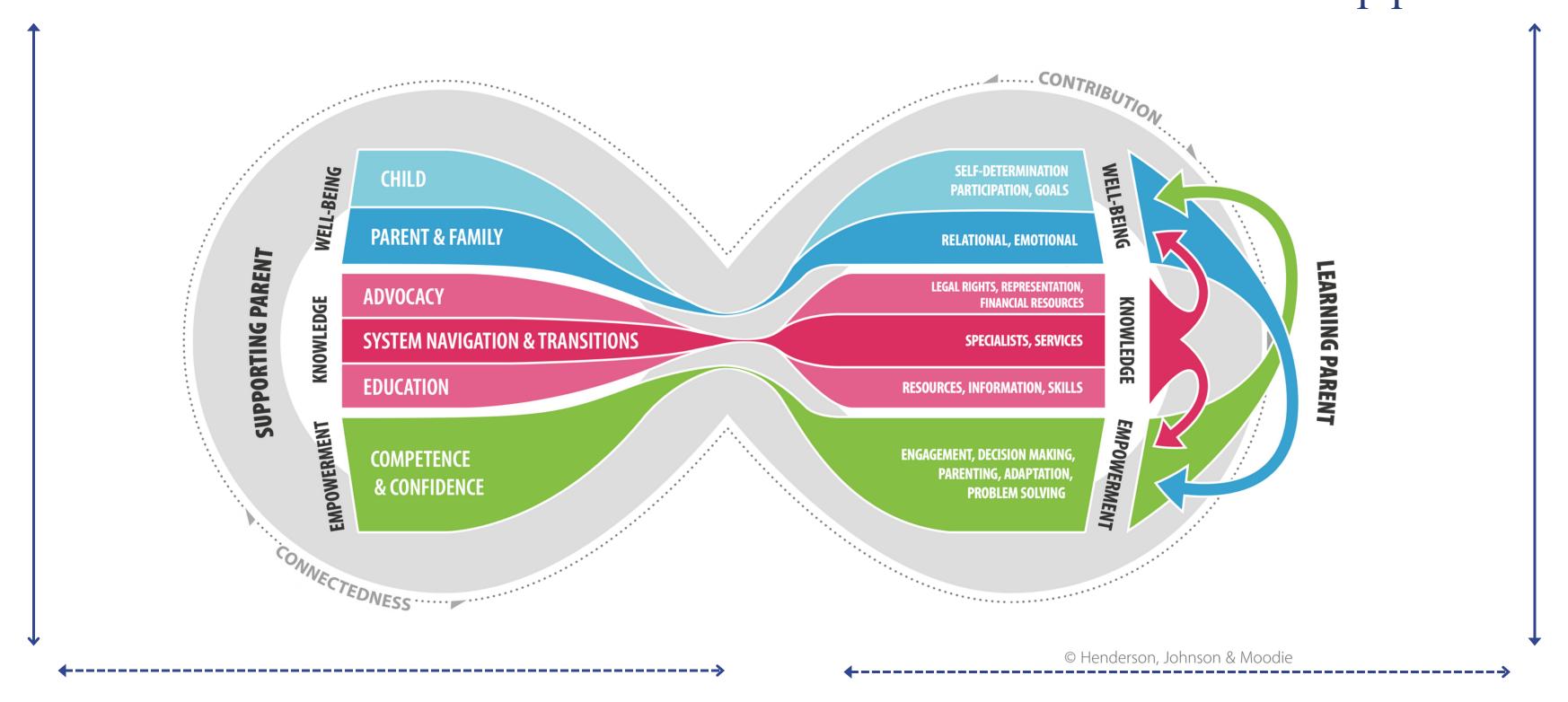


MCHB Blueprint for Change:

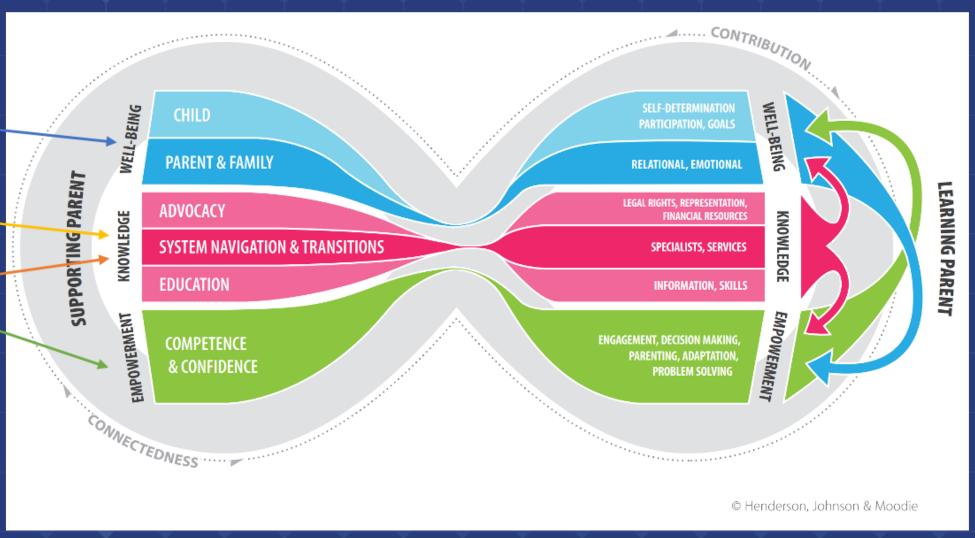
Quality of Life and Well-Being

Lisa Kovacs and Carrie Balian

Hands & Voices Implementation of an Evidence-based Modelof Parent-to-Parent Support



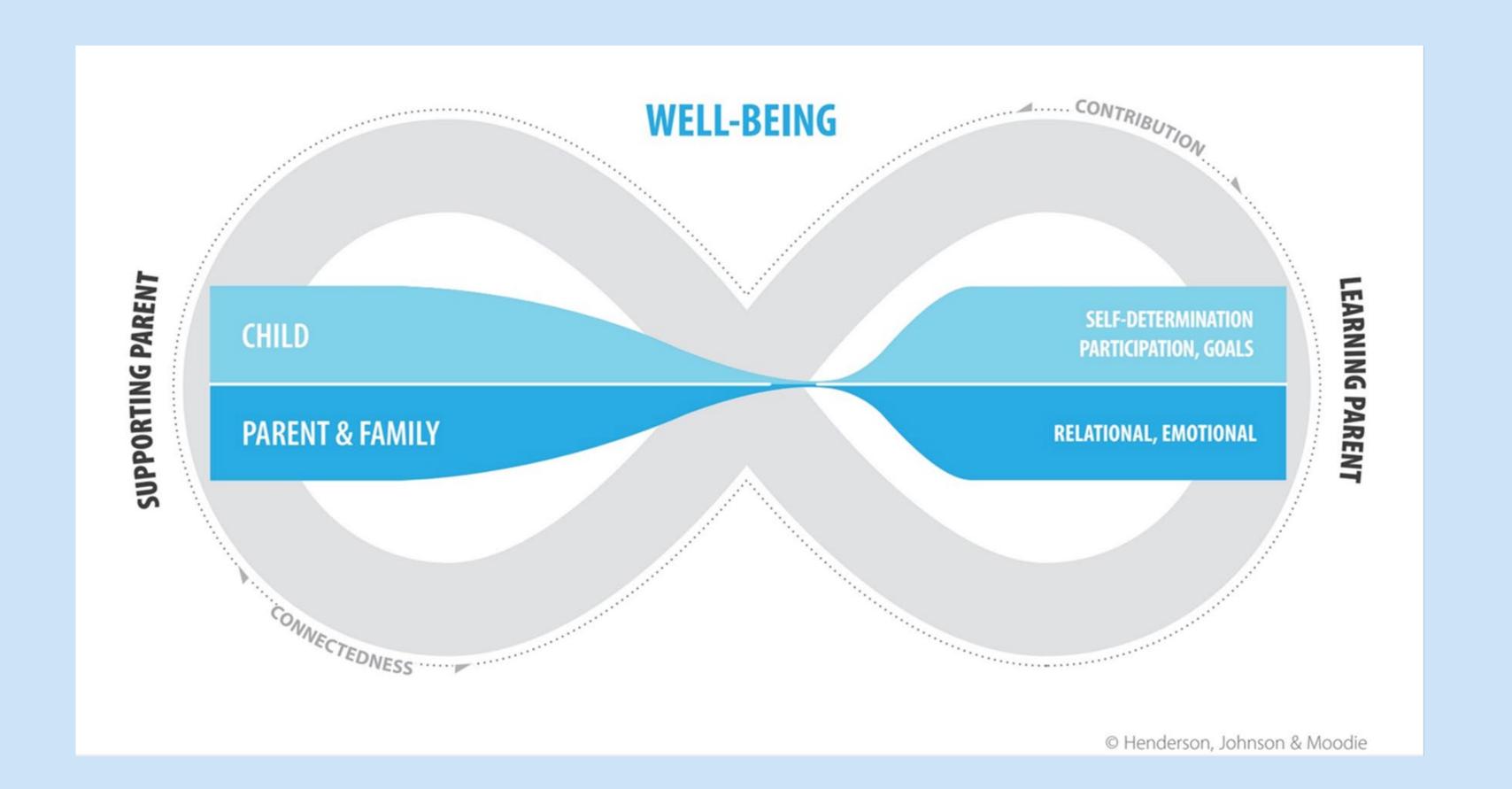




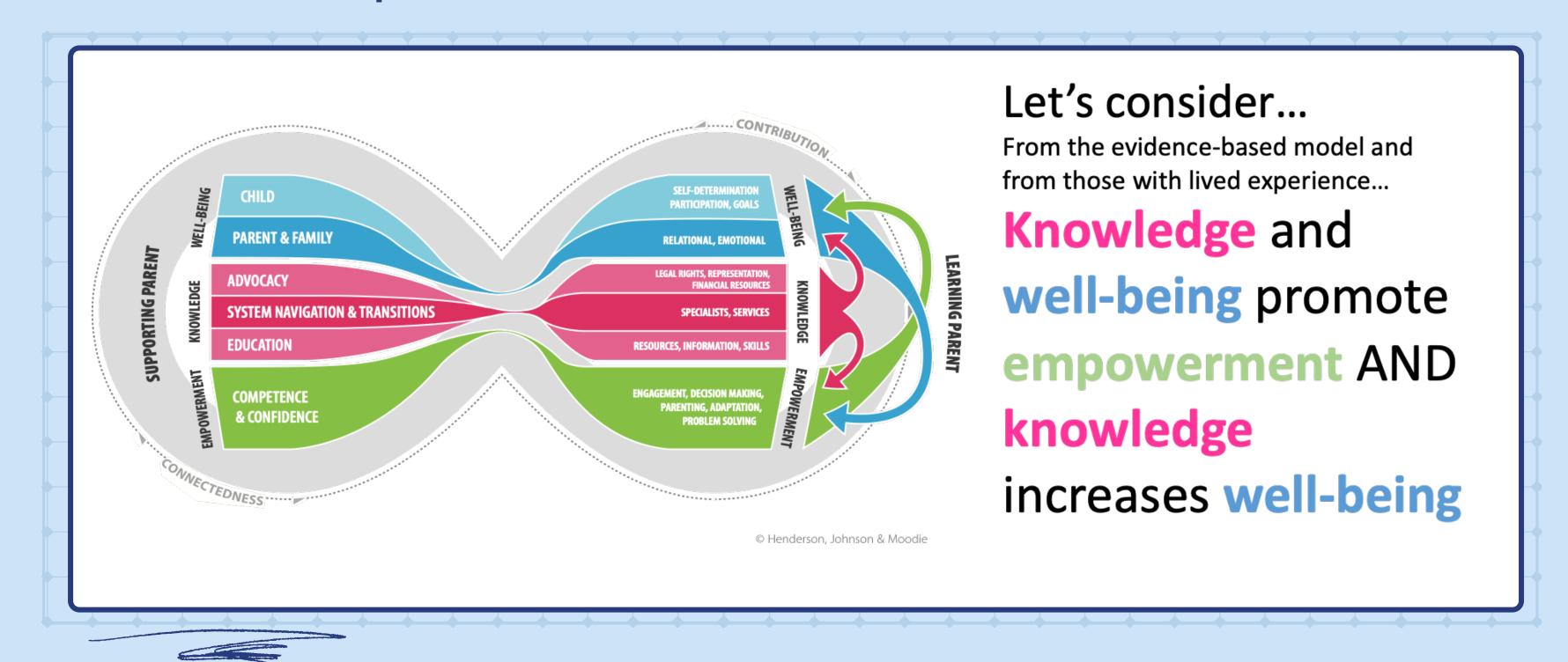
MCHB Blueprint for Change: Quality of Life and Well - Being

The concept of well-being and quality of life (QOL) are interdependent and influenced by multiple factors, including sense of community and social integration; socioeconomic and employment status; self-perceived physical, cognitive, emotional, and social functioning.

WHO definition "an individual perception of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns."



Relationship between the 3 constructs



The Blueprint recommends measuring:

Quality of Life and Well-Being

For the healthcare system to promote dignity, autonomy, and independence for children and youth with special health care needs (CYSHCN) and their families, greater value must be assigned to quality of life and well-being as defined by individuals and families with lived experience.

Prioritizing well-being and quality of life outcomes places value on measuring what matters most to CYSHCH, the WHOIE PERSON (whole child, whole family) not just the diagnosis.

Just think of the potential impact of EARLY family support!

IFSE - Measuring Well-Being



https://handsandvoices.org/ fl3/resources/data.html

Impact of Family Support and Engagement (IFSE) Learning Community - Question Bank

Impact Questions:

IFSE recommended questions:

In 2056 an Evidence-based Conceptual Framework was developed by researchers from Western University, led by Dr. Shella Moodie. The findings from a dual-stage scoping review and electronic Delphi study provide a conceptual framework that defines the vital contribution of parents in Early Hearing Detection and Intervention programs that will be a useful addition to these programs. In developing the framework, three overarching themes (constructs) are included (a) well-being, (b) knowledge, and (c) empowerment. These constructs are what the IFSE Learning Community used in developing family to family support impact questions. http://aia.gutn.asha.org/article.aspx?articleid-2527721

Construct #1 Well-Being - Child and Family

All questions used the following Likert scale unless otherwise indicated (Strongly agree, Agree, Disagree, Strongly disagree) (adding N/A was also discussed as an option)

- 1. I have learned I am not alone, there are other families I can connect with and learn from.
- 2. I feel hopeful about my child's future.
- 3. My ability to focus on everyday moments that bring joy to our family has improved.
- 4. Meeting an experienced parent, has provided me with encouragement in raising my own child who is Deaf or Hard of Hearing.
- 5. My overall well-being (for example; state of being comfortable, healthy, or happy) has improved because of the support I received.

Construct #2 Knowledge - Advocacy, Systems Navigation, and Education

All questions used the following Likert scale unless otherwise indicated (Strongly agree, Agree, Disagree, Strongly disagree) (adding N/A was also discussed as an option)

- 1. I better understand the impact of a hearing loss/difference on my child's development.
- 2. I have an increased understanding of the different language/communication options for children who are Deaf or Hard of Hearing.
- 3. I better understand my role in advocating for my child's needs.
- 4. I have more knowledge of information and resources that will support my child/family.
- Name the one most important piece of information you learned from your family-to-family support provider (Open comment box: 200-character limit).









Family Learning Outcomes-

Parents/caregivers will:

- Learn that they are not alone, there are other families they can connect with and learn from.
- Feel hopeful about their child's future.
- Be able to improve their focus on everyday moments that bring joy to their family.
- Find encouragement in raising their own child who is Deaf or Hard of Hearing after meeting another experienced parent.
- See an improvement in their overall well-being (for example, state of being comfortable, healthy, or happy) because of the support they receive.

What activities/ resources do you do that promotes child/ family Quality of Life and Well-Being



Family Support Impact on Child/ Family

QOL& Well-Being

New Resource:

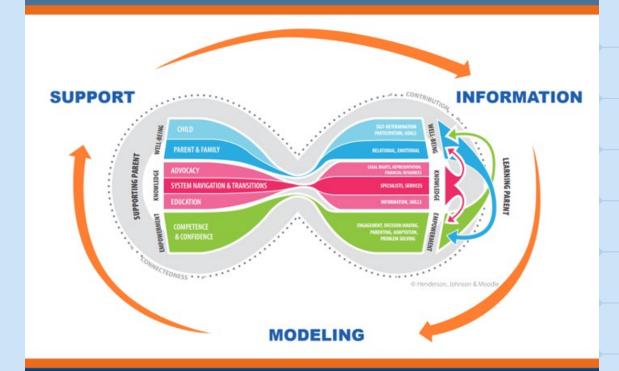
For Parents by

Parents





HANDS & VOICES FAMILY SUPPORT ACTIVITIES GUIDE



A guide that includes family support activities developed from an evidence-based parent-to-parent support framework for families with children who are Deaf or Hard of Hearing.

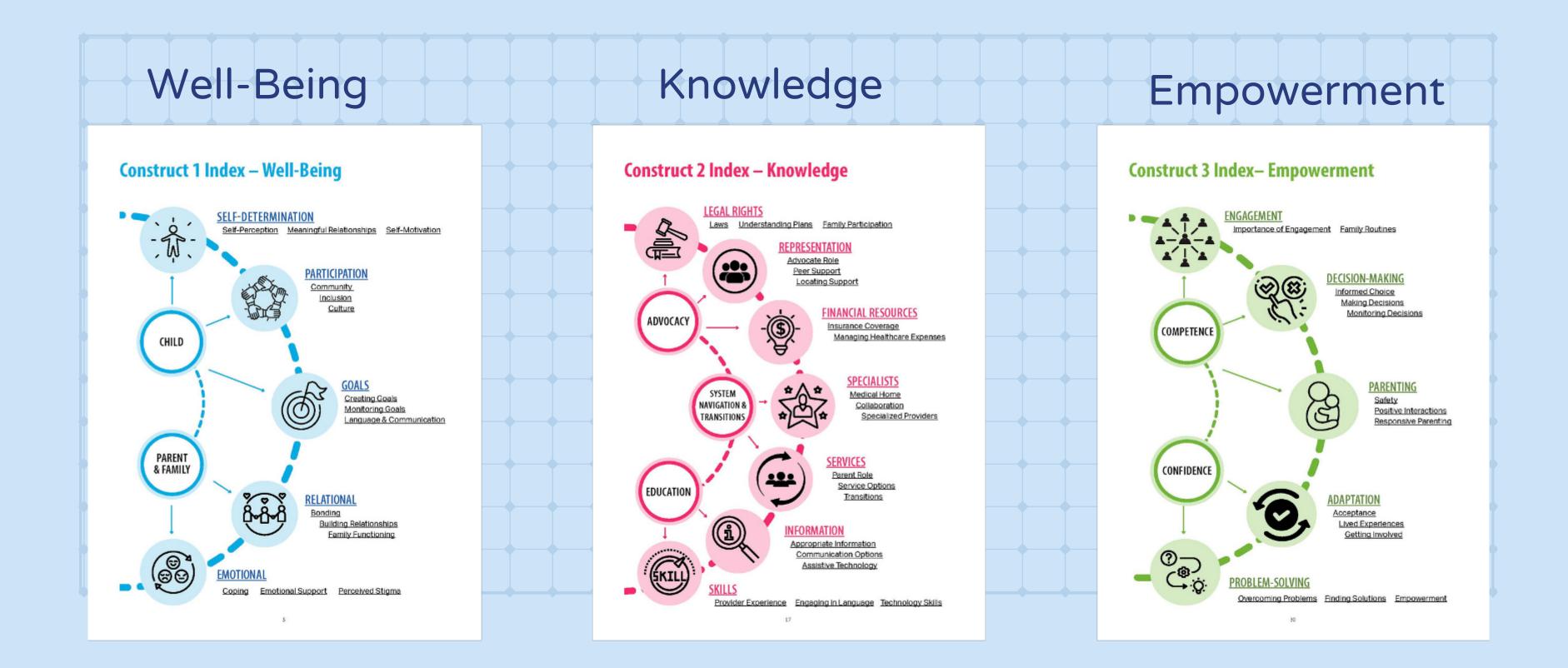


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Guide Highlights:

- Featuring many H&V/FL3 Center resources all in one place
- 192 website links, 160 unduplicated
- Additional Languages now highlighted and linked
 - 68 Spanish resources
 - Over 25 other languages
- Family Learning Outcomes included
- Visual index at the start of each construct
- Smile icon to highlight language & literacy activities:
- Topical "concerns/ needs" words to assist with search feature

Visual Index



Topical Concerns/ Needs.

Resources in more than English,

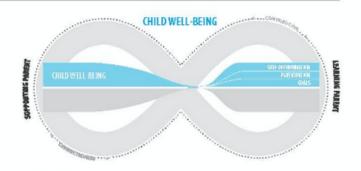
Language & Literacy Activities

Construct 1A - Child Well Being

Family Support Activities

Construct 1A:

Child Well-Being



Component 1 - Self-Determination

Self-motivation, positive self-perception, and meaningful relationships.

	TOPIC	FAMILY SUPPORT ACTIVITIES
	Self- Perception	Positive self-perception is important for a child who is D/HH. A good understand- ing of who they are and what they are capable of leads to confidence, strong social skills, and meaningful relationships.
	Activity:	Use the following Social Emotional Tip Sheet and Family Activity Plan to choose 1-2 tips to work on each week that will support the child's self-perception. www.handsandvoices.org/fi3/topics/lang-lit-soc-development/social-dev-resources.html Tip Sheet also in Spanish - Family Activity Plan also in Spanish
	Activity:	Watch the following video of a D/HH teen sharing her journey of finding a positive self-perception. https://youtu.be/A2DfJQ2DmUE
	Activity:	Use the following tip sheet to support building a natural and loving parent/caregiver-child connection through everyday activities that lead to experiences of positive self-perception. https://handsandvoices.org/resources/fostering-joy/ts-eng-FamilyTipSheet.pdf Also in: Spanish, French, Hmong, Italian, Somali, Urdu, Mandarin, Japanese, Thai, German, ASt
4	Meaningful Relationships	Good communication with a child who is D/HH is essential to developing meaningfurelationships between the child and those that they interact with such as parents/caregivers, siblings, extended family, and those within the community.
	Activity:	Use this resource to learn and apply simple changes in the family routine and the child's environment that promotes communication between the child and family. Be mindful to not use phrases with a child who is D/HH such as, "never mind or I'll tell you later" https://www.handsandvoices.org/fi3/fi3-docs/maximize-visual-access-tips.pdf Also in Spanish

6

Time to Dive In

- Each of you should have a 4x4 bingo board
- · We will draw a word that you can mark off your board
 - We will share something about the word that is drawn
- First to get four in a row or four corners wins!
- Programs can use this tool with their team to help acclimate themselves to the guide

Well-Being building relationships creating goals monitoring self-perception language & communication solf-motivation coping bonding culture family functioning a great start meaningfure stionships emotional support inclusion community perceived stigma myfreebingocards.com

Off to a Great Start

A Family Toolbox, Off to a Great Start, will include FL3 Center materials that Family Support Leaders and EHDI Programs can use to promote enrollment and family engagement in EI:

- A newly created resource for B-5 about general development principles for DHH children.
- 8 Reasons to Say Yes to, El
 5 Reasons to Say Yes to Assessment
 Language and Literacy Tip Sheets,
 the Family Activity Guide(to infuse Language and Literacy at home),

Making a Plan for Your Child (CDC), Language Milestones Document, and the

Family's Guide to El Recommendations

• Linkable badges, family friendly promotional resources, a download style sheet/ images, and QR codes for the new *Off to a Great Start*Family Toolbox







Dissemination considerations:

Websites

Social Media

Providers

Family-based organizations/ Family Support

Dissemination support:

Badges

Plug and post messaging

What do you need to be able to post/ disseminate this by next week?

Training materials for Family Support Providers:

- Tip sheet on how to use the Guide
- Recorded training video



Questions and Comments





Thank you for coming today!

• Resources:

- Blueprint at a Glance: https://www.aap.org/en/patient-care/national-center-for-a-system-of-services-for-children-and-youth-with-special-health-care-needs/blueprint-for-change-strategies-at-a-glance-overview/
- Blueprint for Change: https://mchb.hrsa.gov/programs-impact/focus-areas/children-youth-special-health-care-needs-cyshcn/blueprint-change
- The Hands & Voices FL3 Center: https://www.handsandvoices.org/fl3/index.html